MENCAP
Understanding learning disability

ANN CRAFT TRUST
ACTing Against Abuse

The Parenting Fund

'Making the difference': Supporting parents with a learning disability

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Ann Craft Trust, Nottingham.

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Contents

Chapter 1

Introduction to the Issues

Parents with learning disabilities form a significant part of today's society. The proportion of parents with learning disabilities has grown substantially over the past two decades. This rise is attributed to a number of factors including deinstitutionalisation, independent living, community participation and increased sexuality and personal relationships education for people with learning disabilities, coupled with the recent recognition that it is neither acceptable nor ethical to sterilise adults based purely on their cognitive ability. Despite this, conflicting policies, societal attitudes and prejudices mean that instead of celebrating the birth of their children, many parents who have learning disabilities are fighting for services and support, to prove their parenting ability and for the right to keep their children.

In 1995 a policy statement made by Nottinghamshire Social Services stated 'we wish to support parents with learning disabilities in the community. We recognise that such families can succeed, with varying amounts of support from family, local networks and agency services. We wish to develop supports which are tailored, creative and flexible, and which are empowering rather than problem-focused…' This is a close match to the way in which Home-Start works and initiated discussions between the Ann Craft Trust (ACT) and Home-Start for ways to better support parents with learning disabilities. In 2001 ACT, in partnership with Home-Start Nottingham, received funding from the Family Service Unit at the Home Office to carry out a three year pilot project looking at the support needs of parents with learning disabilities. The findings of this study were reported in 2005 (Cooke 2005).

Following the findings from the above study - which highlighted the need for appropriate, accessible support for parents with learning disabilities - Mencap and the Ann Craft Trust applied to the Parenting Fund for a project grant to fund the development and implementation of a training programme for volunteers working with parents with learning disabilities, the funding was received in 2004. Shortly after this the 'Making the Difference' training pack was developed and in April 2005 three training co-ordinators were appointed to deliver and evaluate the training programme in three pilot areas.

The following report has a primary focus upon the evaluation of the 'Making the Difference' training programme. In doing this the background policy, research and practice will be reviewed. The report will offer recommendations for the future of the 'Making the Difference' project and will also draw broader conclusions which will have implications for disabled parents, staff and professionals, organisations and wider society.

Historical Perspectives

The lives of people with learning disabilities have always been greatly affected by the perceptions and actions of others in the society in which they live. Throughout history attitudes towards people with learning disabilities have been those of fear, discrimination, intolerance, and lack of understanding. Attitudes are slowly changing and people with learning disabilities are beginning to get their voices heard when it matters. Despite this move ahead, many people with learning disabilities are still being denied the things that they want.

For most people parenthood is a matter of choice; however for people with learning disabilities who are, or who plan to become parents, the story is somewhat different. Today's disabled parents are still plagued by negative judgements, prejudicial views and stereotypes. To understand why this is, it is important to examine past attitudes towards learning disability, sex, relationships and parenting.

Historically people with learning disabilities have been denied the opportunity to express their sexual identity and so consequently have not had the opportunity to become parents. In the early twentieth century people with learning disabilities were segregated from society in single sex institutions in the fear that they would procreate and 'threaten' society. Even up until relatively recently care staff have been reported to have restrictive attitudes towards the sexual expression of the people they support. Back in the 1900's much of society believed that people with learning disabilities and others with mental health needs or physical disabilities would take over and 'infect' others. This type of thinking spurred the development of the Eugenics movement which was underpinned by a belief that the human race could be improved by eradicating 'defective' genes from the gene pool. During this period many people with learning disabilities were sterilized involuntarily in order to ensure that they could not reproduce. Consequently, people with learning disabilities were prevented from forming sexual and social relationships, and were certainly not 'allowed' to become parents.

The Eugenics movement was quickly discredited, however some of the basic ideas of the movement still continued to affect the lives of people with learning disabilities. Studies in the early 1970's found that 80% of parents, carers and support staff supported sterilisation (whether voluntary or involuntary) as birth control for people with learning disabilities (Alcorn 1974, Whitcraft & Jones 1974, cited in Aunos & Feldman 2002). More recent research indicates that this attitude has changed very little in twenty years. Wolfe found that the majority of school staff in his 1997 study supported sterilisation as a means of birth control for people with learning disabilities.

It is increasingly being recognised that people with learning disabilities have the same sexual needs and desires as people who do not have a learning disability. Sexuality is a key concept of 'normalisation' which emphasises the importance of individuality, choice, opportunity and inclusion for people with learning disabilities.

> 'To be a human being is to be a sexual being. Although there may be a range of intensity, varying over time, we all have sexual needs, feelings and drives, from the most profoundly handicapped to the most able among us. Although we can shape (and mis-shape) sexual expression, sexuality is not an optional extra which we in our wisdom can choose to bestow or withhold according to whether or not some kind of intelligence test is passed.'
>
> Ann Craft, 1980

Despite this leap forward with regard to sexual rights for people with learning disabilities societal attitudes have still got a long way to go before people with learning disabilities have truly equal sexual rights. Today this is echoed in people's treatment of, and attitudes towards, parents with learning disabilities and the support available to disabled parents.

Current Practice

The number of parents with learning disabilities is growing steadily and so too are the number of disabled parents known to social services departments. In 1997 McGaw estimated that there were around 250,000 parents with learning disabilities known to social services departments in the UK. More recent figures indicate that there are 2.1 million disabled parents in the United Kingdom (Stickland, 2003), however actual numbers of parents with learning disabilities are unknown.

When discussing the current situation for parents with learning disabilities it is important to be aware of the legislation and guidance affecting both parents and children. Over the past 10 years there have been some major legislative changes affecting the lives of parents with learning disabilities, some of which have been developed in direct response to the needs of people with learning disabilities. Below is a brief description of current guidance and legislation and the implications for parents with learning disabilities;

- The **Children Act 1989** does not assume that children are "in need" simply because a parent has a learning disability. It does assume, however, that children are best cared-for within their own family, which implicitly suggests that parents should receive any support they need to perform their parenting role, and therefore protect the welfare of the child.

- **National Health Service (NHS) and Community Care Act 1990** aims to enable people with physical or other needs to live in their own homes - this explicitly includes disabled parents. Local authorities are required by this Act to carry out assessments of anyone who appears in need of community care services. If the person being assessed is disabled then according to related legislation cited in the Act, the practical needs of that person, in terms of their "greater safety, comfort or convenience," must be assessed.

- The **Community Care (Direct Payments) Act 1996** enables local authorities to provide payments in lieu of services directly to those who have been assessed as being in need. This may include services to support parenting.

- The **Human Rights Act 1998** dictates that there should be no discrimination in access to services on grounds of disability. The Act also gives individuals the right to marry or have a family and states that cultural and linguistic differences should be taken into account in the provision and delivery of services.

- **Part 3** of the **Disability Discrimination Act 1998** covers the provision of goods, facilities and services. This Act sets down that it is unlawful for a service provider to discriminate against a disabled person. Local authorities, as well as the voluntary and independent sector, must ensure that any services offered to parents are equally available to parents with disabilities or impairments. The Act also demands that these services and organisations "promote equality of opportunity" for disabled parents.

- The **Framework for the Assessment of Children in Need and their Families 2000** describes a framework for assessing children's and family's needs to identify "whether the child being assessed is in need . . . and which services would best meet the needs of this child and their family". This implies that services should not be solely children centred but should also consider the needs of other family members.

- The **Health and Social Care Act 2001** enables parents to access direct payments via the Children Act 1989 to prevent their child becoming or being categorised as "in need".

- **Valuing People 2001** is underpinned by the values of choice, independence and inclusion for people with learning disabilities. The White Paper states that the Department of Health and Sure Start should work together with the National Family and Parenting Institute "to ensure that the needs of parents with learning disabilities are recognised".

- The **Every Child Matters: Change for Children** programme is a new approach to the welfare of all children and young people. It is focused around the five 'Every Child Matters' outcomes, which aim for all children and young people to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being. However, it is also intended to deliver better information and support to parents and carers who need help, from maternity right through to teenage years.

- The **Fair Access to Care 2003** guidance provides councils with a framework for setting their eligibility criteria for adult social care. It emphasises that reviews of individual service users' circumstances should be carried out by appropriate council professionals on a regular and routine basis. This guidance document recommends that local authorities acknowledge and support the possible needs of disabled parents in their "parenting roles and responsibilities". This includes parents who may themselves have additional care or support needs.

- The recent government report **Improving the Life Chances of Disabled People 2005** sets out a programme to support "disabled people to help themselves" by participation and inclusion.

In 1973 it was reported that in England only 30% of parents with learning disabilities had legal custody over their child (Scally 1973). There is growing evidence to suggest that despite the above legislation the capacity of parents with learning disabilities is still being underestimated and the right support is not available to parents with learning disabilities. In support of this statement are findings by Booth (2000) which show that parents with learning disabilities face additional barriers compared to parents who are not disabled and in fact often have their parenting skills judged against stricter criteria than non-disabled parents. If people with learning disabilities are to be given the same rights as everyone else, it is essential that the right to be a parent is included.

Myths about parents with learning disabilities;

- ☒ The children will be disabled
- ☒ Disabled parents will have a large number of children
- ☒ Disabled parents will be inadequate parents
- ☒ Disabled parents cannot learn parenting skills

Espe-Sherwindt & Crable 1993

Although research has shown that there *are* increased risks to children whose parent(s) have learning disabilities including antenatal risks, development delay, behaviour problems, language delay and increased risk of abuse and neglect, when this claim is explored in more depth it appears that the relationship between learning disability and parental competence is a tentative one (Tymchuck 1992). Research which has demonstrated the effectiveness of parental education programmes and ongoing appropriate support has suggested that the parental competence of people with learning disabilities may be affected by other factors (McGaw and Sturmey, 1994).

Environmental factors associated with disability are hypothesised to have a huge effect on the competency of parents with learning disabilities. Factors such as poverty, single parenting, social isolation, unemployment, financial difficulty and housing problems directly affect family life (Dowdney & Scuse1993).

A further explanation for the perceived incompetence of parents with learning disabilities has been offered by Booth and focuses on the policies and practices of services for parents with learning disabilities. Booth (2000) found that parents with learning disabilities were less likely than non-disabled parents to have adequate support before care proceedings took place and were also less likely to receive support in changing the circumstances which led to child protection proceedings being initiated. The findings of this research also seems to show that when it comes to parents with learning disabilities who are involved in child protection cases the boundaries are somewhat different to those for non-disabled parents. They are likely to have their parental competence judged against stricter criteria and hence are at risk of having their children removed based on evidence that would not be accepted for non-disabled parents.

At present much of the support available for parents with learning disabilities is fragmented and crisis driven, and despite national frameworks for disabled parents there is a huge variation in services based on geographical location. There are often disputes with social services departments when it comes to deciding who should provide services to disabled parents and their families as their needs fall between the Children and Families team and the Learning Disability team (Morris 2004). For many people the support that they receive is child-focused and although this may be perceived to be beneficial to the child it means that the needs of the parent(s) are overlooked. This type of competence inhibiting support deskills the parent, not allowing them to build on their strengths as a parent or learn any new skills. Similarly, because parents with learning disabilities tend to have small support networks which are often 'service centred' (Rosen & Burchard 1990), and information resources are not accessible to them parents may find themselves turning to 'child protection' professionals in their time of need. The conflicting responsibilities for child protection professionals inevitably lead to higher percentages of child protection proceedings for parents who try to access support in this way, compared to those who have other avenues of support. Finally, many people with learning disabilities have had negative experiences with social services in the past and so are reluctant to ask for help, consequently many people only ask for help or get referred in a crisis. These factors highlight the importance of increasing voluntary sector support for parents with learning disabilities.

Until recently parenthood for people with learning disabilities has been studied in a vacuum, without consideration of the social context in which parenting takes place. More recently however, researchers have started to study parenting as a social interaction hopefully leading to new ways to support parents. Social support has a profound effect upon the way in which we think and feel about ourselves and others around us. There is overwhelming evidence to suggest that social support has a stress buffering role and has a positive effect upon physical and psychological well-being (Cassell 1976, Cobb 1976). Peers and social contacts for people with learning disabilities appear to play a similarly important role increasing life satisfaction and buffering stress as they do for people who do not have learning disabilities (Edgerton et al 1984). Despite this, relatively little is known about the social networks of parents with learning disabilities. Recent studies have consistently highlighted the importance of social support for parents with learning disabilities. Tymchuck and Andron (1990) found that those disabled parents who had higher levels of social support were less likely to have abused or maltreated their children. There is growing evidence to suggest that practical and social support may enable parents with learning disabilities to parent with improved competence and, crucially, to avoid being identified as neglectful parents when they fail to carry out some aspect of child care which they did not understand might cause harm to their children (Booth & Booth 1993; McGaw, S. 1997; Cooke 2000). Worryingly then, mothers with learning disabilities are among the most socially isolated people in the community, they tend to have small support networks which are service centred and short term. Booth and Booth (1995) revealed that parenthood may increase social isolation for people with learning disabilities and much research has shown that there is a noted absence of friends in the support networks of parents with learning disabilities, for example not one of the parents in Cant's 1993 study had friends who were also parents. This highlights the importance of schemes such as Home-Start where the majority of volunteers and support workers are parents themselves.

It is not enough for social support to just be available to families, it must also be appropriate and acceptable to the family. Relationships can be restrictive and poor support can actually be detrimental to parenting (Tucker & Johnson 1989). This was demonstrated by Booth and Booth (1994) who found that presumed incompetence, negative attitudes and not being listened to actually increased perceived parenting stress. This finding is particularly salient in relation to familial support. Family support is central to many disabled parents support networks, however support from family can often be constraining and competence inhibiting for parents. This was demonstrated by Tucker and Johnson's (1989) research which revealed that in many cases families intervene 'for the good of the child' and parents reported feeling 'belittled' by family members attempts to discipline their child without consulting them. Support from professionals can also be detrimental to parents with learning disabilities. Untrained staff with a lack of flexibility, negative attitudes and competence inhibiting practices can lead to increased stress and cause reduced parenting competence (Llewellyn

1995). Research by Llewellyn and McConnell (2002) that explored the support networks of mothers with learning disabilities supported previous findings that they are among the most isolated people in society. The authors suggested that formal support may be more beneficial if professionals and support staff use their time to facilitate family ties and to support parents to meet friends and neighbours rather than maintaining reliance upon professional relationships.

In order for support to be effective in increasing parental competence a number of basic principles must be adhered to. It is essential that the support is empowering, person centred, flexible, non-judgemental, individualised, non-threatening, acceptable to the person receiving it, competence promoting and support must be offered right from the start (Llewellyn & McConnell, 2002). In addition to this Ray et al (1994) emphasise the importance of ensuring that the volunteer or support worker is well matched to the family that they are supporting. Being person-centred is of particular importance in this model - Llewellyn (1995) suggests that support is most acceptable to parents when it matches the support that they think that they need. This implies that parents should be consulted and allowed to self-direct the support they receive. A whole family approach should be adopted. In a study by the Department of Health, ('A Jigsaw of Services' 2000) it was found that very few local authority services focused on the whole family, instead the focus was either on the child as a 'child in need' or the parent as an 'adult with a learning disability'.

Today support for parents with learning disabilities is inconsistent. There is an overwhelming need for independent family support services with staff that possess the skills and knowledge to provide effective, acceptable support to families where one or both of the parents have a learning disability. In recent years numerous pockets of good practice have developed thanks to specialist local and regional projects by voluntary organisations. We now want to bring this good support into the mainstream by enabling all types of parent support providers to work with parents with a learning disability. The Home-Start and Sure Start schemes already provide an effective model of support for parents who are not disabled, however at present the majority of support staff in these organisations only receive basic disability awareness training as part of their standard induction. More in depth training is required to enable these staff to provide more effective support to disabled parents. The 'Making the Difference' training pack was developed in response to this need.

Development of the Training Pack

In 2004 Mencap[1], in partnership with the Ann Craft Trust[2], successfully applied for funding from the Parenting Fund to develop and deliver training to established parent support providers to improve and expand their work with parents with a learning disability.

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[1] Mencap is the leading UK charity working with children and adults with a learning disability and their families and carers. Its main activities are campaigning, housing and support, education and employment and community support.

[2] The Ann Craft Trust (ACT) is a national registered charity committed to the protection of people with a learning disability from abuse. ACT works with staff in the statutory, independent and voluntary sectors in the interests of people with learning disabilities who may be at risk from abuse. ACT responds to the needs and concerns of professionals by providing information and advice, peer group support and networks, publications, research and training, seminars and workshops.

Between 2001 and 2004 the Ann Craft Trust completed a three-year project aimed at supporting parents with a learning disability. The project used a small group of Home-Start Nottingham volunteers, who visited local families where the parent(s) had a learning disability, to offer ongoing support in the care of their children. The volunteers received the usual training and support offered by the Home-Start co-ordinators. This was supplemented by additional training in supporting parents with a learning disability which was delivered by ACT and others. The aim of this project was to enable parents with a learning disability to develop parenting skills by facilitating access to appropriate parenting support. It aimed to do this by training established parent support providers to work with parents with a learning disability, in addition to their current user group.

The Ann Craft Trust's research and training of volunteers supporting parents with learning disabilities clearly showed that with the right level of training and support volunteers were able to support parents effectively in the community and empower them to access services. This project aimed to build on the lessons learned and to develop a training pack and facilitate the training across three regions in the UK. This training would be accessed and the pack used by parent support providers to enhance their service provision and help them to understand the issues for parents with a learning disability, and how they can best support these parents.

The 'Making the Difference' pack was developed by the Ann Craft Trust in consultation with a number of specialist professionals. The pack includes information on communication strategies, child protection issues and where to go for further support. The training enables parent support providers to extend the scope and range of their services to include a hard-to-reach group of parents.

The sessions in the pack are:

- What is a learning disability?
- The role of the parent and the volunteer
- The reality of having a learning disability
- Disclosing concerns
- Professional/friend, attachment/detachment
- Supporting parents with a learning disability.

Apart from the course content the pack also includes learning outcomes, overheads, training materials, session timings and trainers notes. It is designed in an 'easy to deliver' format which means that once the organisation has received the training, they can then deliver the training themselves from the pack, thus ensuring consistency and continuity.

The pack can be used flexibly – organisations can offer a 2-day training course or they can divide the pack into bite-size sessions, using the exercises that are most useful for their volunteers and staff. There are training notes for each session as guidance but they are not prescriptive and can be adapted to meet the needs of the organisation and the trainer's preferred style. The pack is presented in a ring binder which means that trainers can add information to it as necessary.

The Ann Craft Trust facilitated training days with the three regional co-ordinators at the beginning of the project looking at the delivery of the training pack to parent support providers. The regional co-ordinators have since promoted, delivered, assessed and monitored the training pack. They have delivered a series of free training sessions to parent support providers to introduce the pack.

It is widely acknowledged that people with a learning disability can be very good parents if they receive the right support. However, for many, the support is simply not available. The impact of appropriate support on families headed by a parent(s) with a learning disability is vast. Support can help to keep families together, prevent children from being taken into care and provide a better environment for the children to develop. It is hoped that this training will have enhanced the knowledge and skills of parent support providers to address the needs of parents with a learning disability, leading to better outcomes for the whole family.

This report takes an evaluative look at the training pack, it explores the impact of the training, and considers feedback received from training participants and training co-ordinators from the participating organisations.

The report concludes by considering the findings of the evaluation which then form the basis for a set of recommendations for future training and practice.

Chapter 2

Evaluation Methodology

Design

The present research is an evaluative study which combines a pre - post and cross-sectional design. The study utilizes both quantitative and qualitative methodologies in order to increase the validity of the findings. The evaluation is split into three discrete sections; training content, attitude and behaviour change and views of the organisation.

Study One: Training Content

Participants

All participants who attended the training were asked to complete the training content evaluation form. In total 488 returned the completed form between June 2005 and February 2006, all those who completed the form were included in the analysis. Age and gender demographics were not recorded for the groups and the training groups were comprised of people from varied occupational backgrounds.

Measures

The training content was evaluated using a multiple choice form which was developed using the aims and objectives from the Making the Difference training pack. Each question aimed to determine how the training affected participants skills in specific areas. Responses were recorded on a 5 point ordinal scale. See appendix 1 for training content evaluation form.

Procedure

Upon completion of the training programme participants were asked to participate in the evaluation of the training programme. Participants were give the appropriate time to complete the questionnaire. At the end of the session the forms were collected by the trainer. Participants were asked not to identify themselves on the questionnaire so to ensure confidentiality.

Study Two: Attitude and Behaviour Change

Participants

All participants who took part in the training were asked to fill in both the pre and post training case studies. Age and gender demographics were not recorded for the groups; however we do know that the job roles differed both within and between the groups. The majority of participants were voluntary or support staff, but in addition to this a number of trained professionals such as social workers, managers and health care professionals also attended the training. Only those participants who returned both parts of the case study were included in the analysis. Participants took part in the evaluation on a voluntary basis.

Measures
A case study of a mother with learning disabilities was developed to measure attitudes and planned behaviours both prior and subsequent to the training. The case study was designed to measure changes in practical and theoretical knowledge as well as highlighting attitudinal shifts and increased awareness. A copy of the case study can be found in appendix 3.

Procedure
Following the training introduction the participants were asked to fill in the pre case study. They were given 20 minutes to complete the case study and the trainer was available to answer any questions relating to the study. The case studies were collected by the trainer at the end of the allocated time. All responses to the cases studies were confidential.

On completion of the training programme participants were asked to fill in the post case study. The procedure was as above.

Study Three: Views of the Organisation

Participants
A total of XX training co-ordinators took part in the semi-structured telephone interviews. Most of the training co-ordinators who took part had also attended the training. As above, all participants took part on a voluntary basis.

Interviews
A semi-structured interview schedule was developed to explore the enduring effects of the training on the participants practice and also to gather more general information about the organisation and the support they offer to parents with learning disabilities.

Training coordinators were contacted by post a minimum of two months after the training had taken place in order to allow for implementation of the training (a copy of the letter can be found in appendices 4). Letters were followed up two weeks later with a phone call to the organisation. Following verbal consent from the coordinators semi-structured telephone interviews were conducted. Due to time constraints interviews lasted around 15-20 minutes. The interviewer explained about the evaluation study and proceeded to ask a series of predetermined questions about the organisation and the training programme. All interviews were transcribed by the interviewer. Upon completion, opportunity was given to ask questions and the organisations were offered further support from the Ann Craft Trust in the future.

Chapter 3

Results

Study One: Training Content

Overall 488 participants took part in the training and returned the training content evaluations forms, all responses are included in the analysis below, none have been excluded from the analysis.

Initial inspection of the frequencies indicated that the overall training content was rated positively by participants who took part in it. The mean values of the scores fell between 1.56 and 2.03 which indicates that most responses to the questions fell at the positive end of the scale between 'a lot' and 'yes'.

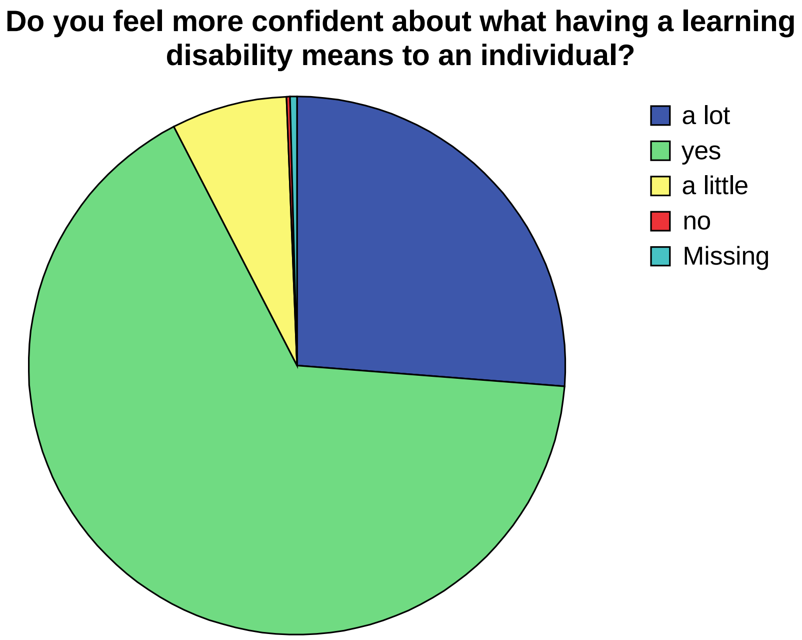
Fig. 1. Mean scores on training content evaluation forms

Question	Mean Score*
Do you feel more confident about what having a learning disability means to an individual?	1.81
Did this training give you a chance to explore the responsibilities of being a parent?	1.95
Did this training give you ideas about your role as someone who can support parents with learning disabilities?	1.80
Was the video helpful in giving you a greater understanding of what it is like to have a learning disability?	1.56
Do you now feel more confident about disclosing any concerns you may have about a family?	1.95
Do you have a greater understanding of the complexities of working as a supporter who is neither a professional or a friend?	1.98
Do you know where to get more information or support for a parent with a learning disability?	2.03

*Score range from 1-5; **1**-a lot, **2**-yes, **3**-a little, 4-no, 5-not at all.

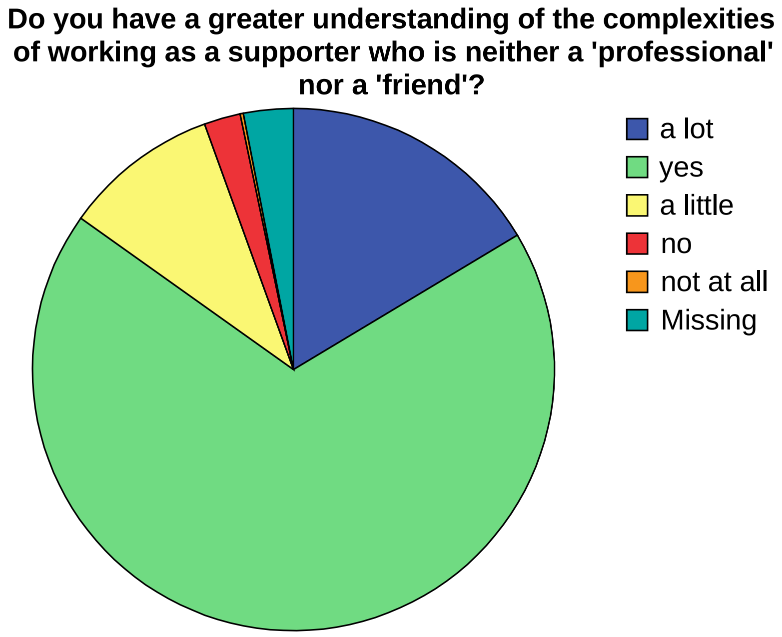
Awareness Raising

Following the training 99.8% of the participants had a greater awareness of learning disability and what this means to an individual, the training played a vital role in raising awareness of learning disability. More specifically the participants found the training video particularly useful, with 99.6% of participants reporting that the video was instrumental in facilitating their understanding of the barriers that people with learning disabilities face. This finding is supported further by the analysis of the pre and post case studies which highlighted a number of attitudinal shifts in the participants.



Professional or Friend?

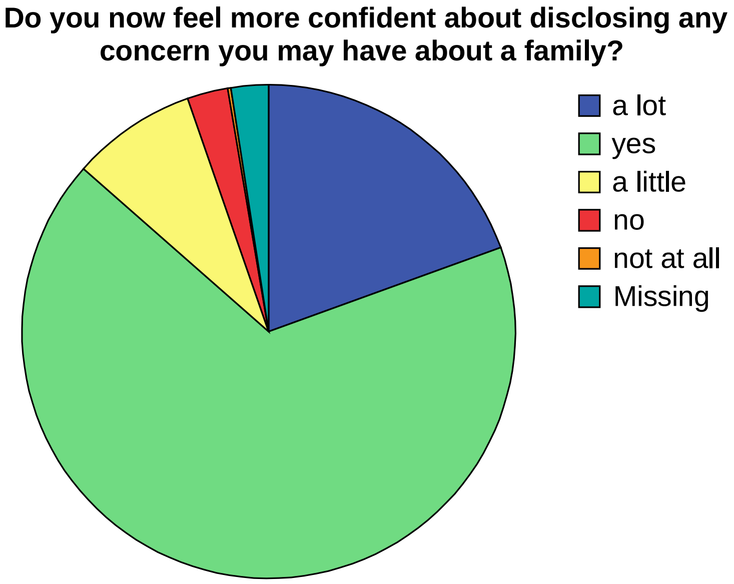
The training appeared to effectively clarify the volunteer/support worker role as someone who supports parents with learning disabilities. *Every* participant reported that the training provided them with ideas about how they could support parents with learning disabilities. This is succinctly illustrated in the findings of the pre and post case studies which will be discussed further in the following section. The training also facilitated the participants understanding of the complexities associated with working as a volunteer/support worker who is neither a professional nor a friend. Despite this a small proportion of the participants did not emerge from the training with a better understanding of the relationship between the volunteer and the service user. Of the 488 participants who answered this question 13 (2.5%) felt that the training had not addressed this issue. Due to differing organisational policies this issue is very hard to address particularly in a multidisciplinary group of participants. Whilst the majority



of organisations reported actively discouraging friendships between volunteers/support workers and service users in the telephone interviews, feedback to trainers throughout the training showed that in some cases organisational policies were not clear, and consequently role boundaries were misunderstood with many people confusing friendly support with friendship. This finding is further supported by the findings from the pre and post case studies in which many respondents said that they would become friends with the parent when asked what support they felt that they could offer. This finding persisted in both pre and post case studies which indicated that perceptions of their role had not changed significantly subsequent to the training. This point will be discussed in more detail in relation to the findings of the cases studies and again in the recommendations section in the final report.

A further explanation of this finding may be attributed to the fact that many people who attended the training sessions were not volunteers but were working with the parents in a professional capacity, consequently this aspect of the training was unlikely to have an effect upon their roles.

Disclosure



Encouragingly 97% of participants reported feeling more confident about disclosing their concerns about a family. It appeared that the remaining 3% of those trained using the Making the Difference pack still felt that they lacked the confidence to disclose their concerns. However, this may simply be because many of the participants already felt confident about disclosing their concerns, so the training had no effect. If this is not the case, it is particularly worrying considering the vulnerabilities that this client group is faced with and may be demonstrative of the above misconceptions about volunteer relationships with the families that they support. Trainers always emphasised the importance of discussing any concerns with the organisation's manager. Where it was felt that people were unconfident about raising their concerns, trainers always tried to suggest how they could increase their confidence, by accessing internal training or looking at their organisations policies and procedures. However, this issue is hard to address in this context and highlights an issue that needs to be further addressed by organisational training and policy. Future training programmes may benefit from more in-depth information and discussion about disclosure, this may be best delivered by a representative from the respective organisation in order to ensure that the information is both accurate and relevant.

Information Needs

Following the training it appeared that almost all (99%) participants felt that they knew where to find more information for disabled parents. This is an encouraging finding, however it was occasionally contradicted when participants were asked if they felt anything should be added to the training. A significant number of participants suggested that they would like further information about local services for parents with learning disabilities. This may reflect unrealistic views about services for parents with learning disabilities held by the participants, and inadequacies in service provision for disabled parents. There were very few specialist services in the areas in which the training took place, even in the areas where specialist services did exist there were no more than one or two. The training pack contains details of both local and national organisations that can provide support, however, it may be beneficial in future training to further highlight the lack of specific services for disabled parents and emphasise the importance of enabling parents with learning disabilities to access mainstream services.

Study Two: Attitude and Behaviour Change

A random sample of 40 pre and 40 post training case studies was selected from each area, resulting in a total of 240 case studies (120 Pre, 120 Post) in the final sample. Initially the data was analysed separately for each region, however following initial inspection of the emergent themes we decided to combine the areas as there were very few differences between regions. The responses from the case studies were analysed using thematic analysis to allow us to discover explicit and implicit themes in the responses. In order to do this the responses from the case studies were broken down into 'meaning units'. A meaning unit is a piece of information that contains **one** meaning. For example the following statement has two meaning units;

"*I would empower her* and *act as an advocate*"

These meaning units were then grouped into themes and analysed below, each question is addressed individually.

Question One: What help do you think this person may need?

This question is about the participants perceptions of what kind of support the mother may need. The question is designed to identify how the training changes participants perceptions of the mothers needs.

The response rate to the case study questions increased quite dramatically following the training. In the responses to the pre case studies a total of 345 meaning units were extracted compared to 519 in the post training case studies. Regardless of content this shows that participants have increased their understanding of the issues faced by parents with learning disabilities which hopefully will enable them to give more effective empathic support. This finding was further substantiated by the outcome of the thematic analysis performed on the data.

The following themes were identified in relation to the above question;

- ***Emotional Support***
- ***Practical Support***
- ***Social Support***
- ***Parenting***
- ***Access to Services and Community Resources***
- ***Advocacy and Empowerment***

In addition to these themes it is worth noting that prior to the training 2.3% of people stated that they 'didn't know' what support this mother may need on the pre training case study. None of these participants offered any suggestions. It is a testament to the training then, that following the training every respondent gave at least two answers to this question.

The table below shows the percentage of meaning units related to each theme both before and after the training, these will be discussed in more detail below.

Table XX. Shows percentage of meaning units in each theme for pre and post data

	Pre (%)	***Post (%)***
Emotional Support	13.6	12.9
Practical Support	35.1	32.0
Social Support	11.6	12.3
Parenting	18.8	13.3
Access to Services and Support	18.6	25.6
Advocacy and Empowerment	0	3.9
Don’t know	2.3	0
Total	100	100

Theme 1: Emotional Support

This theme focused on the emotional aspects of support that the mother may need. The size of the theme stayed fairly constant across both pre (13.6%) and post (12.9%) measures, however the content shifted from general comments in the pre measures to more specific suggestions in the post measures. The majority of people in the pre measure used terms such as ‘help’ or ‘support’ but did not elaborate any further on what type of support they thought the mother may need except in some cases to say ‘emotional support’. In contrast with this the responses to the post training case studies were more specific in nature, participants talked more about encouragement to achieve goals, confidence boosting support and support to help raise her self esteem.

This result is not unexpected. The training does not aim to increase the *level* of emotional support offered by the support workers, instead it aims to increase the *quality* of support to provide a more insightful, appropriate and targeted level of emotional support to families. It is important that the training did not foster dependent relationships between supporters and parents by basing the relationship on emotional support. The supporter’s role should be one of a facilitator, supporting people to become more independent, giving support to find solutions to practical challenges and facilitating links within the local community. The above finding coupled with the issues that are discussed in the following sections show that the training is key in working towards this vision of the support worker as a facilitator.

Theme 2: Practical Support

Both before and after the training a large number of the responses to the case studies related to practical aspects of support, 35.1% and 32.0% respectively. It was possible to split the theme into the following sub-themes;

- ***Support with maintaining routines***
- ***Household and domestic support***
- ***Support with bills, benefits and form filling***
- ***Support to travel to and attend meetings/appointments***
- ***Childcare***
- ***Communication***

These sub-themes persisted across the training, with very few significant changes between pre and post training measures. This may be because the needs of parents with learning disabilities are not dissimilar to the needs of any parent who has young children. All parents need support with childcare and household chores from time to time. There were slight increases in the more learning disability specific areas of support such as reading, form filling and establishing routines, which are a direct result of aspects of the training that were designed to raise awareness about the support needs of parents with learning disabilities. This aspect of the training has hopefully increased participant's confidence in providing support to parents with learning disabilities by highlighting that they already have the skills to support them.

Both before and after the training participants recognised how communication could act as a barrier to parents with learning disabilities, which shows a sound overall understanding of the importance of communication. Pre training responses focused mainly on general issues such as assistance with reading and writing. This theme increased and became more specific following the training. This was demonstrated by the following suggestions of what the parent may need;

'[support in] understanding labels on medicine bottles'

'accessible information on what is available'

This shift shows how the training has made participants more aware of issues specific to parents with learning disabilities, and will hopefully enable them to give more effective support to families they are supporting following the training.

Theme 3: Social Support

Theme 3 focuses on social aspects of support that the mother in the case study may need. Again there were very few differences in the size and content of the theme between pre and post training measures.

Social support is an important factor for all parents and in particular for parents with learning disabilities as discussed in the introduction to this report. Participants correctly identified a need for social support, but what is also essential is that participants understand how this knowledge should be applied. The need for friendship was the most commonly identified sub-theme both before and after the training, it is however, important to see how participants say they will support this person with this need. We would hope that following the training participants would look at ways to facilitate social support from within the community that the person lives in, rather than trying to provide social support themselves by becoming a friend to the person. This confusion of boundaries is unsustainable and in the longer term may actually be detrimental. It is encouraging then that a number of responses to the post case study talk about 'social links in the community', 'support to socialise with other mums' and 'peer support circles'. This will be discussed further in the following section.

Theme 4: Parenting Support

A relatively large number of people identified parenting support and education as something that the mother of this family may need, this theme decreased slightly following the training from 18.8 to 13.3%.

The decrease in the size of this theme may be a direct result of the training exercise which asked participants to think about different scenarios and then make a judgement about the capacity of the parents. This exercise was designed to enable people to explore their values about what good parenting is, and to recognise that good parenting is a subjective experience and is not the same for everyone. As a consequence of this the participants values about parents with learning disabilities have been challenged and have developed, so that they do not immediately assume that people with learning disabilities will need support with all parenting skills.

Again there was very little difference in the content of the theme before and after the training. However like theme 1, responses became noticeably more specific in the post training measures. The majority of the meaning units in the pre training responses were very general such as ‘parenting skills’ and ‘parenting advice’. In the responses to the post training case study although participants still gave some very general answers, the proportion of general answers had decreased slightly and the proportion of more specific answers had increased. In the post training case study participants responses focused on specific aspects of parenting that the mother may need support with such as ‘dietary advice’, ‘advice on child development’, ‘discipline’ and ‘providing appropriate play activities’. This demonstrated that the training provided the participants with an insight into what types of parenting support the mother may need.

Theme 5: Access to Community Services and Resources

This theme focuses on community involvement and local services. A large number of respondents both before and after the training highlighted this need for community involvement. This theme increased significantly following the training, from 18.6% to 25.6% which may be a direct result of the training which highlighted the social exclusion and isolation often faced by parents with learning disabilities, and also emphasised the importance of inclusion and community involvement. This reinforces the role of the support worker as someone who can help facilitate links within the local community.

Respondents acknowledged that the mother not only needs to be included as part of the community, but she may also need support and advice about *how* to become part of the local community. This finding was much more prevalent in the post training measures which may indicate that the training made participants rethink the support needed by disabled parents. Parents who are not disabled are more likely to get advice and information about what support is available to them, whereas many disabled parents are not given this information, partly because it may not be seen as appropriate for their needs. The training has made participants more aware of this type of discrimination and will hopefully enable participants to help disabled parents to access mainstream services especially childcare, GP’s, health visitors, nurseries and schools.

Following the training a small number of participants started to use ‘buzz’ words, such as ‘inclusion’ and ‘social justice’ when describing what they thought parents with learning disabilities need. This is a very positive change as it signifies a change from a service centred way of thinking, to a person centred way of thinking. Perhaps a recommendation for future training would be to place more emphasis on these values, so that more staff use these values to guide their practice.

Theme 6: Advocacy and Empowerment

The emergence of this theme is probably one of the most significant findings from the evaluation of the Making the Difference Pack. This finding is particularly important as the theme was only present following the training which means that the training has had a positive effect on the underlying values of the participants. Following the training a small theme (2.5% of all meaning units) emerged which we have called 'Advocacy and Empowerment'. Responses in this theme clustered around having your voice heard, making decisions about your life, and feeling empowered to take control. These values are central to todays disability rights and self advocacy movements which both work towards enabling disabled people to have a say over what happens in their lives. Hopefully this finding will be reflected in the ways in which the participants support parents with learning disabilities.

Question 2: How might you be able to help or support them?

This question explores the type of support that the participants feel that they can offer to the mother. It has links to the previous question as many of the needs identified by the participants will be met either directly or indirectly by the support worker.

Again there was an overall increase in responses to this question from 301 in the pre-training measure to 496 in the post-training measure. This suggests that as a result of the training participants have both realised how they can use their pre-existing skills to support parents with learning disabilities and have also learnt new skills that they will be able to apply in practice.

The following themes were identified in the participant's responses to Question 2;

- ***Emotional Support***
- ***Practical Support***
- ***Social Support***
- ***Parenting Support***
- ***Access to Services and Support***
- ***Needs Assessment***
- ***Advocacy and Empowerment***

The themes identified in relation to Question 2 closely match themes extrapolated for Question 1. Despite this superficial similarity the size and the content of the themes differed somewhat from the themes in Question 1. This may suggest that the participants do not feel that they can meet all the needs of the participants. If this is the case this should be interpreted as a positive finding. It is unrealistic to expect that volunteer support workers would be able to meet the many and diverse needs of parents with learning disabilities. An important part of learning about supporting people is learning about the boundaries of your role. For example a support worker should not be required to meet the friendship need, instead their role should be to facilitate links with community support networks. These factors will be considered in more detail below.

As in Question 1 a small percentage of participants (1%) did not answer this question, or 'did not know' how they could support the mother in the case study. Following the training, all participants gave at least 3 separate responses to the question.

Table XX: Shows percentage of meaning units in each theme for pre and post data

	Pre (%)	***Post (%)***
Emotional Support	24.9	21.6
Practical Support	19.3	28.4
Social Support	11.3	10.1
Parenting Skills	8.3	5.0
Access to Services and Support	26.2	28.2
Needs Assessment	6.0	2.8
Advocacy and Empowerment	3.0	3.9
Don't know	1.0	0
Total	100	100

Theme 1: Emotional Support

Both before and after the training a relatively large number of responses clustered around giving emotional support to the mother of the family, suggesting that many people feel that they would provide emotional support to this mother. The size of the theme does decrease slightly following the training from 24.9% to 21.6%

When you compare this theme with the corresponding theme in Question 1 it appears that participants do not perceive the mother's need for emotional support to be among one of her highest support needs, despite this they do prioritise it when they are considering what kind of support they can provide. This may suggest that participants feel most comfortable or skilled in providing emotional support. This suggestion is supported by the fact that the size of this theme decreases following the training. The training may have increased the participants skills and knowledge about providing other types of support - such as practical support. It may also have emphasised the need for alternative types of support and it may have raised participants awareness about the risks of forming a dependent relationships between the supporter and the family.

When we explore the content of the theme a few differences are apparent between the pre and the post data. Similar to the findings in Theme 1, responses become more specific following the training, rather than saying 'emotional support' responses to the post case study talk about 'encouraging confidence and independence', praising the mother and 'building her self-esteem'. Many participants talked about building the mother's confidence by supporting her to access local community activities by accompanying her to initial visits to schools and nurseries. This type of support is both emotional and practical in its nature, it is aimed at enabling people to become more confident and independent - this is a really positive finding.

Theme 2: Practical Support

Again this theme is very similar to the practical support theme in Question 1. The size of the theme increased quite dramatically following the training (19.3% pre - 28.4% post) which may suggest that the training provided the participants with new ideas of how they could provide practical support to the family, and may also have had the effect of increasing confidence in their ability to provide practical support.

We were able to identify the following sub-themes both before and after the training;

- ***Support with everyday tasks – shopping, cleaning etc.***
- ***Support with forming and maintaining routines***
- ***Support with bills, benefits and form filling***
- ***Support to travel to and attend meetings/appointments***
- ***Childcare***
- ***Communication***

These sub-themes correspond to those identified by participants in Question 1 which suggests that participants feel that they are able to meet the majority of the mothers practical support needs.

Both the theme about routine and the theme about support with form filling increased following the training. This may be because the training highlighted the specific difficulties that people with learning disabilities face, and also gave the participants some practical tips on how to support people in these areas. This implies that the participants will now apply this skill and knowledge in practice.

There appears to have been a shift in the type of support the participants feel they are able to give. Before the training participants responses focused on doing things *for* the parents, such as 'getting her benefits sorted for her', this type of support inhibits competence and is less likely to be accepted by the parent, also the long-term effects of this type of support are difficult to maintain once the support stops. Effective support should promote competence and independence. Encouragingly then, following the training participants talked more about doing things *with* the mother, and finding other people/services who could provide support in specific areas, e.g. 'take her to a benefits advice session'. This is also reflected in the increase in the size of Theme 5 'support to access community services and support'. This shows that following the training participants are looking for longer-term avenues of support for the family, which are more likely to continue when the support worker no longer works with them.

A change was also observed in the communication sub-theme, again the support changed from competence inhibiting to competence promoting. Responses developed from 'reading letters for her' before the training, to 'providing accessible literature, timetables and pictures' subsequent to the training. Support of this sort is more likely to increase independence and have more sustainable effects.

Theme 3: Social Support

The findings in relation to this theme are quite unexpected and may be due to a number of factors which are discussed below. There was very little variation in the size of the theme before and after the training, however the content of the theme is quite different.

Many of the responses in the pre training measure focused on facilitating support networks within the person's community, encouraging contact with other mothers and supporting involvement in community groups. A relatively small proportion of people (9%) suggested that they would offer friendship to the mother.

In contrast only 38.7% of participants suggested facilitating support networks within the community after the training, 67.3 % suggested that they would become the mothers' friend. This is a very worrying finding especially as the training aims to clarify the boundaries of the support worker and make clear the difference between being a friend and supporting someone. Volunteers are in a difficult position, being neither a professional nor a friend, so their role can often be confusing, however this does not explain this increase following the training. It may be possible that the content of the training has effected this. Certain aspects of the training focus on the social isolation of parents with learning disabilities. This emotive issue may have made the participants want to offer their friendship to disabled parents.

It should be clearly laid down in organisational policy that volunteers, or support workers should not become 'friends' with the parents they are supporting this should be reinforced by the Making the Difference training. Future training may benefit from collaboration between the organisation and the trainer.

Theme 4: Parenting Skills

This theme focused on parenting support that participants could offer to the mother. There was very little variation in this theme before and after the training. The size of the theme decreased slightly following the training, but this was not a significant decrease (8.3% - 5%). Participants suggested that they would support the parents by helping them enrol on to parenting classes and support groups and also by providing direct advice on parenting issues, such as child development, play and dietary issues.

Participants are providing this type of support everyday to parents who are not disabled so are already skilled in this area, which may explain why there is no change in this theme before and after the training.

Theme 5: Support to Access Community Services and Support

This theme focused on facilitating access to community based services and resources. This was the largest theme both before and after the training.

This is a positive finding - it shows that support workers are aware of the need for social inclusion for disabled parents. This approach means that much of the support workers time will be taken up by collecting resources and facilitating friendships and supportive relationships between the mother and other members of the community. As a consequence of this less time will be spent providing more traditional types of support such as help around the home etc, however time spent building support within the community will hopefully result in the mother having a more stable, natural and longer-term support network, which will be sustained beyond the remit of any support worker.

The content of the theme remained fairly constant both before and after the training, participants focused on collecting information about local resources and services, linking with other agencies and professionals, setting up appointments at groups and clinics, and practically supporting the mother to access the groups. The language used by the participants developed throughout the training. Before the training participants talked about 'helping people' whereas following the training participants used more positive, empowering language such as 'supporting' or enabling' people.

The size of the theme grew slightly after the training, this may be a direct result of the training which emphasised the importance of creating sustainable community based support networks. Or it may simply reflect an increased knowledge of services available to parents with learning disabilities and an improved awareness of how mainstream services can be used by disabled people.

Theme 6: Assessment of Needs

A small percentage of the respondents suggested that they would assess the mothers needs to find out what kind of support she required. Before the training participants talked generally about 'finding out about her needs' and 'assessment of needs', a small proportion of respondents said they would talk to the mother about what she needed. Following the training respondents almost exclusively talked about assessing the mothers' needs by talking and listening to the mother and the rest of the family. This demonstrates that following the training participants are taking a much more person centred approach and relying less on traditional professional-led needs assessments.

In addition to this the size of the theme also decreased following the training. This may suggest that 'needs assessment' is becoming less important to the participants. This adds further support to our hypothesis that the training is enabling participants to think in a more person-centred way.

Theme 7: Advocacy and Empowerment

This was a very small theme (around 3% of meaning units related to this theme) which focused on facilitating access to advocacy services, advocating on the mothers' behalf and empowering the mother to be independent. Again there was very little difference before and after the training, which suggests that a greater emphasis should be placed on the value of advocacy and empowerment in the training package.

Question 3: What things do you need to consider before you visit?

This question was designed to identify what the supporter would need to consider before they visited a parent with a learning disability and their family and how this changed following the 'Making the Difference' training.

In line with the preceding analyses of the first two questions response rate increased significantly between pre and post measures. In the pre case study the 120 participants gave a total of 247 responses to the question 'what things do you need to consider before you visit', this figure increased considerably to 401 responses in the post measure. This suggests that the participants developed a more in-depth understanding of the issues that they would need to give consideration to before visiting a mother with learning disabilities as a result of the training. This suggestion is supported by the analysis of themes in the participants responses to this question.

A number of themes emerged from the analysis of the third question, again the themes persisted in both pre and post measures, but as with the other two questions more in-depth analysis revealed some fundamental differences within the themes. This will be discussed below.

The following themes were identified in pre and post training responses to the case study exercise, each theme is discussed individually below

- ***Practical Considerations***
- ***Family History***
- ***Needs of the Family***
- ***Local Services and Resources***
- ***Mother's Feelings and Expectations***
- ***Roles and Responsibilities***
- ***Values***
- ***Specific Learning Disability Issues***
- ***Communication***

The table below demonstrates the changes in frequency of meaning units related to a theme from pre to post training. This may reflect the changing perceptions and priorities of the training participants and is discussed in relation to the theme.

Table XX: Shows percentage of meaning units in each theme for pre and post data

	Pre (%)	***Post (%)***
Practical Considerations	6.5	7.9
Family History	34.4	21.2
Needs of Family	4.0	10.4
Local Services and Resources	6.9	7.5
Mother's Feelings and Expectations	8.1	9.5
Roles, Responsibilities and Values	16.5	28.0
Specific Learning Disability Issues	15.4	7.7
Communication	8.5	7.8
Total	100	100

Theme 1: Practical Considerations

This theme represents very practical issues that would be considered by the participants prior to visiting a parent with a learning disability. It remained very constant across the training with little difference between pre and post measures. The content of the theme was also very similar, issues such as where the person lives, transport, health and safety issues, timing and length of stay were commonly cited by the sample. There was slightly more emphasis on planning in the post training responses with a higher proportion of people involving the parent in the preparation for the visit such as ensuring that the mother knows they will be visiting and ringing the mother to confirm the appointment. Although there are few differences pre and post in this theme the changes that have taken place are encouraging. Increased involvement of the mother in the planning may mean that participants have a better understanding of the mother's needs and empathy for the mother following the training. This will ultimately give the mother an increased feeling of control which will make the support more acceptable to her.

Theme 2: Family History

This theme is the largest theme both before and after the training with 34.4% (pre) and 21.4% (post) meaning units relating to it, this is obviously something that participants feel it is important to consider before visiting a parent. Within this theme participants identified a need for information about family relationships, involvement with other agencies, support networks, specific skills and challenges, health, religious and cultural beliefs, parenting skills as important.

It appears that as a result of the training family history becomes less important to the participants; this is clearly demonstrated by the 13% drop in meaning units related to this theme in post case studies. This may be a direct result of the training which has an emphasis on building relationships and getting to know the parent as a person or may simply reflect increased awareness and development of priorities in other areas such as their roles and responsibilities and values.

An encouraging find within this theme is the shift towards looking at people's strengths and gifts, this more positive perception of people enables support staff to build on a person's strengths rather than just focusing on their weaknesses. This approach hands control back over to the person and is a really positive way of increasing a person's skills and independence, whilst also making the support more acceptable. The following statements show the emerging person centred way of thinking;

'What are mum's strengths?'

'What does she do well?'

It is however important to bear in mind that only 2 meaning units out of the 85 in this theme related to this strength based approach. This highlights a need for a more explicitly strength based approach to training.

Despite this positive finding there were also some instances of more negative language used in the responses to the post case studies compared to the pre case studies. Respondents talked more openly about peoples 'problems', where as in the pre training responses more neutral terms such as 'background' and 'experiences' were used. Again this was only a very small proportion of the sample and may simply be reflective of increased awareness of day to day issues that parents with learning disabilities face.

Interestingly more people explicitly mentioned the father of the children and the mother's relationship with her partner in the pre case study responses. The reason for this is unknown, and highlights the need for future training to take a more 'family centred' approach.

Theme 3: Needs of the Family

This theme focuses on the support needs of the family and centred around issues such as the need for support and what type of support is needed. The number of meaning units increased significantly between pre and post measures from 4.0% to 10.4%. The content of this theme also changed quite considerably before and after the training, while the responses to the pre measure generically focused on ascertaining need, the responses to the post measure appeared to be a lot more person centred, many people suggested asking the mother what support she needs, rather than relying upon 'professional' needs assessments. In addition to this the responses were more focused on the whole family rather than just the individual with the learning disability.

This is a particularly exciting finding for this project as it demonstrates that the values and attitudes of the participants are starting to shift from being centred on services and professional needs assessments to family centred working focused on letting the family guide the support that they receive.

Theme 4: Local Services and Resources

This theme ties in with themes in Questions 1 and 2 about helping people to access activities in the community, it specifically addresses the need to prepare for the visit by gathering information about local resources and services for the family. This theme was constant across pre and post measures with only a slight increase in the percentage of related meaning units after the training. In the responses to the pre measure the respondents talked very generally about 'what's available in area' and 'what resources are available'. Contrastingly following the training the respondents gave more specific examples of what type of resources they would prepare such as 'local addresses of family centres' and 'information about schooling and local groups'. This shows an increased knowledge of what is important to disabled parents and the resources available to support disabled parents. This may also show an increasing awareness of how mainstream resources can be used to support parents rather than only specialist services. If this is the case it represents a major attitudinal shift in the participants following the training, and may signify a change in their values to think in a more inclusive, mainstream way.

Theme 5: Mothers Feelings and Expectations

This theme addresses how the mother will react to the visit by the supporter, the theme is underpinned by an assumption of mistrust of professionals and that the mother may not want to accept the support that she is offered. It appears that this theme changed very little as a result of the training with 8.1% of meaning units related to it before the training compared to 9.5% after. Before the training the participants talked mainly about whether the mother wanted the help of a support worker, saying things like 'are you welcome in the home' and 'she may not want intervention at this stage'. Following the training respondents appear to show more insight into the reasons behind why the mother may feel hesitant about accepting support. The respondents talk more about the mother's expectations of support and the mother's emotional state i.e. is she feeling nervous? Following the training participants appear to show more empathy for the mother, which allows them to explore the reasons why she may not want their support. Hopefully this will help the participants to make her feel more at ease on their first visit.

Theme 6: Roles, Responsibilities and Values

It appears from this theme that the training made the participants consider their role in more depth, and also allowed them to develop their values. Although the content of this theme remained fairly constant both before and after the training the theme almost doubled in size between pre and post measures which indicates a very significant increase.

A sub-theme that was only present in the post responses was that of 'taking time to build a relationship with mum'. Participants explored issues of giving enough time to build a relationship with the mother and establishing a mutual bond. This is both a positive finding, but also one we should be wary of. It is of course essential that the support worker builds up a relationship with the mother in order to provide appropriate acceptable support to her, there has to be a level of trust involved in the relationship. However supporters must also be cautious not to nurture a personal relationship, or encourage dependence on this relationship. In light of this, it is particularly significant that the training appeared to *reinforce* the participant's views on the importance of professional boundaries. In the pre measures participants talked generally about what type of support they could offer and how they were planning to do this, one participant out of a sample of 120 mentioned boundaries. In the post measures participants not only talked explicitly about setting boundaries but also talked more implicitly about boundary issues such as the limitations of their role, levels of emotional involvement and attachment.

'Make them aware of what you can and cannot help them with'

'Be aware of the person becoming too dependent upon you'

The number of meaning units related to participants values increased dramatically between pre and post measures. This is a very encouraging finding as often values and attitudes are the hardest things to change or develop. Further analysis of the theme revealed that the reported values of the participants have changed very little. Both before and after the training participants values clustered around the following core values; respect, non-judgemental attitudes, sensitivity, non-patronising and open mindedness. Consequently it appears that the training has had the effect of making the participants more aware of their values.

Theme 7: Specific Learning Disability Issues

An unexpected finding emerged in relation to specific learning disability issues. The results of the analysis show that significantly less people stated that they would think about learning disability issues before they visited the mother in the post measure, compared to the pre measure. In responses to the pre measure a lot of people said that they would consider factors such as the type of learning disability, the severity of her learning disability and her level of understanding. At first glance this might appear counterintuitive, that people who have been on a course to raise their awareness about learning disability actually come out thinking about learning disability less! However there are a number of explanations for this result.

Participants may have developed a better understanding of learning disability, and what having a 'mild learning disability' means to a person as a result of watching the video and taking part in exercises designed to raise awareness. Therefore they would already have the answers to some of their questions as a direct result of the training.

A further explanation of this finding is that the training enabled the participants to think in a more person centred way. Because people are now focusing on the person rather than the disability it becomes less important to find out specific facts about her learning disability, and more important to find out things about her as a person. This is supported by the finding that after having the training participants were more likely to consider needs in a family centred way.

Theme 8: Communication

This theme focuses on communication issues between the mother and the supporter. This was a comparatively small theme and decreased slightly following the training, although this was not a significant decrease (8.5% to 7.8%). Before the training participant's responses centred mainly on weaknesses in the mother's communication, participants said things like 'mum might not be able to read or write very well', 'how well is mum able to communicate and understand?'. Of the 120 participants in the sample only one talked about accessible communication. In contrast the post case studies showed an increase in practical suggestions on how to facilitate communication including confirming visits by telephone rather than in writing, having easy to understand information available for the mother to use and by giving 'clear uncomplicated instructions'. This demonstrates that following the training participants are looking beyond communication difficulties to how they can facilitate effective communication.

Study Three: Views of the Organisation

> "thinking and learning was certainly enhanced which will increase skills when supporting families in the future"
>
> *Home Start Co-ordinator 2005*

Semi-structured telephone interviews were conducted with the training co-ordinators from the organisations due to time constraints interviews lasted 15-20 minutes. The training co-ordinators were asked general questions about their organisation and its current position with regard to supporting parents with learning disabilities followed by specific questions about the training (see appendix 4)

Supporting Parents with Learning Disabilities

There was a great deal of variation in the number of parents with learning disabilities supported by organisations who took part in the interviews. Most of the organisations which received the training were currently supporting only 2 or 3 parents with learning disabilities though all said they had the capacity to support more if they were referred. A number of organisations were frustrated that they had not received referrals to support parents with learning disabilities even though they felt that their volunteers were equipped to do so. Only one organisation was currently supporting a larger number of families where one or both of the parents had learning disabilities. They had some difficulty in giving accurate statistics as they did not have clear definitions – there was some confusion between mental health and learning disabilities – but they estimated that they were supporting twenty one families with learning disabilities of the 280 families in total.

The interviews revealed the diverse mix of staff supporting and referring parents with learning disabilities. The majority of parents with learning disabilities who had been referred to the organisations for support were referred by social services teams, schools, midwives and health visitors. Other referral agencies were mentioned including project workers, schools and housing associations. A small number of parents had been referred to the organisations for support prenatally, by midwives, health visitors or social workers. This experience had been varied and outcomes were very different for each referral. Where the parent with a learning disability was included in planning the support package –in meetings that were inclusive and accessible information was available and so on – the experience had been positive. The parent had been given the opportunity to gather information before the birth and to decide the best way they could be supported. They were able to get to know the people who would be supporting them and to feel that they were empowered and respected. Other experiences had shown excellent professional planning but without including the parent themselves. These resulted in the parent feeling devalued and uninformed which affected their confidence to deal with their baby later.

This highlights the need for more specialised training for professional staff in order to ensure that support is consistent and effective. At present prenatal support staff - midwives and health visitors - receive very little, if any, training on how to support parents with learning disabilities. Although these professionals are expected to have a good understanding of disability, their knowledge is in relation to babies who may be born with a disability, and is not generalisible to supporting adults with learning disabilities and parental responsibilities. This may indicate that midwives, health visitors and others who support parents prenatally are not fully equipped to support parents with learning disabilities through pregnancy. This assumption is supported by the interviewee who cited the case of a parent with a learning disability whose prenatal support package 'fell apart' after the birth of her child. The interviewee attributed this breakdown in support to the inability of the prenatal support team to involve the mother in the planning. Mother and child health are interdependent, midwives and health visitors play a huge role in the lives of both the parent(s) and the child so it is essential that these staff are correctly trained to provide appropriate, acceptable support at this critical time. This point will be discussed further in the recommendations section.

"there is difficulty in getting people to recognise that we support people with learning disabilities as well as physical disabilities"

Support Co-ordinator 2006

All organisations interviewed had the capacity to support more parents with learning disabilities, and the majority embraced the idea of increasing the support offered to them. Many felt frustrated by the few parents with learning disabilities who were referred and although there were a few parents with learning disabilities who had self-referred the majority depended on professionals to support them in their pregnancy initially and to refer them appropriately for support once the baby was born. The low referral rate of parents with learning disabilities highlights a need to promote the expertise of local organisations such as Home-Start working with parents with learning disabilities and also suggests that staff supporting parents prenatally may benefit from an increased awareness of learning disability and services available to disabled parents.

"They developed a pre-natal support package but did not consider making it really accessible for the mum herself so she felt isolated. She hadn't a clue what was happening in meetings. She did not keep the baby later."

Support Co-ordinator 2006

Making the Difference Training Feedback

"refreshing" … "fascinating"… "empowering"… "thought provoking"

*Participants on **Making the Difference** training 2005/6*

The interviewees made a number of general comments about the effect of the training on their staff team, all said that the training had made a positive impact on the way in which support staff were working with parents with learning disabilities. A theme which ran throughout the interview transcripts was one of increased confidence and improved awareness of learning disability. Also mentioned was the way in which the training encouraged open discussion of topics allowing people to share their experiences and learn from each other. A number said that even though they had previously included training on disability issues in their induction it served as a refresher and volunteers and others had the opportunity to discuss the issues with some experience of already having worked with families. At their induction training they had not been able to relate their learning to practice.

They referred to the flexibility of the training pack – that it could be used for two day training or for a number of shorter sessions. They also liked the fact that they could select certain exercises for training without having to use the entire pack if they had specific training needs.

A number of very positive comments were made about specific aspects of the training and in particular many interviewees highlighted the value of the Perfect People video used in the training.

> "I thought the video was extremely good. A big eye-opener to my views on how we view people with learning disabilities"
>
> *Home-Start Volunteer 2006*

Various exercises in the pack were discussed during the interviews. The exercise looking at dealing with disclosures appeared to be useful for clarifying the role of the volunteer when they had a concern. The 'professional or friend' exercise linked to this and although most organisations said that they did cover this issue in induction training and in their policies and procedures it allowed for the topic to be raised and discussed again. Two specific issues were raised here – one organisation had experienced a parent with a learning disability not being able to accept a new volunteer when the previous one had left. She had been very well supported but had developed such an attachment that she had experienced both a loss and a mistrust of future support. Secondly an incident was recounted where the volunteer agreed to be introduced to people as the mother's sister. This appears to be a real concern for parents as they are reluctant to introduce people as volunteers because of the stigma attached to needing help.

Another issue raised was the difficulty for their volunteers of the cut-off point when the child went to school at the age of 5. Volunteers may have supported the family for a number of years and to stop the support so suddenly was not easy for them or the family. This is addressed in more detail below.

An encouraging finding of the telephone interviews was that all organisations trained said that they would be using the training pack again although one said that any training was inevitably constrained by funding issues. The pack should assist organisations with these funding constraints as it offers an effective way of providing in-house training by in-house trainers with training materials provided.

A significant number of participants commented that they would have liked more in-depth information about learning disability issues and at a higher level. This perhaps reflects the difficulty of training multidisciplinary groups including social workers, volunteers and managers in some cases. Although this training pack was designed for support staff and volunteers, there was a high demand for this training from professional staff, probably due to the lack of specific training in this area. Because of this professional staff often accompanied volunteers and support staff on these training days. It has highlighted the need for training for all staff – volunteers, support co-ordinators, health visitors, midwives, social workers – and that this training needs to be developed to meet their particular needs. Only if training is available to all staff and volunteers concerned with supporting parents with learning disabilities will we see an increased understanding of the issues and services tailored to meet their specific needs.

> "It would maybe be good to have more on what a learning disability is – how it is acquired, what the syndromes are and how this will affect the way we work with people"

Additional Support for Parents with Learning Disabilities

Apart from the volunteers support visits we were interested to know if additional support was available to parents with learning disabilities. The majority of interviewees said that the parents with learning disabilities who they supported were also encouraged to attend the parent support groups with other mothers and fathers. Some provided transport to encourage attendance although many groups were very local to families and travel was not then an issue. This appeared to be most successful where the groups were 'closed' groups – only available to other parents receiving support. These groups gave the parents the opportunity to share ideas about, for example, how to play with their children and where to access information as well as the chance to share concerns and have some time out of the house. No organisations had developed groups specifically for parents with learning disabilities and did not feel the need to do so as they considered an integrated approach to be most beneficial.

Some parents have also continued to receive support from their health visitors and social workers with a few also having access to an advocate. It appeared that few had peer group support other than the group sessions and their family members. The difficulties of communication, confidence and travel were raised and one interviewee expressed her concern about the parents isolation.

> "they are often isolated and easily influenced by those who support them – I think this means they are pretty vulnerable"

General Issues

During the telephone interviews a number raised their concerns about the lack of support for parents with learning disabilities after the age of 5. For example Home-Start support is specifically available for children aged 0-5. The support for parents of school age children is minimal and so they are not supported with a range of new issues that arise at this time – contact with the school, attending meetings, responding to letters, coping with the child becoming an adolescent and the related physical and emotional issues. Without this support the parent may find it increasingly difficult to manage and care for their children and the children may feel bewildered and unsupported themselves.

One organisation had recognised and been concerned enough about this to apply for independence from their main organisation and they planned to change their remit to include support for children up to the age of 13 from April 2006.

> "The problems of looking after older children are as big as younger children even if they are different so they need the help as much then as earlier."
>
> Co-ordinator of organisation now supporting up to the age of 13

There was also concern about the few referrals that were being made to support parents with learning disabilities and the worry that if their support was not accessed the parents might not be able to care for their child at home. The fact that 50% of parents with learning disabilities are currently not caring for their children would suggest that these services are not being recognised and referred to for support as often as they could be. It might indicate that their specialist services need to be marketed more prominently to ensure that the statutory agencies involved with the parents will consider referral for support as an additional resource when considering the future plans for the family.

Finally a number of interviewees said that the training had raised the fact that they were currently not producing their information in accessible formats for parents with learning disabilities. Although they had looked at accessibility in terms of language they had not considered it in terms of signs, symbols and with attention to words, sentence construction and format.

It was encouraging to hear that the training had not only been effective on the training day with the delivery of the training exercises and materials in the pack but other issues had also been raised and discussed, with a number being taken from the training and raised as organisational issues to be addressed later.

Chapter Four

Discussion of Findings

In this section the findings of the above evaluation of the 'Making the Difference' pack are summarised. Conclusions drawn from this research are then used to form a set of recommendations.

Summary of Findings

Overall the present research revealed some very positive findings about the 'Making the Difference' training, the research also highlighted areas of improvement for future training and practice.

The training appeared to have a profound effect upon both the attitudes and behaviours of the training participants. As a result of the training participants attitudes towards supporting parents with learning disabilities developed to become more person-centred and inclusive. A shift from doing things 'for' the person to doing things 'with' the person was observed and following the training participants were exploring more creative solutions to everyday challenges. In addition to this participants became aware of the importance of empowerment and advocacy for people with learning disabilities.

The training increased the participants' knowledge about learning disability and issues specific to parents with leaning disabilities. Following the training they had a clearer understanding of the needs of parents with learning disabilities and how to support them. This was demonstrated by a shift from general responses in the case study questions to very specific responses and was also supported by the views of the training co-ordinators in the telephone evaluations.

The importance of facilitating access to community support networks was emphasised by the training. This had a profound effect upon the training participants, who following the training were more aware of the importance of creating long-term support systems for families they were supporting.

The evaluation raised slight concerns about the nature of the relationships between the support worker and the parent. This is addressed in the recommendations section, along with a number of other recommendations for future training.

The current research highlighted the effectiveness of training support staff to support parents with learning disabilities.

Recommendations

The following recommendations have been developed from the evaluation of the 'Making the Difference' project. These recommendations are split into recommendations for future training and more general recommendations which have implications for anyone working with parents with learning disabilities.

Recommendations for Training

- For support to be effective it is important that it is available right from the start. Pre-natal support plans should be developed and in place prior to the birth of the child. These need to be accessible, inclusive and involve the parents in discussions about the support that they need and that would be acceptable to them. The support packages that have been most successful have been those that have included the parents and ensured that all information is accessible and understood by them. This suggests that training for pre-natal support staff must be developed. Health visitors, midwives and GP's should all be included in this training, in order to enable them to work more effectively with parents who have a learning disability.

- The evaluation of the training revealed some confusion about the role of the support worker. Many training participants believed it to be part of their role to become a *friend* to the mother in order to provide support. As highlighted in the results section this is a worrying finding. It is vital that future training addresses these misconceptions, and properly defines the boundaries of the support workers role. Although this is a largely organisational issue which affects the roles of all support workers whether they are working with disabled parents or not, it has particular salience for staff working with disabled parents who may have fewer social contacts. An effective approach to delivering this aspect of the training may be to work in partnership with a representative of the organisation in order to clarify the role of the support worker, this way we could avoid undermining or contradicting organisational policy.

- The training was originally designed for support staff (paid and unpaid) with little prior knowledge of learning disability issues. As the training progressed it became apparent that there was very little training available for trained staff who already possessed knowledge of learning disability issues. This high demand resulted in a number of trained staff taking part in the 'Making the Difference' training. Although multi-disciplinary training is beneficial, in this context it meant that it was difficult for the trainers to meet the information needs of every member of the group as there was so much variation in prior knowledge. Future training may benefit from taking a tiered approach to training, offering different levels of training from basic awareness training to more in-depth advanced training. This would ensure that all participants had a similar level of knowledge prior to the training, and would still allow all levels of staff to train together and share experiences.

- Throughout the training a number of participants commented that they would have valued some input from someone with a learning disability. This has implications for future training. There are already a number of organisations in which people with learning disabilities deliver the training, future training may be well advised to work more closely with these organisations, and should explicitly signpost participants to these organisations for further training.

Implications for Practice

- The difficulties faced by parents with learning disabilities and their families do not disappear after the age of five. Throughout the child's life the family will be faced with new challenges and for this reason it is vital that support is made available for the families after the age of five. Very few of the organisations that we worked with during this project could offer support when the child started school. This could be offered by extending the remit of organisations currently supporting pre-school children or by other organisations offering a service from age five upwards. Extended schools are also ideally-placed to offer this type of mainstream support within the community.

- As we already know, there is very little appropriate support available for parents with learning disabilities. Despite this organisations supporting parents with learning disabilities would welcome more referrals and often felt frustrated that they were offering the support to so few families. Marketing their services to ensure that the statutory agencies – health, social services and so on – are aware of the support that can be offered would seem essential if there is to be an increase in referrals.

- A major barrier for people with a learning disability is communication, in particular written communication. This poses a particular challenge for parents with learning disabilities. There is a need to develop more accessible resources to ensure that the parents with learning disabilities understand the information that they are given and to enable them to care for their children more effectively. Professionals working with parents with learning disabilities should be made aware of this and be prepared to provide information in a format that is easy to understand. This would involve training and awareness raising.

- At present support for parents with learning disabilities is provided by a wide range of 'professionals' and is somewhat fragmented. Multi-agency working would benefit all concerned and ensure that each organisation is aware of the service that each can provide when supporting parents with learning disabilities. This would offer the opportunity to share information and good practice. Further research in this field may be useful to inform this process.

- Parents with learning disabilities benefit from the informal support available by accessing parent groups as well as the formal support from the volunteer. Organisations should ensure that all groups are accessible to parents with learning disabilities by considering both the practical and emotional needs of the parents – communication, transport, confidence etc.

- All volunteers working with parents with learning disabilities should receive additional training to their induction session on disability. This should include training on the parents practical and emotional needs.

- A programme of work with local communities and schools should be established to increase their awareness and understanding of the needs of parents with learning disabilities and their children.

We still have a long way to go until we achieve our vision of effective support for parents with learning disabilities. However, it is encouraging that this issue is attracting increasing attention both in the media and from the government. By addressing support for parents with learning disabilities in this way we can improve support from the bottom-up and put pressure on organisations and government to rethink the way that disabled parents are supported.

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Appendices