Inclusive support for parents with a learning disability

A project funded by the Department of Health

In partnership with

mencap
The voice of learning disability

ACT
ACTing against abuse

nct
Contents

Acknowledgements p4
1 Executive summary p5
2 Background p9
3 Making The Difference p19
4 The current project – Making The Difference + p21
5 Development and evaluation of the training p23
6 Parents’ steering group p25
7 Midwife survey p35
8 The training p45
9 General evaluation p53
10 General discussion and recommendations p59
11 References p63
Acknowledgements

We would like to thank:

- the Department of Health for funding this project
- heads of services within the NHS in Leicestershire, Derbyshire, Walsall and Nottinghamshire for engaging with the project and offering invaluable support and expertise
- all parents who gave their time and spoke candidly to the project team about their experiences of pregnancy, birth and the post-natal period
- all those professionals who gave their time to complete surveys and speak about their work
- all those professionals who attended the training and contributed enthusiastically on the day
- Mencap parents advocacy service Walsall for sharing their experiences with us and facilitating meetings
- professionals who offered the use of their resources and who signposted the project team to other relevant resources
- Dr Sandra Baum and the Newham Special Parenting Project for allowing the use of excerpts from their DVD during the training and for sharing their experiences of developing similar training in the Newham area
- Tina Thordal for her enthusiastic training sessions delivered throughout participating regions.
Executive summary

An increasing number of people with a learning disability are having children (Booth 2000, Guinea 2001, Pixa-Kettener 2008). Research has shown that parental IQ is not in itself a predictor of parenting performance (Feldman 1994), however many parents with a learning disability lose their parenting rights (Hayman 1990).

Many contextual factors can affect parenting skills, for example: parental history and experience, health, stress, social support, financial status, access to services or health inequality (Feldman 1998, Feldman et al 2002). Children of a parent with a learning disability often display poorer development. This has been associated with adverse pregnancy and birth outcomes such as premature birth and low birthweights (McConnell 2003). These outcomes may be related to a range of risk factors, for example: nutritional intake, maternal weight, smoking, use of medications, lack of social support, poorer access to appropriate antenatal care, or mental health problems such as stress, anxiety and depression (McConnell 2008).

Good quality and appropriate antenatal care is therefore vital for women with a learning disability. However, this group of women may have difficulty accessing good antenatal care, as services are often not equipped to respond appropriately to their very specific needs (Kapell et al 1998). Previous research suggests that many healthcare professionals may receive insufficient learning disability training (Powrie 2003, Phillips et al 2004), and this lack of training can be a barrier to effective healthcare. Learning disability training for health professionals has been shown to have positive results, for example improved knowledge and confidence, skills and clinical practice (Adler et al 2005, Melville et al 2006).

This report describes a project funded by the Department of Health (DH) and conducted by Mencap, in partnership with the Ann Craft Trust (ACT) and the National Childbirth Trust (NCT). The project built on previous work by ACT and Home-Start (2004) and Mencap and ACT (2005). This offered learning disability training to non-health professionals, voluntary workers...
Executive summary

and support staff involved in supporting parents with a learning disability during the post-natal period and early childhood. This work highlighted the importance of early intervention in improving outcomes for both children and parents. Recommendations included the extension of the training to include professionals involved with supporting parents with a learning disability during the antenatal period.

The main aim of this current project was to train health professionals working with parents through pregnancy and into early parenthood to be more effective when assisting parents with a learning disability. The aim of the training was to help them provide accessible, inclusive and appropriate care, support and information. Specifically, the aim of the training package was to make sure that the range of professionals who work with women during pregnancy, and the early days of parenting, understand more fully how to engage with parents with a learning disability so that essential information is accessible to this hard-to-reach group.

The project had three primary objectives. These were to develop:

- a learning disability awareness training pack with a specific focus on the learning or training needs of professionals who work with women during pregnancy and the early days of parenting
- an effective parenting resource pack for professionals to use when they support parents with a learning disability
- a database of participants to provide signposting facilities to parent support services or helplines, which are sensitive to the needs of people with a learning disability.

The training was developed for delivery, free of charge, in four pilot target regions – Walsall, Derbyshire, Leicestershire and Nottinghamshire. The development of the training was informed by:

- a review of current resources, services and good practice in antenatal and post-natal care for parents
- steering group meetings with parents with a learning disability to explore their experiences of antenatal and post-natal care – this included their perceptions of a selection of information about antenatal or post-natal care, breastfeeding and baby care
- a survey of midwives in three of the project regions, to explore their current knowledge of the health and communication needs of people with a learning disability, their training needs, their current level of access to specialist services and resources, and how accessible they think their service is to parents with a learning disability.

Steering groups with parents with a learning disability revealed some of the difficulties that they face. This group of parents reported that they:

- often feel socially isolated and scrutinised by others
- were reluctant to join in mainstream antenatal classes, excluding them from receiving support alongside their peers
Executive summary

• found resources such as leaflets and booklets about antenatal health and baby care, provided by mainstream services, too difficult to read
• needed help to understand the information they were given.

Most parents said that they had not breastfed their babies, despite being able to report the advantages of breast versus formula feeding. Parents also said they rarely saw women in their peer groups breastfeeding. The important role of health professionals was emphasised; parents valued positive experiences of midwives and health visitors, but also reported some negative incidents. These incidents highlighted the value of professionals’ good communication skills when supporting parents with a learning disability.

A survey of midwives in three of the project regions revealed that many of the respondents reported fair or limited knowledge of the additional health and communication needs of people with a learning disability.

• Most respondents did not know how to access specialist resources and services to support this group of parents.
• Many reported finding it difficult to identify whether a parent has a learning disability.
• The majority of respondents had never received any specialist learning disability training, but most reported that they would find it useful.

This suggests both a need and a desire for this type of training for professionals involved in maternity and early parenthood services.

A one-day training package was developed and delivered to 135 participants in the four project regions. Participants were mostly midwives, nurses, allied health professionals and support workers. The training covered key issues considered by participants to be important when supporting parents with a learning disability. It also covered: definitions of learning disability, a fact quiz, a case study of a young woman with a learning disability, trios exercises, how to communicate with people with a learning disability, appropriate terminology and action planning.

Learning goals were to:
• improve knowledge of learning disability
• understand different syndromes
• be confident in recognising and responding to the specific needs of a person with a learning disability
• understand how to make information accessible
• improve knowledge of the support available to parents with a learning disability
• improve knowledge of the difference between learning disability, learning difficulty and mental health distress
• improve knowledge of resources available for professionals to support parents with a learning disability
• improve communication.

Pre- and post-training evaluation showed that all these areas were significantly improved following the training. The training was positively received by participants in all of the project regions.
A number of recommendations have been made. These include:

- health professionals and external organisations working together more effectively
- flexibility in the time allowed for appointments and numbers of appointments or home visits for parents with a learning disability
- inclusion of similar learning disability training in the undergraduate curriculum
- the provision of accessible Baby-Friendly resources to cover information relating to pregnancy, childbirth and baby care
- more widespread training – in different regions
- link workers to facilitate the distribution and signposting of accessible resources, specialist services and useful information
- inclusive antenatal and post-natal education for parents with a learning disability.
Recent legislation and guidance indicates that parents with a learning disability have a right to support that enables them to have a normal family life (Human Rights Act 1998, Disability Discrimination Act 2005, DH 2009). It is now widely recognised that people with a learning disability have the same rights as everybody else to pursue valued social roles (Perrin and Nirje 1985, BILD 2000, DH 2001). One of the most valued social roles in western society is parenthood. Throughout the UK and abroad an increasing number of women with a learning disability are having babies (McConnell 2008, Mayes et al 2006, Woodhouse et al 2001). The government white paper Valuing People: A New Strategy for the 21st Century (2001 p81) states that:

“People with learning disabilities can be good enough parents and provide their children with a good start in life, but may require considerable help to do so.”

Valuing People Now 2009 (2009 p12) took this strategy further by stating:

“This strategy emphasises the importance of enabling people with learning disabilities to meet new people, form all kinds of relationships, and to lead a fulfilling life with access to a diverse range of social and leisure activities. It also emphasises their right to become parents and the need for adequate support to sustain the family unit ... Parents with a learning disability do not get sufficient access to support, putting families at risk of enforced separation.”

Although there is limited research into the needs and experiences of parents with a learning disability (Booth and Booth 2006), a consistent finding of the available research is that mothers with a learning disability learn parenting skills when education and support are individually tailored to their own particular circumstances and learning needs (Feldman 1994, Ray et al 1994, Llewellyn et al 2003). Such a consistent finding offers tremendous potential to all health and social care staff involved in supporting this group of parents. It demonstrates that appropriate support
offered at the right time, and in a way that is accessible to the individual, can have a very positive effect on mother, father and baby.

2.1 Parents with a learning disability

Parents with a learning disability face a range of challenges. Poverty, social isolation, stress, mental health problems and communication difficulties are common issues affecting their lives (Booth and Booth 1993, Clayton et al 2008, Feldman 1997). The lives of parents with a learning disability and the effect that these factors have on their experiences of parenthood have received increasing attention. Research indicates there is an increasing number of parents with a learning disability, although estimates of this figure vary. McGaw (2004) estimates that between 0.004% and 1.7% of parents, across a number of countries, have a learning disability. Meldon et al (2003) estimated that in Australia, at least one parent has a learning disability in 1-2% of all families with children under the age of 18. In the UK, 7% of adults with a learning disability were parents (Emerson et al 2005). Evidence to suggest these numbers have been rising comes from research that shows an increase of over 40% since the early 1990s in the number of children born to parents with a learning disability, and in the number of people with a learning disability who become parents (Pixa-Kettner 2008). Also, Booth (2000) and Guinea (2001) report an increase in the number of families where a parent has a learning disability coming to the attention of service providers in health, education and welfare.

Most parents with a learning disability have mild to borderline cognitive impairments (IASSID 2008). This is one of a range of factors that makes establishing the number of parents with a learning disability difficult. Individuals with a mild learning disability are often difficult to identify. Edgerton (2001) refers to a ‘hidden majority’ – those who may have been labelled as ‘slow’ during their school years, but lived subsequently in the community with little, if any, specialist support. Concern over their intellectual ability may only be raised once they become parents.

Other factors that make it difficult to accurately assess the number of parents with a learning disability are: the lack of a universal definition of the term ‘learning disability’, variable population screening and diagnostic practices, and inconsistent record keeping (IASSID 2008). However, despite these difficulties, an increasing number of studies into the lives of parents with a learning disability in recent years have provided an insight into the challenges they face (for example Booth and Booth 1993, Feldman et al 2002, Sheerin 1998).

2.2 Parenting with a learning disability

Research has shown that parental IQ is not a predictor of parenting performance (Feldman 1994, Hur 1997, Aunos 2000, Aunos et al 2003). These studies show that while some parents with a learning disability need additional support and skills training, others do not. However, it is all too common for parents with a learning disability to lose their parenting rights (Hayman 1990). Recent studies indicate that many complex factors,
other than below average intellectual functioning, underlie the inadequate parenting that often leads to a child being removed from the parents’ care (Feldman et al 2002). Wade et al (2008) point out that parents with a learning disability are ‘a heterogeneous group, demonstrating variability in parenting skills and living circumstances’ (pp. 352). It is important to consider that contextual factors – a range of personal, social and environmental factors – will affect parenting skills. These include: parental history and experience, health status, stress, social support, financial status and access to services (Feldman 1998, Feldman et al 2002).

Research suggests that many parents with a learning disability are likely to live under conditions that may lead to poorer parenting. Many risk factors contribute, including low income, low literacy and poor health. This group of parents often live in conditions of poverty (Palmer et al 2006) and are more likely to suffer greater social isolation than parents who do not have a learning disability (McConnell et al 2008). The effect of these factors on parenting outcomes is discussed below.

### 2.2.1 Social isolation

The effect of social isolation on parenting skills has been the subject of a number of studies. Feldman et al (2002) demonstrated a relationship between a lack of social support and levels of parenting stress in parents with a learning disability. Parenting stress has subsequently been linked to parenting style and perceived child behaviour problems reported by mothers with a learning disability (Feldman et al 2008). Sterling (1998) tested the relationships between depression, parenting stress, satisfaction with social support and parenting abilities in mothers with a learning disability. Results from this study suggested that those parents who were more socially isolated and more depressed displayed poorer parenting ability. Feldman (2002) proposes a model of parenting for parents with a learning disability that takes account of child, family, parent and social variables. This model assumes ‘accumulated risk’ – that parenting abilities and parental health are the accumulated product of a range of psychosocial and environmental factors. The more risk factors present, the larger the potential negative impact on parenting ability (also see Aunos and Feldman 2007).

Assuming parental incompetence purely on the basis of parental intellectual ability ignores many factors. These factors can be positively addressed through parent skills training or other interventions. Parents with a learning disability may need additional support and more time to learn skills. For example, how to stimulate their children through play or specific childcare skills like nappy changing and feeding. The evidence suggests that if the extra support is there, parenting skills can improve. Several studies that have implemented various parental training programmes and increased support have demonstrated successful results. Techniques shown to be effective include: teaching childcare skills through behavioural modelling, using visual manuals and audiotaped instructions, and using simple behavioural instructions.
(for example Feldman et al 1997). Positive outcomes from these interventions include an increase in responsiveness towards children, and improvements in childcare skills such as child safety, meal planning, grocery shopping and home cleanliness (see Feldman 1994 and Feldman and Case 1997 and 1999). Giving praise and feedback, and breaking down complex tasks into smaller chunks have all been shown to increase the effectiveness of parent training (Wade et al 2008). A consistent finding is that tailoring support and training to individual parents’ learning needs and personal circumstances can improve learning outcomes (Feldman 1994, Ray et al 1994, Llewellyn et al 2003).

2.3 Outcomes for children of parents with a learning disability

Several studies have investigated the impact of having a parent with a learning disability on children. These studies have found that 30-50% of children whose mothers have a learning disability are at risk of poorer development, compared to their peers from similar socio-economic groups (Feldman and Walton-Allen 1997, Keltner et al 1999, McConnell et al 2003). A common assumption is that parents with a learning disability are more likely to give birth to children with a learning disability. Research has shown that this is not the case (see IASSID 2008 for review). However, children of parents with a learning disability have been shown to be more likely to have developmental delays, lower IQ (Keltner et al 1999) and be less able in a range of academic skills such as spelling, reading and maths (Feldman and Walton-Allen 1997). This group of children is also more likely to display behavioural problems.

Longer-term outcomes have also been studied. Faureholm (2006) studied a sample group of adult children of parents with a learning disability. Although they recalled negative experiences such as being bullied, stigmatised and ostracised by other children at school, most of the group reported that they had maintained a warm and loving relationship with their parents. Similarly, Booth and Booth (2000) reported that the majority of a small sample of children of parents with a learning disability had described their childhood as happy. Most also described feeling love and affection towards their parents. Unfortunately, one common outcome for children of parents with a learning disability is that they are more likely than any other group of children to be removed from the care of their parents (Booth et al 2005).

Poorer development seen in children of a parent with a learning disability has been associated with adverse pregnancy and poorer birth outcomes (McConnell 2003). A study of children born to mothers with a learning disability by McConnell et al (2003) found that 28% of the group they studied were born prematurely, and 22% had low birthweights (under 2.5 kgs). A later study by McConnell et al (2008) found that in a sample of 57 pregnant women with a learning disability, their babies were more frequently admitted to neonatal intensive care or a special care nursery despite no significant differences in APGAR scores (tests for activity, pulse, grimace, appearance and respiration at one minute and five minutes after birth). One possible explanation for these
findings is that ‘staff perceptions of maternal ability play a role in decisions made about appropriate healthcare’ (McConnell et al 2008 p.534).

More research is needed to explain the causes of these findings. A range of biomedical risk factors may be implicated and are worthy of further study. For example McConnell et al (2008) suggest a potential role for nutritional intake, maternal weight, smoking, use of medications (such as epilepsy medication), lack of social support, access to appropriate antenatal care or mental health issues like stress, depression or anxiety. Mental health issues may be particularly significant for this group of mothers. A study by McConnell et al (2008) found that one third of their sample of pregnant women with a learning disability reported moderate to severe levels of stress, depression and anxiety.

2.3.1 Health inequalities

These findings suggest that good quality and appropriate antenatal support is vital for women with a learning disability. They also highlight the potential role of a range of risk factors in poor pregnancy and birth outcomes, for example low literacy, low income and social isolation. In terms of general health, women with a learning disability have been shown to display poorer overall health than women without a learning disability (Gibbs et al 2008). A range of health problems have been shown to be more prevalent for people with a learning disability than the general population. These include epilepsy, respiratory infections, gastrointestinal disorders, obesity, dental problems, mental illness and sensory disorders (for example Robertson et al 2000, Janicki et al 2002, Cooper et al 2006, Melville et al 2006, see Gibbs et al 2008 for review). A number of health problems are caused by the underlying aetiology of the learning disability, for example heart disease and dementia (Hill et al 2003, Muir 2004). However such factors alone cannot explain why people with a learning disability are 58 times more likely to die prematurely than the general population (Disability Rights Commission, 2006), with a number of high-profile reports recently showing the difficulties people with a learning disability have in gaining full and fair access to health services.

A further contributing factor is poverty. It has been well established that social deprivation is a major cause of poor health (Graham 2004), and as a disproportionate number of people with a learning disability live in financial hardship, this is likely to be a factor in their health inequality.

However, studies have shown that social deprivation alone does not account for all of the preventable poor health in this group of people (Llewellyn et al 2003). Poor access to health services has also been implicated (Nocon and Sayce 2008). Access to primary care services has been shown to be difficult for people with a learning disability. Emerson and Hatton (2004) explored access to primary care services for parents with a learning disability and identified a number of issues. Some people were not registered with a primary care service provider – of these, some had been registered but had been removed for being overly demanding or aggressive. The study
also found that many people with a learning disability struggled with making appointments. This was either due to a lack of confidence on the telephone, or frustration with negative attitudes and a lack of understanding of learning disability by reception staff.

Another key issue is that health information is often inaccessible to people, including those with a learning disability, who have low literacy skills. This has implications not only for encouraging behaviours that prevent ill-health, (healthy eating, stopping smoking and so on) but also for health screening information, for example invitations for cervical screening. Nocon and Sayce (2008) report the number of women with a learning disability going for cervical screening as between 13% and 47%, compared to between 84% and 89% for the general population. Health information is frequently written at a level that is too difficult for people with low literacy skills. This therefore deprives those who cannot read sufficiently well of a vital source of information about a range of health issues, as well as information about baby care or breastfeeding etc.

2.3.2 Antenatal education

Women with a learning disability have been shown to be vulnerable to stress, anxiety and depression, pre-eclampsia and poor birth outcomes for their baby, such as the need for neonatal special care and low birthweight. Such women are likely to have difficulty accessing good antenatal care, as services are usually not equipped to respond appropriately to their very particular needs (Kapell et al 1998). These needs include: extra time and support for appointments, the opportunity to have the information repeated, information that is presented in a form that the parent can understand, involvement of family carers and understanding the complexity of consent issues. Appropriate antenatal care and support is therefore particularly important for this group of parents. Early intervention from a wide range of health and social care professionals to support parents with a learning disability has been shown to improve outcomes for both parents and their children.

Another area for positive practice is in the provision of health education, which aims to increase control, decrease helplessness and increase a client’s ability to make informed decisions about their care (Rankin 1996). Antenatal education is critical as it can have a positive effect on a family’s experience of having a baby. As soon as a baby is born, parents with a learning disability may find themselves having their parental competence assessed, and this may often happen before parents have had sufficient time to learn and develop their skills as parents. This makes the antenatal period particularly significant, as it offers the parents the time to learn and develop skills, and become more confident before they encounter formal assessment.

It has not been possible to identify any particular research specifically addressing the issues of antenatal education and learning disability. However, research and discussion papers do note that public prejudices and discrimination have both contributed to a situation where people with a learning disability are put off accessing – or in some cases excluded
from – mainstream services which include antenatal classes (Madsen 1979 cited by Booth and Booth 1994).

It is vital that antenatal education is accessible to women with a learning disability. Classes should be enabling and empowering, with facilitators having both the commitment and skills to make sure that each person has the opportunity to gain confidence, develop skills and make meaningful relationships regardless of disability. The attitude of those delivering support to parents with a learning disability is consistently regarded as a crucial factor in determining its effectiveness. Booth and Booth (1994: 18) assert that for people with a learning disability:

“A positive relationship between trainer and parent is one of the most valuable curriculum resources.”

At its most basic level this must mean that information must be presented in an accessible way to parents, in a format they understand and can relate to. There is a shortage of accessible information for people with a learning disability across national healthcare services (Lennox and Kerr 1997, DH 2001). This places people with a learning disability at an immediate disadvantage to their peers as they find it impossible to research any of their concerns independently. This makes them dependent on others for access to information, and translation of that information in an unbiased way.

Resources used in class settings must be highly visual and words should be in plain English, backed up with pictures wherever possible. People with a learning disability often prefer visual and kinaesthetic styles of learning, so antenatal educators must be practical and not intellectual, giving parents the opportunity to try practical skills out more than once. They must be creative in their use of strategies for learning – for example role play, modelling, DVDs and personalised props. Research has shown these examples of practical and visual styles of teaching to be the most effective when supporting parents with a learning disability (SCIE 2005). One of the most important and difficult challenges for people with a learning disability is to be able to transfer the skills they have learnt to new and different situations. Research has shown that effective group teaching positively promotes the generalisation and maintenance of learning through different settings (Booth and Booth 1994). Staff must be flexible in their approach if they are to positively support this group of parents (McGaw et al 2002). They need to be confident and able to identify, and build on, the strengths the family already has, so that parents feel confident and ready to learn new skills and tackle new areas of learning.

Blackford et al (2000) highlight the need for antenatal education tailored to the specific needs of marginalised populations. The need to recognise diversity when it comes to providing antenatal care has been proposed for several years (Maloni et al 1996) but it is unclear what progress has been made in this area.

Women with a learning disability may miss out on appropriate antenatal support for a number of reasons. Many of these reasons reflect the issues highlighted above for healthcare in general. For example apprehension...
about engaging with a service because of previous negative experiences, inaccessible written antenatal resources and a lack of social support. Blackford et al. (2000) also suggest that women with disabilities may be reluctant to attend group antenatal classes due to a lack of confidence and a sense of diminished status. That lack of confidence may also prevent them from raising issues of concern with healthcare providers or other members of antenatal classes.

Antenatal health professionals are in a position to support mothers-to-be with a learning disability in many ways. These professionals provide health checks, screening advice and information about a range of issues relating to pregnancy, childbirth and baby care. They also deliver antenatal classes, putting them in a position to monitor group dynamics and encourage full participation.

Adequate training for antenatal health professionals about how to engage and communicate with parents with a learning disability is therefore very important.

2.3.3 Fathers

Much of the existing research has focussed exclusively on women with a learning disability – overlooking the role and experiences of fathers (Llewellyn, 1990, SCIE 2005). Education and training for parents has historically been targeted at the mother (Booth and Booth 1994) although now that fathers are playing a larger part in parenting, this may change for the better. The engagement with men as fathers in antenatal and postnatal care and education is particularly significant when considering parents with a learning disability. Their role in the family has been found to be quite different – Booth and Booth (2002) attempted to redress the bias of research towards women with a learning disability and rather explored the role of men in the lives of mothers with a learning disability. They concluded that the primary input of the father into the relationship was not the role of breadwinner but was knowledge and skills. This differs considerably from society’s usual perception of what a father might bring to the family and illustrates the importance of involving men right at the beginning of any care, support or education programme.

2.4 Learning disability training for health professionals

Previous research suggests that many health professionals may receive insufficient learning disability training (for example Thornton 1996, Kerr 1998, Dovey and Webb 2000, Powrie 2003, Phillips et al. 2004). It is acknowledged that many professionals in mainstream services have had little training (NHS Executive 1999, Horwitz et al 2000) and this has been cited as an important barrier to effective healthcare (Melville et al 2005). Although there has been little research specifically into the training needs of antenatal health professionals, the learning disability training needs of other groups of health professionals have been studied.

Powrie (2003) and Melville et al (2005) found that general practice nurses had a significant need for learning disability training. Although these studies found that the nurses had positive attitudes
towards meeting the health needs of patients with a learning disability, their knowledge of the specific health needs of this group of patients was low due to lack of training and infrequent contact. Adler et al (2005) found that over half of optometrists in their sample had not received learning disability training. An earlier study (Band 1998) found that only 1 out of 8 optometrists had received specialist training in this area.

Learning disability training for health professionals has been shown to have positive outcomes. A recent research study recognised the educational value of learning disability acute liaison nurses within the hospital setting (MacArthur et al 2010).

Adler et al (2005) showed that an educational programme about learning disability for optometrists improved knowledge and confidence. A training programme for practice nurses (Melville et al 2006) resulted in a self-reported improvement in knowledge, skills and clinical practice. In light of these findings, a tailored learning disability training programme for antenatal health professionals may be effective in making this service more accessible for parents with a learning disability.

2.5 Summary
- An increasing number of women with a learning disability are having children.
- A large proportion of parents with a learning disability have their children removed from their care.
- IQ is not in itself a reliable predictor of parental competence.
- A complex range of factors influences a person with a learning disability’s ability to be an effective parent.
- Poverty, stress and social isolation adversely affect parenting ability.
- Tailored parenting interventions have been shown to improve parenting skills.
- Early intervention improves outcomes for parents and their children.
- People with a learning disability have a higher proportion of unmet health needs than people without a learning disability.
- Adverse pregnancy and birth outcomes in women with a learning disability are related to poorer development in their children.
- Health inequality is a barrier to effective antenatal care.
- Health inequality for parents with a learning disability has many causes. These include social deprivation, aetiology of learning disability and poor access to health services, information resources, health promotion and screening programmes.
- Many health professionals do not receive sufficient learning disability training.
- Learning disability training has been shown to improve attitudes and increase confidence, knowledge and expertise.
The need for effective support for parents with a learning disability was addressed by a project conducted by ACT in partnership with Home-Start (2001-2004). The project, called Making The Difference was supported by the Family Policy Unit at the Home Office. It developed and implemented a parenting support scheme using volunteer parents. The aim of the project was to enable parents with a learning disability to be more effective parents (Cooke 2004). Following on from the success of this project, Mencap, in partnership with ACT, received funding from the Parenting Fund in 2005 to develop and deliver training to established parent support providers. The training was offered free of charge in target areas. 488 participants from a range of occupational backgrounds received the training. Many participants were voluntary or support staff but participants also included social workers and managers, and worked for a variety of organisations such as Home-Start, Sure Start and local groups.

The training focused on several key areas. These included:

- definitions of a learning disability
- the role of the parent and volunteer
- the reality of having a learning disability
- how to disclose concerns about a family
- communication strategies
- child protection issues
- how to access more support.

The initial training was delivered by specialist trainers. However, training packs were left with the relevant organisations so that it could be incorporated into their future in-house training.

The training evaluation reported several successful outcomes. All participants reported increased confidence about what having a learning disability meant to an individual, and stated that the training gave them ideas about how they could support parents with a learning disability. Participants also reported that...
it had given them a chance to explore the responsibilities of being a parent, and an increased awareness of issues specific to parents with a learning disability. Participants also reported an increase in confidence in their ability to disclose any concerns that they have about a family.

This training focused on parenting support. Participants who attended were involved on the whole in post-natal support. Early intervention has been shown to be effective in improving parenting skills. One of the key recommendations from the training was that training was needed during the antenatal period to start preparing for parenthood before birth. Prevention is of paramount importance. In all too many cases, the extra support needs of parents with a learning disability are only recognised after problems have already arisen. When this is the case, removing the child from the parent may be considered. By providing preparation and training during the antenatal period, many problems could be anticipated and avoided.

Although Making The Difference was a success for support staff and social workers, it became apparent that there was a lack of training specifically for health professionals involved in maternity and early parenthood care. Currently, staff involved in these areas, for example midwives and health visitors, often have little or no access to training on disability awareness or the support and communication needs of parents with a learning disability, and no access to support networks to share their knowledge. They also have little opportunity to coordinate work with parent support providers. Mencap, in collaboration with ACT and the NCT, was awarded a grant from the DH to evaluate current practice in maternity and early parenthood services for parents with a learning disability, and to develop a training package targeted at health professionals in these areas.
4.1 Aims
The main aim of the project was to train health professionals working with parents during pregnancy and early parenthood, to be more effective in assisting those with a learning disability – helping them provide accessible, inclusive and appropriate care, support and information. Specifically, the training package aimed to make sure that the range of professionals who work with women during pregnancy, and through the early days of parenting, understand more fully how to engage with parents with a learning disability. This is so that essential information is accessible to this hard-to-reach group. The training also aimed to make these professionals more aware of available complementary parenting support so that public, community and voluntary sector organisations work together to make sure they are meeting the needs of parents with a learning disability.

4.2 Outputs
The project had three specific intended outputs:

- Developing a learning disability awareness training pack, with a focus on the learning or training needs of professionals who work with women during pregnancy and through the early days of parenting.
- Developing an effective parenting resource pack for professionals to use when supporting parents with a learning disability.
- Developing a database of participants to provide signposting facilities to parent support services or helplines, which are sensitive to the needs of people with a learning disability.

4.3 Longer-term outcomes
While the immediate outcomes of the project relate to the professionals who have attended the training, the longer-term goal is to benefit parents with a learning disability and improve outcomes for their children. Although it is not possible to evaluate these outcomes within the timescale of the project, we hope that the following proposed
long-term outcomes will be achieved, to some degree, as a result of the training.

- Parents and parents-to-be with a learning disability, within the project regions, will benefit from increased awareness and person-centred support from professionals involved in their care. They will also gain the knowledge and confidence to fulfil their parenting responsibilities.

- Well-being of the children of parents with a learning disability will be improved as parents start to understand their child’s needs more, and have easier access to more inclusive parenting support services.
The training was developed for delivery, free of charge, in four pilot target regions – Walsall, Derbyshire, Leicestershire and Nottinghamshire. Due to time and budgetary constraints, any more training in these or wider areas will be available after the conclusion of the project. These must be paid for by individual trusts and/or commissioners of local services.

5.1 What informed the training

The development of the training was informed by:

- a review of current resources, services and good practice in antenatal and post-natal care for parents
- steering group meetings with parents with a learning disability, to explore their experiences of antenatal and post-natal care – this included their perceptions of a selection of information books, leaflets and DVDs about antenatal or post-natal care, breastfeeding and baby care
- a survey of midwives in three of the project regions, to explore: their current knowledge of the health and communication needs of people with a learning disability, their training needs, their current level of access to specialist services and resources and how accessible they think their service is to parents with a learning disability.

5.2 Evaluation of the training

The training was evaluated in the following ways:

1 Pre- and post-training self-reports of:
   - knowledge of learning disability
   - understanding of different syndromes
   - confidence in recognising and responding to the specific needs of a person with a learning disability
   - understanding how to make information accessible
   - knowledge of the support that is available to parents with a learning disability
Development and evaluation of the training

2 A general evaluation of the training – participants rated whether the training:

- met its aims
- met participants’ learning needs
- was relevant for the participants’ work
- was clearly presented
- was the appropriate pace
- would be useful for their future work
- venue was appropriate.

3 General comments about the training as a whole.

5.3 Health professionals group exercises

The training developed for this project was pilot training and we hope that it will be more widely available at a later stage. It was important to explore any issues found to be key for antenatal and post-natal health providers so that they may be incorporated into the training in the future. For this purpose, before the training, participants were given the opportunity to: discuss their experiences of supporting parents with a learning disability, establish the key issues for them when supporting this group of women, and consider the perceived barriers to accessible, inclusive support. At the end of the training, participants were asked to generate action plans that they could either follow themselves or would like to be implemented to enable them to support parents with a learning disability more effectively. This data is reported in the results section along with results from data collected in the above methods.
6 Parents’ steering group

6.1 Aims

The aim of the parents’ steering group was to:

- learn about the experiences of parents with a learning disability when engaging with health professionals involved in their care
- identify features of antenatal or post-natal resources that improved their usability, ease of understanding and perceived usefulness to parents with a learning disability
- look at antenatal or post-natal information in different media (DVDs) to explore whether these were more useable and useful for the parents
- explore issues raised by health professionals at the training sessions.

6.2 The parents

Members of the parents’ steering group were recruited through Mencap’s Parent advocacy service, Walsall. Six parents who use this service took part in the steering group meetings. Six meetings took place in total. Not all parents took part in each meeting, with the number of participants ranging from three to five.

6.3 Antenatal and birth stories

The first meeting focused on parents’ experiences of pregnancy and birth. Parents discussed how they found out they were pregnant, what information they were given and whether that information was useful. They talked about their expectations and experiences of labour, and discussed the antenatal care they received from health professionals. Key issues to emerge from this steering group session are presented below:

- Parents often did not know what to expect in pregnancy and birth with their first child, even though they said they had been given information by health professionals.

“I had arrived to the delivery suite really scared and frightened because I had no idea what this woman was going to do to me or what she was going to say.”
Parents’ steering groups

• Most parents had not attended antenatal classes even though they had been offered them.

“I did get offered breathing classes from my community midwife but I had rejected them because I did not like to interact with big groups.”

• Parents would have preferred continuity of care, for example the same midwife throughout.

• Parents recounted positive experiences of midwives and health visitors, and raised the issue of how important it was for health professionals to be “nice”.

• Comments made by health professionals can be taken at a literal level and therefore the tone may be misunderstood. For example “I’m your new midwife. You’re stuck with me.”

• One parent felt that she was not listened to during the birth (about issues of her physical mobility).

• One parent had to walk to the hospital when she was in labour as she had no money put aside for a taxi and no credit on her mobile phone.

“I got to the hospital with great struggle, stopping and going all the way there.”

6.4 Evaluation of existing antenatal and post-natal leaflets

The second meeting focused on evaluating a sample of existing leaflets relating to antenatal and post-natal care. Some of the leaflets were written specifically for parents with a learning disability and some were generic leaflets written for all parents. Parents read the leaflets and then in pairs discussed how easy they were to read, understand and remember, and how useful they were.

Participants read: NCT Bumps and Babies; Off to a Good Start; Clean, Healthy and Warm; Now I Can Crawl; Medact; and CHANGE 0-1. Key issues affecting people’s perceptions of the leaflets are presented below. The positive and negative features do not relate to specific leaflets but to general features that people said affected their usability and usefulness.

Negatives:

• Hard to read.

• Small words.

• Too many words on a page.

• Technical language, too much writing.

• Pictures can be scary when not accompanied by extra information, for example picture of a Caesarean section.

• No pictures of dads or grandparents.

• Too expensive.

• Pictures are confusing if there is too much going on.

Positives:

• Pictures and colour.

• Fewer words on a page.

• Simpler words.

• Text that is easy to follow.

• Clear ordering of information.

• Information that is helpful.

• Photos.

• Free DVDs with magazines.

• Pictures containing only one item at a time.
Other general issues relating to the leaflets are presented below:

- Parents said that they preferred to have someone help them to read information leaflets. They felt that if someone went through the information with them they found it easier to understand.
- More explanation was needed for some information. For example, “It says to hire a vacuum but it doesn’t say where you would get one from.”
- Some information was perceived to be patronising, for example one leaflet “says to turn the plug on but that’s not necessary - it should just say to hoover.”
- One leaflet was reported to be difficult to read, “We could probably read it but we would give up – too many big words.”
- “The bits where the pictures are with the words are easier to remember.”
- One parent found pictures in the baby safety leaflet (for example a baby about to fall out of a highchair) too scary to look at and said she would throw the leaflet in the bin.
- Parents reported that they would often lose leaflets that they had been given. Some parents organised all the information into one folder which was helpful.

6.5 Evaluation of antenatal and post-natal DVDs

The third meeting focused on evaluations of antenatal and post-natal information presented on DVD. Two DVDs were viewed by parents. These were the NCT’s Happy Birthday, and From Bump to Breastfeeding (NHS). Parents generally preferred the Bumps to Breastfeeding DVD – they found it easy to understand, very helpful, and said it contained useful information. Parents liked the pictures – especially pictures of breastfeeding in public.

The parents liked the NCT DVD less. They said the language was too complicated (for example it talked about labour being a “normal physiological event”), and that it would not be easy to remember the information.

Parents reported that they thought the information on the DVDs was useful, and that they didn’t know a lot of it before they gave birth. They also thought that watching the DVDs made them think positively about choices.

“I wish I had seen it – I might have breastfed then.”

“I would need to get it out and watch it when I needed the information. I’m not good at remembering.”

“I need people to tell me the information again and again.”

6.6 Post-natal stories

The fourth meeting focused on parents’ experiences in the early days and weeks after the birth, in hospital and back at home with their babies. Parents talked about their stay in hospital and the care
they received at home from community midwives and health visitors. Key issues from this session are presented below.

- Parents recounted positive experiences of their care in hospital after the births of their babies. They would have preferred to stay longer.
- Similarly, once home, parents reported that they would have preferred the midwife to come around more often, “All the time!”
- Parents were given leaflets about contraception but said they did not understand them.
- Some parents were happy to ask the midwife questions when she came round. However, some parents reported that they are reluctant to speak out when they do not understand information.
- All parents attended baby clinics and found them useful.
- Parents reported that they don’t like to be “talked down to” by health professionals, “I like someone to be firm but not nasty”. “Giving respect” and listening were felt to be important.
- Parents preferred to be told information rather than simply being left with leaflets.
- Support from partners and their own mothers was perceived to be important.
- Parents reported that they would have liked a parenting group on how to be a parent. They would have preferred a group rather than individual sessions.

6.7 Breastfeeding

The fifth meeting focused on breastfeeding. All of the parents in the group had fed their babies formula, although some had briefly tried breastfeeding and given up. The reasons for their decisions were explored in this session. The key issues are presented below.

- “I didn’t think breastfeeding existed.”
- Parents reported that they felt formula feeding would be easier than breastfeeding. However they realised that it was actually harder to make up all the bottles than it would have been to breastfeed. Formula feeding was found to be inconvenient.
- Some parents saw someone breastfeeding and thought “that looks horrible” or “weird”. Parents thought that it was rare to see people breastfeeding in public and this was a factor in them choosing bottle feeding.
- Most of the parents said that they regret not breastfeeding, “My daughter is underweight but she might not have been if breastfed”.
- One parent thought she wouldn’t be able to breastfeed. Staff at the hospital had encouraged her but she had no confidence and felt that she couldn’t. She wished that staff had pushed her a bit harder “in a positive way”.
- Parents felt that more television programmes should show breastfeeding, and in a positive way.

Parents were then asked to give a list of reasons why both formula feeding and breastfeeding were perceived to be easy or difficult – see tables 6.1 and 6.2 below.
Table 6.1 Table to show parents’ perceptions of formula feeding

<table>
<thead>
<tr>
<th>Formula feeding</th>
<th>Difficult</th>
<th>Easy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finding the right teat</td>
<td></td>
<td>Can get someone else to feed the baby or make up the bottles</td>
</tr>
<tr>
<td>Making the bottle up</td>
<td></td>
<td>Could make them up in advance</td>
</tr>
<tr>
<td>Can be too hot or too cold</td>
<td></td>
<td>Not embarrassed feeding in public</td>
</tr>
<tr>
<td>Knowing the right amount</td>
<td></td>
<td>Easier to hold</td>
</tr>
<tr>
<td>Finding the right-sized bottle</td>
<td></td>
<td>Can go out and about</td>
</tr>
<tr>
<td>Sterilising</td>
<td></td>
<td>Get a couple of hours extra sleep</td>
</tr>
<tr>
<td>Sometimes get it wrong if you’re tired</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expensive – milk and bottles</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worrying about if you’ve cleaned them properly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can get thrush from teats</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 6.2 Table to show parents’ perceptions of breastfeeding

<table>
<thead>
<tr>
<th>Breastfeeding</th>
<th>Difficult</th>
<th>Easy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leaky under t-shirts – have to wear breast pads</td>
<td></td>
<td>Quicker</td>
</tr>
<tr>
<td>Have to watch what you eat and drink</td>
<td></td>
<td>Cheaper</td>
</tr>
<tr>
<td>Soreness, blocked ducts, redness</td>
<td></td>
<td>Can express</td>
</tr>
<tr>
<td>People looking at you in public</td>
<td></td>
<td>Healthier</td>
</tr>
<tr>
<td>No privacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hard to use breast pump</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Put weight on</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Parents reported that they felt breastfeeding was healthier than formula feeding. Therefore they were asked to give a list of reasons why they believed this - see table 6.3 below.
Parents' steering groups

Table 6.3 Parents’ perceptions of why breastfeeding is healthier than formula feeding

<table>
<thead>
<tr>
<th>Reasons breastfeeding is healthier</th>
<th>For mum</th>
<th>For baby</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bond with baby</td>
<td></td>
<td>Stops colds</td>
</tr>
<tr>
<td>Health benefits</td>
<td></td>
<td>Stops cot deaths</td>
</tr>
<tr>
<td>Lose weight</td>
<td></td>
<td>Stops hayfever</td>
</tr>
<tr>
<td>Good-shaped breasts</td>
<td></td>
<td>Stops sickness or diarrhoea</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stops asthma</td>
</tr>
</tbody>
</table>

Parents displayed a good knowledge of breastfeeding, including the health benefits for both mother and baby. They also gave many reasons why breastfeeding was convenient, yet none of these mothers had breastfed their own children. One possible reason for this appears to be their cultural norms. The parents reported rarely seeing anyone breastfeeding in public – and in fact, the one example on television that they had seen resulted in the TV mother being asked to leave a café. These findings may be a reflection of the socio-economic and cultural groups that the mothers belong to, rather than an inability to understand information about the benefits of breastfeeding.

6.8 Closing issues

The final meeting recapped the issues raised in the previous steering group meetings, and also addressed issues that had been raised by health professionals during the training. Key closing issues are presented below.

- Feelings about pregnancy: some parents did not understand what was going on in pregnancy, “not a thing – I knew I was pregnant but I didn’t believe it”, “I didn’t know about anything”.

- Feelings about their antenatal and post-natal care: parents wanted more home visits when pregnant, more midwives at night time, more information, more support after the baby is born and positive rather than judgemental support.

- Important characteristics of a good midwife or health visitor: good personal manner, empathy and understanding, openness and honesty – not “going behind our backs”.

- One parent praised Team Around Families (TAF), “I couldn’t ask anything more … she was right on my side … she [the midwife] came to meetings and reported back to the professionals.”

- Issues of informed consent: all of the parents felt they had been asked properly for consent. Some remembered signing consent forms for various tests and procedures, and stated that a health professional had gone through it with them. Some parents could not specifically remember but thought they would have, and did not recall any test
or procedure being carried out against their wishes. One parent felt that her birth plan was ignored.

- Parenting classes were requested by parents, who suggested that topics could include: how to cook on your own; confidence – to talk to others, speak your mind and admit when you can’t cope; how to relax when a child has tantrums; safety tips for children and behaviour management tips.

- All the parents at this meeting said that they had been reported to either social services or the police. They felt that they are judged more harshly than other parents – they have “seen others with mouldy houses, no food, but no social services”. They reported feeling scrutinised and watched. Some still feel stared at and intimidated by neighbours.

Finally, the steering group was asked what they liked best about being a parent:

- “The kids saying ‘I love you Mummy’, ‘You’re my Mummy’, ‘Good morning Mummy.’”

- “When the kids give you kisses and cuddles.”

- “When they wave goodbye on the way to school.”

- “When people say ‘you’ve got lovely kids’, ‘he looks like you’.”

6.9 Discussion

6.9.1 Social isolation

The parents contributed enthusiastically to the steering group sessions. Bonds were formed between parents who had not previously known one another and these parents now keep in touch. The adverse effects of social isolation on parenting stress have been well documented (Feldman et al 2002). Women with a learning disability have been shown to become more socially isolated once they become mothers (Llewellyn and McConnell 2002), and that this increases the risk of mental health distress (Feldman et al 2002), which impacts on the quality of care they give their children. Some of the parents in this study reported that they had few friends, and others that they did not have their family around to support them. Those who did have family close to them said it had been a great source of support during their pregnancy and in the post-natal period.

Many of the parents had not attended antenatal classes although they had been offered them. This raises issues of how to include parents with a learning disability in appropriate and inclusive antenatal education. Antenatal classes not only provide important information that can inform decisions about labour, birth, feeding and baby care, but they also provide a setting where parents can network and make friends. Indeed, encouraging parents to develop meaningful friendships and support one another through pregnancy, and into the early days of parenting, is a key aim of current antenatal education, with studies showing that women attend classes to meet others in a similar situation (Schneider 2001, Jansen and Blizzard, 1999).

Much of the research around positive post-natal mental health emphasises the importance of strong social support.
systems and relationships (Dennis et al 2009, Senguin et al 1999, Usher 2004) and that antenatal education has a part to play in providing a forum for parents to develop their own circles of support. For a vulnerable population such as parents with a learning disability, these friendships may help to reduce the stressful effects of social isolation and the subsequent impact on parenting, adult relationships and both physical and mental health.

Possible ways to make antenatal education more inclusive for parents with a learning disability have been suggested. Blackford et al (2000) suggested that separate antenatal classes for women with disabilities, where mutual problem solving and peer support can be achieved, may be effective. Similarly, a buddy system was proposed, where health professionals initiate contact between mothers-to-be with similar disabilities. Another possibility is that parents are encouraged to attend extra antenatal classes provided outside the healthcare system, for example by the NCT. The NCT is increasingly recognising the issue of diversity, and already runs antenatal classes for vulnerable parents. It is possible that this kind of setting may be appropriate for parents with a learning disability. Building support networks for parents with a learning disability as early as possible should be a key priority for professionals involved in antenatal care.

6.9.2 Resources

Parents in the steering group sessions were asked to evaluate existing antenatal and post-natal booklets, some of which were targeted at parents with a learning disability and some targeted at the general population. Parents consistently preferred the easy-read accessible information, and found many of the other leaflets difficult to read and understand. Inaccessible information is a serious barrier to behavioural change. Previous research in other areas of healthcare has shown that health information is often not available in a form that is appropriate for people with a learning disability (for example Gamble 1998, Saino and Erikson 2003, O'Regan and Drummond 2008). In fact, much healthcare information has been shown to be written at a level that is too difficult for those with low literacy skills. A first step to making sure that parents with a learning disability have the information they need, for effective care of both themselves and their children, is to make sure that they have accessible information. The issues surrounding the provision of more accessible antenatal and post-natal information is explored in more depth in the general discussion.

Parents in this study also reported that they preferred to have support when presented with an information booklet, so they can ask questions and clarify their understanding of the information. This requires a commitment of extra time from the care provider. McConnell et al (2003) argue that antenatal practitioners need more funding so they can give the extra time to support parents with a learning disability.

6.9.3 Breastfeeding

One of the parents who participated in these steering groups had attempted to breastfeed one of her children, but had not been successful. The majority of parents in the group fed formula to
all of their children. However, these parents displayed a good knowledge of the issues surrounding breast and formula feeding, including the costs and benefits of each. They also reported that if they had known how difficult formula feeding was going to be (making up the bottles, checking temperature etc) they would have tried breastfeeding. While watching the breastfeeding DVD, they also commented on how unusual it was to see breastfeeding in public, and how watching the DVD when they were pregnant may have persuaded them to breastfeed. It therefore seems likely that these parents’ feeding decisions were based on social and cultural factors rather than a lack of knowledge. Mothers from poor socio-economic groups have lower rates of breastfeeding than the population as a whole (James et al 1997). As many parents with a learning disability live in socially disadvantaged conditions (Booth and Booth 1993, Feldman 1998), it may be that living circumstances, more than intellectual capabilities, are guiding feeding decisions. More research into the reasons behind feeding choice, and the incidence of breast versus formula feeding in mothers with a learning disability, may help to shed light on these issues.

6.9.4. The role of health professionals

Most of the experiences that the parents had of health professionals, during the antenatal period, their stay in hospital and at home post-natally, were positive. Personal attention was particularly valued, for example one mother’s health visitor had brought her a vase and some toys for the baby on her visit, and another mother’s midwife had “been on my side” during distressing child protection proceedings involving other agencies. However, incidents where health professionals were perceived in a negative light were also clear in their memories. Communication skills, such as an awareness that comments can be taken very literally by some people with a learning disability, would benefit health professionals when supporting this group of parents. Health professionals play a key role in the distribution of antenatal and post-natal information. It is therefore very important that they know how to communicate this information to parents, who may have poor literacy skills or need to be told the same piece of information several times, in an accessible way. Health professionals would also benefit from knowing how to access easy-read resources so they can give them to parents to keep at home.

6.9.5 Attitudes

Finally, the negative attitudes and assumptions of others with regard to the parenting ability of these parents were highlighted. The parents said that they had, at some stage, been reported by neighbours to either social services or the police for poor parenting. This reflects the scrutiny that parents with a learning disability face with regard to their parenting skills. Parents felt that they were judged more harshly than parents who do not have a learning disability.
Parents' steering groups
Research has shown that many health professionals feel uncomfortable and unprepared when supporting people with a learning disability (Slevin and Sines 1996, Philips et al 2004). This is attributed to a lack of specialist training in issues surrounding people with a learning disability, and a lack of knowledge and experience of their care (Gibbs et al 2008). Booth and Booth (1993) argue that with an increase in independent living, it is now even more important for health professionals to learn how to plan and deliver health services. Melville et al (2006) highlight the importance of analysing the specific training needs of health professionals to deliver inclusive care. Such analyses have been conducted for a range of healthcare professionals, such as practice nurses (Powrie 2003), primary healthcare professionals (Melville et al 2006) and optometrists (Adler et al 2005). There is little information available that focuses specifically on the training needs of antenatal professionals. Therefore a survey was developed to identify the specific training needs of midwives in the project regions, with the aim of targeting these needs in the training package.

7.1 Methods

7.1.1 Measures

The survey was based on items shown to be relevant in previous surveys about the training needs of health professionals who support people with a learning disability. Some of the items included in the survey are below.

Training: Have you ever received specialist training in communicating with adults with a learning disability? And, how useful do you feel more training in supporting parents with a learning disability would be?

Health needs: Do you think that women with a learning disability are more likely to have health problems? If yes, what are these? Please rate your knowledge of the additional health needs of parents with a learning disability.
**Communication needs:** Please rate your knowledge of the additional communication needs of parents with a learning disability.

**Inclusive practice:** Is your service accessible to parents with a learning disability?

**Identification of learning disability:** Would you be able to recognise whether one of your patients has a learning disability?

**Access to services and resources:** Do you know where to access extra information or resources that support parents with a learning disability? Do you know how to access specialist learning disability services or professionals when necessary?

**Good practice examples:** Please describe any examples of good practice either locally, nationally or internationally. Give examples of protocol or procedure that have helped support parents with a learning disability (in relation to maternity or early parenthood services).

### 7.1.2 Survey distribution

Approval was given by the relevant research and development departments for the survey to be distributed to midwives. The regional ethics committee confirmed that the survey fulfilled the criteria of a service evaluation and did not therefore need ethical approval. 300 paper versions of the survey were distributed to midwives by their team leaders, 100 surveys in each of the 3 project regions. Collection boxes were placed strategically within the workplace for respondents to leave their completed surveys. The surveys were also sent via email by trust contacts to midwives within these project regions, allowing them to email their completed surveys back to the project team if they preferred. 86 completed surveys were received. 80 of these were left in the collection boxes and 6 were emailed back. The number of paper copies returned indicates a response rate of 27% across the three regions.

### 7.1.3 Participants

Participants were 86 midwives who had spent on average 17.3 years in their current occupation and on average 21.7 years in the NHS. All participants were female.

### 7.2 Training experience

Midwives were asked whether they had received learning disability training. The vast majority (91.9%) reported that they had not. Only 8.1% of those surveyed had received learning disability training.

Asked whether they believed that learning disability training would be useful, 43% reported that they would find this type of training very useful, 53.5% would find the training useful, and only 3.5% reported that they would hardly find the training useful.
7.3 Health needs awareness

Midwives were asked whether they believed parents with a learning disability were likely to have additional health needs. While 66.3% of midwives were aware that parents with a learning disability were more likely to have additional health problems, 27.9% of midwives reported that they would be no more likely.

7.4 Health needs – qualitative responses

Subsequently, midwives were asked to list the additional health needs associated with parents with a learning disability. The responses to this question are reported below. The health needs they listed have been categorised into themes according to the underlying cause – whether:

- the health problem had an underlying physical cause such as epilepsy, respiratory infections, heart disease
- the health need was due to preventable causes, such as those associated with a disadvantaged lifestyle or poor access to health promotion information
- the health problem is potentially due to poor access to health services, for example screening programmes.

What are the additional health needs associated with parents with a learning disability?

<table>
<thead>
<tr>
<th>Health needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Causes</td>
</tr>
<tr>
<td>Physical</td>
</tr>
<tr>
<td>Preventable ill-health</td>
</tr>
<tr>
<td>Access to services</td>
</tr>
</tbody>
</table>
### Key health needs within themes

<table>
<thead>
<tr>
<th>Preventable ill-health</th>
<th>Physical</th>
</tr>
</thead>
</table>
| Nutrition-related, for example poor diet causing:  
  • obesity  
  • anaemia  
  • diabetes  
  • malnutrition  
  • low weight  
Lack of exercise  
Poor hygiene  
Increased risk of infections due to poor hygiene  
Lack of awareness of hazards leading to accidents  
Access to early detection such as smear tests  
Poor understanding of lifestyle choices leading to:  
  • raised blood pressure  
  • heart disease  
  • inability to understand health promotion literature | Physical disability  
Respiratory disease  
Mobility  
Deafness  
Physical problems part of relevant syndrome  
Bladder problems  
Heart conditions  
Epilepsy  
Depression |

### Access to health services

| Difficulties communicating with health professionals  
Understanding routine of health services  
Fear of admitting to health professionals that they need help  
Difficulty attending appointments  
Difficulty accessing care  
Lack of understanding about the meaning of tests  
Poor understanding about the importance of healthcare in pregnancy |
It is acknowledged that some of these health problems have multiple potential underlying causes. For example, heart disease may be associated with a particular syndrome or may be caused by lifestyle choices like smoking. While staff were able to identify some issues shown in the research which are pertinent to people with a learning disability (for example epilepsy, Kerr 2004), other suggested issues have not been indicated in the research as more prevalent in people with a learning disability.

7.4.1 Health needs – knowledge
Midwives were asked to rate their knowledge of the additional health needs of parents with a learning disability. 8.1% reported their knowledge to be good and 1.2% very good. 30.2% rated their knowledge as fair, 57% as limited, and 3.5% as nil.

7.5 Communication needs
Midwives were asked to what extent they were aware of the additional communication needs of parents with a learning disability. 5.8% reported that their knowledge of this was nil, with 40.7% reporting that their knowledge was limited. 34.9% described their knowledge as fair, with only 17.4% describing their knowledge as good and 1.2% very good.

7.6 Identification of learning disability
Midwives were asked how confident they were in their ability to recognise whether a parent has a learning disability. 3.5% of midwives reported that they would be able to recognise a learning disability all of the time, with 59.3% reporting that they would recognise a learning disability most of the time. 33.7% felt they would recognise a learning disability some of the time, with the remaining 2.3% reporting feeling that they would not be able to.

When asked how many parents with a learning disability they had supported over the past year, midwives reported a wide variation in numbers, ranging from 0 to 75, with an average of 3.7. These figures may not be an accurate reflection of the actual numbers of women with a learning disability seen. Rather the variation suggests differences or difficulties in identification.

7.7 Accessibility of service
Midwives were asked if they agreed that their own practice was accessible to parents with a learning disability. Only 1.2% strongly disagreed and 8.1% disagreed. 34.9% neither agreed nor disagreed. However, almost half (48.8%)
agreed that their practice was accessible, and 7% strongly agreed.

With regards to whether the midwives felt that the service they worked in was accessible to parents with a learning disability, a greater proportion disagreed (24.4%) or strongly disagreed (2.3%). 37.2% neither agreed nor disagreed. Fewer midwives felt that the service was accessible to parents with a learning disability as compared to their own personal practice, with 32.6% agreeing and 3.5% strongly agreeing.

When asked if they agreed that they knew how to access specialist learning disability services, 5.8% strongly disagreed and 45.3% disagreed. 27.9% neither agreed nor disagreed. Only 18.6% of respondents agreed and 1.2% strongly agreed.

7.8 Information, resources and specialist services

Midwives were asked if they agreed that they knew where to access specialist resources (accessible information). 4.7% of respondents strongly disagreed and 34.9% disagreed. 26.7% neither agreed nor disagreed. 31.4% agreed that they knew where to access these resources, and 1.2% strongly agreed.
7.9 Examples of good practice

Midwives were asked if they knew of any examples of good practice that were employed when supporting parents with a learning disability. Examples are reported in table 7.1 below.

Table 7.1 Examples of good practice suggested by midwives

<table>
<thead>
<tr>
<th>Are you aware of examples of good practice in your area when supporting parents with a learning disability?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• “First reference is the GP for any related health problems.”</td>
</tr>
<tr>
<td>• “Training on literacy and ways to support anyone who has literacy problems ie font and colour paper to aid reading.”</td>
</tr>
<tr>
<td>• “Picture on leaflets regarding diet in pregnancy.”</td>
</tr>
<tr>
<td>• “Making up of bottle feeds leaflets in pictures.”</td>
</tr>
<tr>
<td>• “Family aid workers visiting three times weekly to assist with other childcare.”</td>
</tr>
<tr>
<td>• “One-to-one parenting classes in home with maternity care assistant done antenatally and post-natally.”</td>
</tr>
<tr>
<td>• “One-to-one teaching of labour and birth with family at home – done by midwife over a number of visits.”</td>
</tr>
<tr>
<td>• “One-to-one antenatal classes.”</td>
</tr>
<tr>
<td>• “Explanations of baby care or feeding etc pictures and explanations in written format.”</td>
</tr>
<tr>
<td>• “Additional time on ward for close support from staff.”</td>
</tr>
<tr>
<td>• “We try to use our maternity care worker to help give extra support by giving her time to provide parenting and support in their own home before the baby is born.”</td>
</tr>
<tr>
<td>• “In the past I have worked very closely with women with a learning disability building up a relationship of trust and good communication. I even taught them how to use the washing machine or hang clothes on the line, as well as feed and bath baby. However I no longer have time for that now.”</td>
</tr>
<tr>
<td>• “It all boils down to having time to look after them properly, preferably in their own environment.”</td>
</tr>
<tr>
<td>• “As part of my training I undertook a study looking into Fragile X syndrome. Their society was very useful and put me in touch with other very useful resources eg CAF directory.”</td>
</tr>
<tr>
<td>• “Access the learning disability link nurse within the hospital.”</td>
</tr>
<tr>
<td>• “Child Concern meeting with other agencies and professionals to come together with parents to meet any needs identified.”</td>
</tr>
<tr>
<td>• “I usually find out if there has been social services contact. From there I will find out if other specialists have been involved with the patient or ask her.”</td>
</tr>
<tr>
<td>• “Find out from the internet names of societies.”</td>
</tr>
<tr>
<td>• “Close families are always a good starting point.”</td>
</tr>
</tbody>
</table>
7.10 Discussion

7.10.1 Knowledge – health needs and communication

Previous research has identified communication difficulties and a lack of knowledge about learning disability as common barriers when caring for people with a learning disability (Adler et al 2005, Melville et al 2006). Results from the current survey showed that many of this sample group of midwives have limited or fair knowledge of the additional communication needs of parents with a learning disability, and an even larger proportion had nil, limited or fair knowledge of their additional health needs.

Mensel (1992) reports that 40-50% of people with a learning disability have difficulty with communication. The importance of effective communication between patient and healthcare provider is well documented. Communication difficulties between healthcare provider and patient represent a significant barrier to effective healthcare (Hart et al 1999, Barr 2004). “Effective communication is essential in providing quality healthcare, being dependent upon the development of a relationship between user and provider” (Sowney and Barr 2007). This may be especially important for midwives, who have several months to develop a positive relationship with the women they care for.

7.10.2 Identification

Midwives reported seeing an average of 3.7 parents with a learning disability in the past 12 months. However, with these numbers ranging from 0 to 75, this may highlight the challenge of identification. Over a third of the midwives surveyed felt that they would only recognise whether one of the parents they support had a learning disability some of the time or never. Most parents with a learning disability have mild to borderline

Are you aware of examples of good practice in your area when supporting parents with a learning disability? (continued)

• “Childrens’ centres also helpful in making assessment and giving training support and supervision.”
• “Have dealt with Mencap on one occasion – extremely helpful and accessible.”
• “Performed visits and assessments prior to delivery and a care package in place.”
• “Joint multi-professional working to achieve antenatal care and delivery.”
• “Mencap.”
• “Sign language course offered.”
• “Study days provided for by the trust.”
• “Working with mother or father individually, giving time and consideration.”
• “Using clock drawings to assist parents with recognition, keeping independence.”
• “Ensuring feedback from parents about their understanding and looking for prompts to help them.”
cognitive impairments (IASSID 2008). These parents may not have their learning disability flagged on their medical notes, and may often go through the system unnoticed. Many parents may not want to be labelled as having a learning disability. They may also not have English as a first language, making identification even more challenging.

Several studies have shown that women with a learning disability often encounter opposition from their family and friends when they announce a pregnancy. Mayes et al (2006) also found that this group of women were likely to receive negative reactions to their pregnancies. Parents with a learning disability are also often the subject of assessment by health and social services. Official labels may, in some cases, not be wanted or necessary for effective support. It is, however, imperative that health professionals are made aware of the signs that someone may have a learning disability, or difficulties with learning, so they give the appropriate support – for example checking they understand the information or providing accessible leaflets.

7.10.3 Access to specialist resources and services

The majority of midwives who responded to the survey did not know where to access specialist resources or services to support parents with a learning disability. Some of these services may not be available to parents with mild or borderline learning disabilities. Some services are available locally (for example parent advocacy services) or nationally (for example voluntary organisations which support people with a learning disability and their family carers). Without accessible information, parents are presented with a barrier to the knowledge they need to develop effective parenting skills or to look after their own health during pregnancy. They are therefore unlikely to feel empowered to make decisions that are right for them, their family and their baby, through pregnancy and beyond.

7.10.4 Need for training

The majority of midwives who responded to the survey had not received any specialist learning disability training, however most reported that they would find it useful. The training needs of healthcare practitioners have been identified as a barrier to providing effective healthcare to people with a learning disability (Thornton 1996). Together these findings support the need and desire for learning disability training for care providers in these areas.
The training

Results from the survey reinforced findings from the literature relating to training health professionals. The training was developed taking account of these findings, focusing specifically on:

- identification of learning disability
- how to communicate with parents with a learning disability, and make both personal and service-wide practice more accessible to this group of women
- lists of resources and specialist services for participants to take back to their workplaces.

8.1 Content

ACT developed the content of the one-day training package. It contained segments of learning relating to the following:

- **Key issues** that participants felt were important when supporting parents with a learning disability.
- **What is a learning disability?** Outlining the differences between learning disabilities and learning difficulties, autism and Asperger’s syndrome, and the differences between learning disabilities and mental health problems.

- A learning disability fact quiz with a focus on parenting facts.
- A case study exploring the needs of a pregnant young woman with a learning disability, focusing on the key issues, how to address those issues and her particular needs.
- How to communicate with people with a learning disability.
- Appropriate and inappropriate terms for people with a learning disability.
- A DVD produced by Newham Special Parenting Project. Excerpts were shown throughout the day, showing parents with a learning disability talking about their experiences with health professionals when pregnant, and after their babies were born.
- Action planning. Discussion of how support for parents with a learning disability can be improved in their area.
8.2 Participants

Participants were recruited via a number of methods. These included the distribution of information flyers and/or presentations to:

- the head of midwifery and health visiting in each project region to distribute to their staff
- maternity services liaison committees
- partnership boards
- Working Together with Parents Network
- Department for Children, Schools and Families
- primary care trust information networks
- La Leche League
- Doulas UK
- National Childbirth Trust.

The training dates for each region were:

- Derbyshire: 15 February, 4 March and 17 March 2010
- Leicestershire: 23 February, 5 March, 25 March and 22 April 2010
- Nottinghamshire: 29 March, 7 April and 23 April 2010

Two training dates (one in Derbyshire and one in Nottinghamshire) were cancelled due to low bookings. The number of participants who booked and attended each training date is presented in the table below:

<table>
<thead>
<tr>
<th></th>
<th>Derbyshire</th>
<th>Leicestershire</th>
<th>Nottinghamshire</th>
<th>Walsall</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Booked</strong></td>
<td>10</td>
<td>12</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td><strong>Attended</strong></td>
<td>9</td>
<td>9</td>
<td>5</td>
<td>21</td>
</tr>
<tr>
<td><strong>Booked</strong></td>
<td>5</td>
<td>18</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td><strong>Attended</strong></td>
<td>5</td>
<td>17</td>
<td>8</td>
<td>17</td>
</tr>
<tr>
<td><strong>Booked</strong></td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td><strong>Attended</strong></td>
<td>6</td>
<td>3</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td><strong>Booked</strong></td>
<td>6</td>
<td>10</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td><strong>Attended</strong></td>
<td>5</td>
<td>5</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td><strong>Total booked all regions: 151</strong></td>
<td><strong>Total attended all regions: 135</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Derbyshire</th>
<th>Leicestershire</th>
<th>Nottinghamshire</th>
<th>Walsall</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Booked</strong></td>
<td>21</td>
<td>47</td>
<td>26</td>
<td>57</td>
</tr>
<tr>
<td><strong>Attended</strong></td>
<td>20</td>
<td>34</td>
<td>21</td>
<td>60</td>
</tr>
</tbody>
</table>
A wide range of professionals involved in antenatal and post-natal care attended the training. These included: midwives, health visitors, nurses, support workers, allied health professionals, doulas, advocacy workers, NCT trainers and children’s centre workers. The number of professionals from each profession is presented in figure 8.1 below.

**Figure 8.1** Training participants

Total numbers for each professional group were: midwives 53; student midwives 14; student nurses 6; nurses 18; allied health professionals 4; support workers 8. ‘Other’ participants included: breastfeeding counsellors 3; Home-Start 1; commissioning managers 1; Learning disability health facilitators 1; volunteers 1; Social workers 4; clinical psychologists 1; advocacy workers 2; development officers 2; doulas 1; family link workers 1; childrens’ centre managers 1; family learning teachers 1.

**8.3 Key issues**

Before the first learning segment, participants were put into small groups and asked to think about the key issues when supporting parents with a learning disability. These issues were subsequently discussed as a whole group. Key issues that were identified as important, for professionals who support parents with a learning disability in an antenatal or post-natal setting, are presented in figure 8.2 below. Key issues were separated into themes.
8.3.1 Key issues within themes

Issues related to either health professionals or parents. Relevant issues for health professionals were further separated into those that involved:

• external support services – for example signposting to specialist learning disability teams and charities, access to available resources etc
• internal systems – issues that were relevant for the internal antenatal or post-natal services, for example having a specialist link worker or needing more time for appointments
• health professionals’ personal skills – for example a lack of knowledge of terminology, communication skills awareness
• parents’ personal skills – for example taking account of differing styles of learning or reading ability
• support for parents – for example financial support or support from family members or friends
• parents’ mental health – for example whether they were more likely to be suffering from mental health distress.

Issues from each of these categories are listed in the tables below.

<table>
<thead>
<tr>
<th>External services or support</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to access services</td>
<td>Where to find accessible information</td>
</tr>
<tr>
<td>Knowledge or awareness of external services</td>
<td>Electronic access to resources</td>
</tr>
<tr>
<td>Working together</td>
<td></td>
</tr>
<tr>
<td>Signposting to external services</td>
<td></td>
</tr>
<tr>
<td>Regional differences in services</td>
<td></td>
</tr>
<tr>
<td>Access to specialist health professionals</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Internal systems</th>
<th>Legal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link worker</td>
<td>Informed consent</td>
</tr>
<tr>
<td>Regular appointments</td>
<td>Child protection</td>
</tr>
<tr>
<td>More time for appointments</td>
<td>Legal rights</td>
</tr>
<tr>
<td>Child Concern meetings or CAF</td>
<td></td>
</tr>
<tr>
<td>Mandatory training</td>
<td></td>
</tr>
<tr>
<td>Shared information or confidentiality</td>
<td></td>
</tr>
<tr>
<td>How to get assessment</td>
<td></td>
</tr>
<tr>
<td>Clarity of roles</td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td></td>
</tr>
</tbody>
</table>
### Personal skills (health professionals)

- Knowledge of terminology
- Communication skills
- Knowledge – how to identify learning disability
- Ability to assess parents’ understanding
- Knowledge of definitions of learning disability

### Personal skills (parents)

- Reading ability
- Education
- Awareness of babies’ needs
- Baby safety
- Understanding labour – pain and process
- Styles of learning

### Support

- Family
- Financial

### Health

- Mental health issues

### 8.4 Learning outcomes

Learning outcomes were measured with questionnaires before and after the training. Training participants were asked to rate the following items on a six-point scale, from poor to very good:

- Knowledge of learning disability.
- Understanding different syndromes.
- Confidence recognising and responding to the specific needs of a person with a learning disability.

- Understanding how to make information accessible.
- Knowledge of support that is available to parents with a learning disability.
- Knowledge of the difference between learning disability, learning difficulty and mental health distress.
- Knowledge of resources available for professionals to support parents with a learning disability.
Significant increases in all learning goals were observed after the delivery of the training.

8.5 Action plans

At the end of the training, participants were asked to reflect on the day’s training and to generate action plans – lists of ways in which support for parents with a learning disability could be improved in their own service. Action points from these plans were separated into themes, these are presented in figure 8.3 below. For the action points, individual issues centred around health professionals themselves, rather than parents, as per the key issues generated at the beginning of the training.

Figure 8.4 Action plans

8.5.1 Themed action points

Participants were able to generate action points they could implement in their practice.
<table>
<thead>
<tr>
<th>External services or support</th>
<th>Internal systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implement multi-agency working, for example La Leche, NCT, Doulas UK</td>
<td>Provision of one-to-one antenatal classes</td>
</tr>
<tr>
<td>Get support from local authority</td>
<td>Birth plans</td>
</tr>
<tr>
<td>List contact numbers for advocacy services</td>
<td>Comprehensive needs assessments</td>
</tr>
<tr>
<td>Include other agencies in care</td>
<td>Focus on prevention not protection</td>
</tr>
<tr>
<td>Set up parenting groups</td>
<td>24-hour service</td>
</tr>
<tr>
<td>Directory of services</td>
<td>Pre-personalised care plan</td>
</tr>
<tr>
<td>Influence NHS or PCT policy</td>
<td>Half-hour appointments</td>
</tr>
<tr>
<td>Checklist of external services</td>
<td>Share knowledge</td>
</tr>
<tr>
<td></td>
<td>Create link or lead workers</td>
</tr>
<tr>
<td></td>
<td>Frequent appointments</td>
</tr>
<tr>
<td></td>
<td>Flagging system</td>
</tr>
<tr>
<td></td>
<td>More home visits</td>
</tr>
<tr>
<td></td>
<td>Mandatory training</td>
</tr>
<tr>
<td></td>
<td>Consistency</td>
</tr>
<tr>
<td></td>
<td>Carry out research or audit</td>
</tr>
<tr>
<td></td>
<td>Individualised services</td>
</tr>
<tr>
<td></td>
<td>Confidentiality on wards</td>
</tr>
<tr>
<td></td>
<td>Single notes</td>
</tr>
<tr>
<td></td>
<td>Care pathways</td>
</tr>
<tr>
<td></td>
<td>Joint training</td>
</tr>
<tr>
<td></td>
<td>Teenage pregnancy special groups</td>
</tr>
<tr>
<td></td>
<td>Extra post-natal support from midwives or health visitors</td>
</tr>
<tr>
<td></td>
<td>Early identification</td>
</tr>
<tr>
<td></td>
<td>Early referrals</td>
</tr>
<tr>
<td></td>
<td>Make reasonable person-specific adjustments throughout process</td>
</tr>
</tbody>
</table>
### Resources
- Make picture symbols available
- Provide accessible information
- Central file of resources in office
- Collate set of references
- Tools to assess current level of knowledge
- Electronic babies
- Aids for mum – baby demos

### Personal skills
- Awareness of own language
- Simplify terms
- Reduce use of jargon
- Use alternative language
- Be positive
- Time
- Patience
- Consideration
- Straight talking
- Use intuition
At the end of the training, participants completed a general evaluation form. They rated whether:

- the aims of the course were met
- their learning needs were met
- the content was relevant to their working practices
- the presentations were clear
- the pace was appropriate
- the learning segments met their training needs.

Results of the general evaluation are presented below.

### 9.1 Were the aims of the course met?

54.1% strongly agreed and 43.9% agreed that the training met its learning aims. Only 1% of participants disagreed.

### 9.2 Was the course content relevant to your work practices?

45.9% of participants strongly agreed and 52% agreed that the course content was relevant to their working practices. 2% disagreed.
9.3 Did the training meet your learning needs?
45.9% of participants strongly agreed and 51% agreed that the training met their learning needs. 1% of participants disagreed.

9.4 Were the presentations clear?
62.2% of participants strongly agreed and 36.7% agreed that the presentations were clear. No participants disagreed.

9.5 Was the pace of the training appropriate?
91.8% of participants rated the pace of the training as just right. 3.1% felt it was too fast, whilst 2% felt it was too slow.

9.6 Individual learning segments
Participants rated each individual learning segment in terms of whether it was relevant to their work practice. Results are presented below:
Most participants agreed or strongly agreed that all of the learning segments would be relevant to their working practices.

9.7 Discussion

9.7.1 Key issues and action points

At the start of the training, participants listed key issues that they felt were important when supporting a parent with a learning disability. The issues were multi-layered, being relevant to individuals, internal systems and external services.

9.7.1.1 Joint working

Participants wanted effective joint working once a person with a learning disability had been identified, and the issue of how to implement it was frequently raised. By the end of the training, participants had suggested some ways to address this issue. These included forming steering groups with all relevant external agencies (for example NCT, acute and primary care trusts, specialist health and social care services, along with other interested voluntary organisations) to formalise protocols on joint working. People also called for closer support for maternity services from specialist learning disability services. A study by Powrie (2003) found that practice nurses wanted stronger links with learning disability services. Sowney and Barr (2006) suggest that community nurses and learning disability nurses have a key role in liaising with accident and emergency staff to improve access for people with a learning disability.

Having people from a range of professions at the training greatly enhanced the learning experience, as they could learn
from each other. This highlights the benefits, not only of inter-professional working, but also inter-professional education for healthcare practitioners.

**9.7.1.2 Time**

At an internal systems level, a recurrent theme was that participants believed there was not enough time allowed to provide the additional support for parents with a learning disability. Participants felt that longer appointments, more frequent visits and more home visits may be appropriate for women with a learning disability.

**9.7.1.3 Identification**

Many participants were concerned that they were unable to recognise if a parent had a learning disability. Also, if the learning disability is mild, the services available to support that parent are greatly reduced. Many of the health professionals stated that there were very clear protocols and services available if a parent had a more severe learning disability, and that in these cases there would be fewer issues. However, protocol was less well defined when the parent fell into the grey area, where learning disability had not been formally recognised and was mild or borderline. As most parents with a learning disability have mild or borderline cognitive impairments (IASSID 2008), this affects many of the parents who will receive antenatal care. Where this is the case and more specialist support is not available, it is important for antenatal and post-natal health professionals to be able to get accessible resources and lists of alternative services (for example Mencap’s parent advocacy service) to offer more tailored support within their own service.

**9.7.1.4 Timing of training**

Many participants felt that the training would be best placed during undergraduate training. This suggestion is supported by the attendance rates on the course. Low attendance for midwives in some of the regions was explained by a lack of time for extra training. Unless training is made mandatory then attendance by practising midwives may not increase. Alternatively, health professionals could receive the training during their undergraduate years, resulting in more midwives being trained and consequently able to spread their acquired knowledge to other midwives once in practice.

**9.7.2 Baby Friendly resources**

Both parents and professionals expressed a need for accessible antenatal and post-natal information. A list of such resources was compiled for distribution at the training. However, concerns were raised by health professionals with regards to whether the resources would meet Baby Friendly standards. Baby Friendly is an initiative by the World Health Organisation and UNICEF. Launched in the UK in 1994 as a hospital initiative, the principles have since been extended to cover community health services. The Baby Friendly initiative offers accreditation to hospitals and healthcare providers that adopt best-practice standards in breastfeeding.

Hospitals and healthcare providers work hard to achieve Baby Friendly accreditation. Part of this initiative requires that formula feeding is not idealised. Unfortunately, many of the
resources written by learning disability organisations contain pictures of mothers bottle feeding their babies. Concerns were raised that use of these resources in hospitals would not be acceptable. Senior midwives and breastfeeding specialists from within the project regions examined all the resources on the list and determined which would be acceptable. Resources that were not considered acceptable were removed from the resources list so that the trusts’ Baby Friendly status would not be jeopardised. There is more about the development of up-to-date Baby Friendly resources that are accessible to parents with a learning disability in the general discussion.

9.7.3 Learning outcomes and general evaluation

All learning outcomes were significantly increased after the training. The training also came out well on the general evaluation questionnaires. Another indication of success was the increase in numbers attending the course after word-of-mouth recommendations from previous participants. Extra training sessions had to be added due to this increase in interest. These findings support the data from the midwife survey, which identified a current lack of learning disability training and a desire for it in the context of their own working practices.

Addressing the learning disability training needs of specific health professionals has been shown to be important for the delivery of inclusive care (Powrie 2003, Melville et al 2005). However, initial uptake of the free training was slow. Nocon and Sayce (2008) note a lack of priority in the planning and commissioning of services to support people with a learning disability. “Primary care trusts (PCTs) in England and local health boards (LHBs) in Wales already have other urgent targets against which their performance is measured and are reluctant or unable to include further non-mandatory work” (Nocon and Sayce 2008 pp. 329). Community midwives in one of the project areas declined to take part in the training, as they mentioned a current priority of other mandatory training.

We hope that the success of the current training will encourage more health professionals to attend future training, and that they will be supported to do this by their management.
General evaluation
The project aimed to develop a training package to enable the range of professionals who work with women during pregnancy, and the early days of parenting, to provide inclusive support to parents with a learning disability. A survey of midwives confirmed a need and a desire for this type of training. Steering group discussions with parents with a learning disability raised issues surrounding accessible information, social isolation and the important role of health professionals in providing effective support. Issues raised at the training included a need for increased joint working, with greater collaboration and communication between relevant agencies. Key recommendations are discussed below.

10.1 Recommendations

- **More widespread training.** The majority of the midwives who responded to the project survey (over 90%) had not received specialist learning disability training. However, most expressed a desire for it. The success of this training package, in terms of learning outcomes and perceptions of relevance to participants’ own practice, suggests a greater need for training of this type. Specialist learning disability training for professionals involved in antenatal or post-natal care should be made more widely available to ensure inclusive care.

- **Training as part of the undergraduate curriculum.** It is acknowledged that antenatal and post-natal health professionals have limited time for training, and that mandatory training would take priority. One solution to this is to include learning disability training as part of the undergraduate curriculum. All new professionals can therefore engage in training around learning disability before entering practice.

- **Coordinated resources.** A main challenge of the project was that many of the accessible resources that were recommended would not reach Baby Friendly standards and therefore had to be withdrawn. Many resources showed inappropriate pictures idealising formula
feeding. Examination of the resources by senior midwives also revealed that many also contained inaccuracies or out-of-date information. This is a major concern. Resources written in accessible easy read by learning disability organisations may contain information about antenatal and post-natal care that is unacceptable and misleading for parents. Organisations that produce up-to-date information that meets Baby Friendly standards do not usually do so in a manner that is accessible to parents with a learning disability (with picture symbols, large font size etc). A key recommendation is therefore the coordination of the production of such information by the relevant organisations. This will ensure that key information is both accessible and accurate.

- **Joint working.** A common action point recommended by participants
on the training was that there should be increased coordination and communication between relevant organisations. These would include health services such as midwifery, health visiting and community nurses, along with learning disability services and also external services such as Mencap, NCT, Doulas UK, La Leche League and so forth. Inter-agency protocols may be in place for parents with more severe learning disabilities, however there are frequently no such protocols for use when a parent has a mild or borderline learning disability.

- **Link workers.** While it may not be possible to train all staff in learning disability due to time limitations, assigning designated link workers may be effective. Link workers would be available to signpost other staff to relevant services and resources, and would act as a central point of contact within the service. Many acute trusts now have health facilitators, who ensure that when a person with a learning disability is admitted, their care is coordinated and support systems put in place.

- **An electronic database of resources, services and useful information.** A central, electronic database that contains links to relevant resources, services and useful information would give all health professionals immediate access to resources that can enable inclusive support for parents with a learning disability. An electronic format would enable greater opportunity to keep the resources up to date.

- **Inclusive antenatal and parenting classes for parents with a learning disability.** Social isolation is a problem for many parents with a learning disability. Mainstream antenatal classes may not be attended by this group of women for a range of reasons. It is necessary to develop strategies to include more parents with a learning disability in antenatal education. This may be through attendance at special classes for vulnerable women, greater support to integrate with other parents in standard antenatal classes or one-to-one antenatal learning sessions.

- **Further research** into the incidence of breastfeeding in mothers with a learning disability and the reasons behind decisions to breast or formula feed. Interventions to encourage and support breastfeeding could then be developed and targeted at this group of women.
Executive summary


Barr O (2004). Promoting Access. The experience of children and adults with learning disabilities and their families or carers who had contact with acute general hospitals in the WHSSC Area and the view of nurses in these hospitals. A Report to the Western Health and Social Services Board. WHSSB, Londonderry.


References


Horwitz SM, Kerker BD, Owens PL and Ziegler E (2000). The Health Status and Needs of Individuals with Mental Retardation. Connecticut Department of Epidemiology and Public Health, Yale University School of Medicine, Department of Psychology, Yale University, New Haven.


Social Care Institute for Excellence (2005). *Helping parents with a learning disability in their role as parents: Research Briefing*.


This report was written by
Joanna Leaviss at Mencap
Wendy Ewins at NCT
Deborah Kitson at ACT
Elizabeth Watling at Mencap

Mencap
123 Golden Lane
London
EC1Y 0RT