



Strathprints Institutional Repository

MacIntyre, Gillian and Stewart, Ailsa and , University of Strathclyde (2008) *Parents with learning disabilities - the lived experience - a study for equal say, Glasgow*. [Report]

Strathprints is designed to allow users to access the research output of the University of Strathclyde. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. You may not engage in further distribution of the material for any profitmaking activities or any commercial gain. You may freely distribute both the url (<http://strathprints.strath.ac.uk/>) and the content of this paper for research or study, educational, or not-for-profit purposes without prior permission or charge.

Any correspondence concerning this service should be sent to Strathprints administrator: <mailto:strathprints@strath.ac.uk>



MacIntyre, Gillian and Stewart, Ailsa (2008) Parents with Learning Disabilities – The Lived Experience - A Study for Equal Say, Glasgow. Discussion Paper. University of Strathclyde, Glasgow.

<http://strathprints.strath.ac.uk/7907/>

Strathprints is designed to allow users to access the research output of the University of Strathclyde. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. You may not engage in further distribution of the material for any profitmaking activities or any commercial gain. You may freely distribute both the url (<http://strathprints.strath.ac.uk>) and the content of this paper for research or study, educational, or not-for-profit purposes without prior permission or charge. You may freely distribute the url (<http://strathprints.strath.ac.uk>) of the Strathprints website.

Any correspondence concerning this service should be sent to The Strathprints Administrator: eprints@cis.strath.ac.uk

**Parents with Learning Disabilities – The Lived
Experience -
A Study for Equal Say, Glasgow**

**Final Report
October 2008**

**Dr Gillian MacIntyre
Ailsa Stewart
Glasgow School of Social Work**

Executive Summary

Introduction

Equal Say has been providing independent advocacy for adults with learning disabilities in Greater Glasgow since 1995. The last few years have seen the work of the organisation grow, both in the geographical areas covered and the range of people they work with. Equal Say, has reported a rise in the number of parents with learning disabilities coming to them or being referred to them for support in relation to parenting issues. Their experiences in terms of working with this group of people suggest a need for early, often intensive intervention and support to ensure the best possible outcome for parents with learning disabilities and their children.

In order to more clearly identify the key issues with regard to parents with learning disabilities, Equal Say commissioned the Glasgow School of Social Work to undertake a small pilot study which aimed to: identify the likely demand for advocacy services to support parents with a learning disability living in the community, illustrate the lived experiences of parents with a learning disability and to highlight examples of good practice in terms of what works in supporting parents with a learning disability.

In order to address these aims, the following research questions were developed:

1. What is known about the experiences of parents with a learning disability and their children from the existing literature and research and what can be learned from this?
2. What proportion of parents with a learning disability are currently being supported of the total in need?
3. Is there a greater demand for this service across the Glasgow area?
4. What are the experiences of those who have received support from an advocate and what are the range of outcomes as a result of this support?

Methods

A range of research methods were employed in order to ensure data was gathered from a number of key stakeholders.

A short survey questionnaire was sent to 94 relevant social work, health and voluntary sector organisations within Glasgow City. Twenty two completed responses were received, achieving a return rate of almost 24%. Whilst statistically this is below the average postal survey return, the findings are still relevant to the study as the key themes identified resonated with those identified both in the literature and the interviews.

Advocacy coordinators identified a sample of parents from within the Equal Say service who had the capacity to give informed consent to participate in the research. Of these, five were selected at random and were approached to take part in the research. Parents were interviewed first to discuss a range of issues in relation to their parenting. Their experiences of being a parent were also discussed as were the range of support services and mechanisms in place to assist them with this role. Parents were also asked to comment on and discuss their experience of working with an advocate. Interviews were also conducted with the advocates of parents who

took part in the research. These interviews were conducted after the interviews with parents (with the permission of parents involved).

In addition, a number of key informant interviews were conducted with Equal Say's development manager, with two learning disability social workers and with the coordinator of a network for parents with learning disabilities. A total of 14 interviews were completed.

Findings

The key findings from the study are summarised below.

Service demand – Service providers knew very little about the experiences of parents with a learning disability, unless they were part of a specialist team. There appears to be limited information on the numbers of parents with learning disabilities which limits the ability of the study to comment on demand. Firstly, where there is no formal diagnosis of a learning disability, individuals are not identified in this way (often despite staff perceptions that individuals have a learning disability). Secondly it appeared to be difficult for organisations to identify in any detail the number of parents with learning disabilities receiving their service. Although not able to conclusively demonstrate a significant increase in demand, the study highlighted a perception from specialist agencies that numbers had increased due to an increase in positive health and social opportunities for young people with learning disabilities and a growing awareness of the need for support.

Complexity of individual situations – Those parents who participated in the study not only faced complex circumstances with regard to parenting but also in their lives more generally including, poor housing conditions and poverty. Referrals also came to Equal Say as a result of concerns around issues other than parenting; however child protection soon became the priority in all of the cases considered in the study. The complex nature of the interaction of these issues and in particular the legalistic nature of the child protection process meant that advocates required intensive and long term involvement with individuals.

Support for individuals and the early identification of support needs – Evidence from the study suggests that in general intervention to support parents with a learning disability comes too late when it is a question of supporting parents through the child protection process rather than supporting them to develop their parenting skills. In addition support services that were being provided were often inappropriate, for example undertaking work for the parent rather than supporting them to do it for themselves. The importance of early intervention provided by professionals who understand the issues faced by parents with a learning disability was clear in terms of ensuring that parents can develop their parenting skills.

Availability of accessible information – The importance of accessible information was noted as key in assisting parents in their role and in ensuring they understood assessment processes and child protection procedures appropriately. Examples of good practice in this area are available.

Experience of the child protection system – A significant concern for parents related to receiving large amounts of complex information before child protection panel

meetings. Advocates noted that they spent a considerable amount of their contact time preparing parents for formal hearings often at short notice. More accessible information over the process and the conduct of meetings would be advantageous. Lack of legal representation and funding for this was a further concern for both advocates and parents.

Appropriate assessment – Where parents had undergone a parenting assessment there was evidence that they had not understood this process and that no account had been taken in administering the assessment of the particular needs of parents with a learning disability. In addition standard assessment tools were not always adapted to take account of learning disability. There are examples of specially adapted tools used in other parts of the U.K.

Joint working, eligibility criteria and funding - The study suggests that the support needs of parents with learning disabilities often fall between adult and children's services for two main reasons firstly because parents often do not meet the eligibility criteria for support for themselves and secondly because the focus is generally on the child's needs rather than the parents. There is therefore an issue about how support to parents could and should be provided through statutory services. Clear protocols and guidance for staff working in this area was thought to be a positive way forward in developing good practice in this area.

Advocacy – There is evidence that advocacy performed a number of key functions including; information translation, keeping parents informed, assisting parents to have their voices heard and supporting empowerment. As with other services, the evidence suggests advocacy support should be provided before the crisis is reached in order to be most effective. Advocacy support in these very complex situations provides challenges for both the advocate and the parent. Long-term involvement by professional advocates with support from other services including citizen advocates could provide the most beneficial model of support. Effective outcomes were indicated though the use of advocacy, particularly in terms of parents feeling their voices had been heard and that they were being included in the child protection process.

Conclusions and Recommendations

This study found that parents were likely to face disadvantage in a number of areas. These included income, social networks, housing and employment. Parents also faced a number of particular challenges in relation to their parenting role. In addition, there is evidence that they are disproportionately represented in the child protection system.

While it was not possible to conclusively demonstrate large increases in the number of parents with learning disabilities, it is important to note that those specialist services that participated in this study had noted an increase in the number of referrals. The study demonstrated a clear need for support for service providers in terms of awareness-raising around the particular needs of parents with a learning disability alongside providing information about the support services available to assist parents in their parenting role.

The study highlights the importance of advocacy as a support mechanism for this group of parents. It was possible to identify a range of successful outcomes that can be achieved with the support of an advocate.

The research also clearly demonstrates the complexity of situations within which parents with learning disabilities find themselves. Consequently advocates working with this particular group deal with a wide variety of issues, often requiring long-term involvement. This in turn has implications for the model of advocacy best utilised. It can be particularly challenging for volunteer advocates to have the capacity and expertise to support parents with learning disabilities through the complex and often legalistic processes and framework of the child protection system. Advocacy co-ordinators, by taking on the role of professional advocate, find themselves – due to the complexity and long term nature of the cases – less able to develop and support citizen advocates to match with individuals. As a result, the research suggests that where there are a complex interaction of issues involving parents with a learning disability perhaps the most effective model of advocacy would involve work with a professional advocate with additional support from a citizen advocate with regard to making community links and building social networks.

It is incredibly difficult to measure outcomes in this area as a successful outcome may not always result in a child being returned immediately to the family home and indeed, in some cases, this may not always be appropriate. However, all of the parents who participated in this study were able to identify successful outcomes from their involvement in the advocacy service provided by Equal Say. These related to feelings of empowerment, being heard, understanding processes of child protection and providing support in relation to daily living. Advocacy can therefore play an important step in levelling the playing field for parents with a learning disability who previously described themselves as being discriminated against by a system that does not recognise their particular needs.

General Recommendations:

1. There should be an increase in focused professional advocacy available on a long term basis for parents with a learning disability.
2. It is essential to raise awareness among professionals working in the health and social care field of the particular issues faced by parents with a learning disability.
3. It is necessary to establish clear protocols for effective joint working to ensure that the needs of both parents and their children are met and that parents needs do not fall between the gap of service provision.
4. Whilst ambitious, in order to accurately assess need and consequently demand, it is essential that a scoping exercise to identify the number of parents with a learning disability is undertaken.
5. A mapping exercise should be conducted to establish current service provision, how it is accessed and levels of use.
6. It would be helpful to build on the existing work that has been carried out as part of this research in terms of identifying good practice. This would be particularly helpful at a local level.

1. INTRODUCTION

1.1 *Background/ context:*

In recent years across the UK there has been an increasing awareness of the numbers of parents with a learning disability living in the community. It has been suggested that the number of parents with a learning disability has been rising, although there is very little statistical information available to support this. (Olsen & Wates, 2003) This means it is difficult to estimate the numbers of parents who have a learning disability which is made even more complex with incomplete records, changing terminology and the exclusion of fathers (Booth & Booth, 2005). An increasing amount of research in this area has been conducted. This research suggests that when adults with a learning disability do become parents they are often judged as inadequate and neglectful by social services and assumed to be incompetent. (Murphy & Feldman, 2002; Booth & Booth, 1996; www.learningdsa.org.uk) The result is that these families become over-represented in child protection figures, with the children often becoming looked after and accommodated by the Local Authority (Olsen & Clarke, 2003). The focus no longer appears to be concerned with the national gene pool, but with the risks posed to children's welfare and development, as a result of inadequate parenting (Bidd & Greenspan, 1984 in Booth & Booth, 1993). This inevitably creates tensions in service provision between what it means to support parents on the one hand, while at the same time protecting the child/children (Booth & Booth, 1996). However, research indicates that if parents with a learning disability are given support in the very early stages of parenting, they "can and do become 'good enough' parents" (Murphy & Feldman, 2002, p281).

There is currently no nationally agreed definition of what constitutes a learning disability. Many different definitions are currently in use. While more medicalised definitions continue to rely on IQ testing, other definitions take a more functional approach, focusing on areas of difficulty in comparison with the general population (MacIntyre, 2008). The definition of learning disability adopted by the Scottish Executive within *The same as you?* (Scottish Executive, 2000) takes account of the diverse nature of learning disability and focuses on individual need. It is defined as a significant lifelong condition which has three facets:

- Reduced ability to understand new or complex information or to learn new skills
- Reduced ability to cope independently
- A condition which started before adulthood (before the age of 18) with a lasting effect on the individuals development

1.2 *Equal Say*

Equal Say has been providing independent advocacy for adults with learning disabilities in Greater Glasgow since 1995. In recent years, this has expanded to include projects in East Dunbartonshire and East Renfrewshire, which represent people from other community care groups. Equal Say was originally established to provide citizen advocacy for the residents and ex-residents of Lennox Castle Hospital, an institution that was situated in Lennoxton, about 10 miles North of Glasgow.

Many of its residents had lived there for decades and had no experience of making choices and living as individuals. It was recognised that people who had not had the opportunity to develop the skills or support networks needed to make choices about their own lives, may need some extra help to do so. The last few years have seen Equal Say grow, both in the geographical areas covered and the range of people they work with. Recently, their role in East Dunbartonshire has expanded to include adults with mental health difficulties as well as those with learning disabilities and in East Renfrewshire they work with people from all community care groups.

Equal Say has reported a rise in the number of parents with learning disabilities coming to them or being referred to them for support in relation to parenting issues. Their experiences in terms of working with this group of people suggest a need for early, often intensive intervention and support to ensure the best possible outcome for parents with learning disabilities and their children.

1.3 Models of Advocacy

Broadly advocacy refers to the process of pleading the cause of and acting on behalf of another person to secure services which they require and rights to which they and their advocate believe them to be entitled.

Advocates owe those they represent a duty of loyalty, confidentiality and a commitment to be zealous in the promotion of their cause

(Gathercole, 1986)

It is acknowledged that there are a number of models of advocacy being used throughout the country. Equal Say offer three models of advocacy and these are detailed below.

Direct advocacy or professional advocacy is when advocacy is provided by a member of staff. This will be issue based and normally short term.

Crisis advocacy is when a volunteer is supported by a member of staff to get to know and represent one person about a specific issue. It is usually short term, but can become long term, depending on whether the advocate and partner choose to continue their advocacy relationship.

Citizen advocacy is when a volunteer is supported to get to know and represent one person in a long-term, unpaid and independent relationship. The advocate and partner will together decide which issues to tackle and how long their partnership will last. When recruiting a citizen advocate for someone, the member of staff will get to know the person to identify what type of person would make a suitable citizen advocate for them and then try to recruit the right person through networking.

All advocacy coordinators in Equal Say are geographically based multi tasking workers. They provide some direct advocacy as well as recruiting and supporting crisis and citizen advocates.

2. THE RESEARCH PROPOSAL

This small scale piece of research has been designed as a pilot in order to identify the key issues in relation to parenting with a learning disability in Scotland. Two researchers from the Glasgow School of Social Work, Gillian MacIntyre and Ailsa Stewart were approached by Equal Say in order to:

- Identify the likely demand for advocacy services to support parents with a learning disability living in the community in the Glasgow area
- Illustrate, in depth the lived experiences of parents with a learning disability living in Glasgow
- Highlight examples of good practice in terms of what works in supporting parents with a learning disability

In order to address these aims, the following research questions were developed.

2.1 *Research questions*

5. What is known about the experiences of parents with a learning disability and their children from the existing literature and research and what can be learned from this?
6. What proportion of parents with a learning disability are currently being supported of the total in need?
7. Is there a greater demand for this service across the Glasgow area?
8. What are the experiences of those who have received support from an advocate and what are the range of outcomes as a result of this support?

2.2 *Methods*

2.2.1 *Survey Questionnaire*

A short survey questionnaire was sent to 94 relevant social work, health and voluntary sector organisations within Glasgow City. The survey asked the respondents to:

- identify the number of parents with learning disabilities, if any, with whom they currently worked and whether this number had increased or not and the reasons for this.
- identify supports currently being provided to parents
- identify supports which should be available to parents
- identify gaps in current service provision.

Twenty two completed responses were received, achieving a return rate of almost 24%. Whilst statistically this is below the average postal survey return rate of 30% the findings are still relevant to the study as the key themes identified chime with those identified both in the literature and the interviews.

2.2.2 *In-depth interviews*

Interviews were carried out with five parents with a learning disability and their advocates. Parents were interviewed first to discuss a range of issues in relation to their parenting. Their experiences of being a parent were discussed as were the range of support services and mechanisms in place to assist them with this role. Parents were also asked to comment on and discuss their experience of working with an advocate.

In four of the five interviews, parents were interviewed with support from their advocate who assisted them in telling their story. At the point in the interview where parents were asked about their experiences of working with an advocate their advocate left the room.

Interviews with parents varied in length and depth. The more detailed interviews lasted for around 90 minutes. The other interviews lasted between 20 minutes and one hour.

Interviews were conducted with the advocates of parents who took part in the research. These interviews were conducted after the interviews with parents (with the permission of parents involved). These interviews enabled the researchers to look in more depth and from a different perspective at some of the issues raised by parents with a learning disability. These interviews also provided a forum to discuss the issues in supporting parents with a learning disability more generally. These interviews lasted for around one hour each.

In addition, a number of key informant interviews were conducted with Equal Say's development manager, with two learning disability social workers and with the coordinator of a network for parents with learning disabilities.

A total of 14 interviews were completed.

2.2.3 Sample selection and characteristics

The sample of parents who were interviewed were approached after consultation with Equal Say. A sample of the total number of parents (n=16) with whom the organisation had worked in recent years was identified. Advocacy coordinators identified which of these parents had the capacity to give informed consent to participate in the research. Of these, five were selected at random and were approached to take part in the research. They were approached initially by Equal Say who explained what the research was about and asked if the individual would be willing to meet with the researcher to find out more about it. Those who agreed to meet with the researchers had an initial meeting where the aims of the research were discussed and it was explained to parents what they would have to do if they agreed to participate. All of the parents who met with the researchers agreed to take part and signed consent forms to indicate this.

The table below outlines in brief the key characteristics of each of the parents who participated in the research.

Name*	Age	Number of children	Living Arrangements	Length of time parent has been working with Equal Say	Other support in place
Catherine	24	Two daughters aged seven and three	Catherine currently lives alone in a high rise flat. Both of her children are in foster care. She does not currently have a partner	Three years	Catherine currently receives housing support from a local support provider. She does not have a social worker
Mary	45	One daughter and three sons. Her three older children are married with families of their own. Her youngest son is 13 years old	Mary lives with her husband and youngest son. Her daughter also currently lives with the family	One year	Mary currently receives a limited amount of housing support from a local support provider. She has a social worker although she does not see her regularly.
Rachel	45	One daughter and one son. The daughter has left home and the son is accommodated by the social work department.	Rachel lives in her own tenancy; she is widowed and lives alone.	One year	Rachel receives no support from other services. Equal Say have spent a significant amount of time trying to find her an advocate which to

Sandra	34	One son who is two years old	Sandra currently lives alone. She has a partner although he lives at home with his parents. They have plans to marry at a later date. Sandra's son is currently in foster care. He has lived with foster carers since birth.	Two years	date has not been successful Sandra currently has input from a psychologist and a psychiatrist. She has a social worker but does not appear to be in receipt of services at the time of the research. She previously had support from community midwifery and her health visitor
Angela	39	Two sons aged 13 and 11	Angela currently lives alone. Her two sons are in foster care. She no longer has a relationship with her partner who is currently in prison	Around one year	Angela currently has limited housing support from a local provider. She has a care manager.

* All of the parents and children's names have been changed in order to protect their identities.

Pen portraits

Catherine

Catherine is 24 years old. She lives alone. She has two daughters aged six and three. Both of her daughters are in foster care. Her oldest daughter is currently being looked after by Catherine's aunt. Her younger daughter is with her second set of foster parents. Catherine's children were taken into care after Catherine's youngest daughter was born. The grounds for concern related to issues of neglect and concerns around Catherine's ability to protect her children from harm. Her previous partner and father of both girls was a schedule one offender. After the birth of her second daughter Catherine allowed her partner to see the girls, resulting in their removal from her care. Catherine has contact with her parents and occasionally goes to stay with them for the weekend. She has lost contact with her twin sister whom she misses a lot. Catherine would appear to be fairly socially isolated although she has recently been attending a class at her local further education college which may alleviate this to some extent.

Catherine no longer has contact with her ex-partner. She has fairly regular contact visits with both of her daughters. These visits are meant to take place on a weekly basis but this does not always happen. Contact with her older daughter takes place at her aunt's house. Contact visits with her youngest daughter take place in a social work contact centre. She has recently been subject to a parenting assessment, which she found particularly difficult. In terms of the assessment, particularly problematic areas related to her lack of ability to provide nutritious meals for her children, her lack of ability to set boundaries and her perceived lack of ability to show the children affection.

Equal Say began providing support for Catherine after a referral was made to them by her support provider. Originally she was matched with a crisis advocate but it quickly became apparent that the complex nature of her case meant she would require fairly intensive on-going support and so an advocacy coordinator took over the case.

The main role of the advocate in Catherine's case is to provide her with support to attend the various panel meetings that she has to go to. The advocate provides Catherine with the support that she needs to prepare for the meetings, reading through the various papers and assisting her to prepare her response to them. Catherine hopes that in time her daughters will be returned home to live her.

Catherine currently has no social work support although both her children have social workers. She receives support on a once weekly basis from her housing provider.

Mary

Mary is a forty five year old woman who lives with her husband. Both parents' have a learning disability. Mary and Fred have four children. Two sons have left home and have children of their own. Their daughter, who is 28, is currently living with the family as is their youngest son, Andrew who is 13.

Andrew has always lived at home with his parents. The grounds for concern which resulted in a referral being made to social work related to issues around neglect. Mary and Fred find it difficult to manage household tasks such as keeping their home clean and paying bills on time. There were some concerns about Andrew's appearance occasionally being somewhat unkempt. More recently as Andrew has

gotten older he has become more difficult for his parents to manage. They find it difficult to get him to attend school on a regular basis and find it difficult to negotiate with him and discipline him.

Both parents currently have their own social worker but they see her on a very infrequent basis. Andrew has his own social worker who arranged a be-friending service for him. This proved to be very successful but has recently been discontinued. The reasons for this are unclear. The family receives some support from a local provider. This support is available once a week and assists them with paying bills, shopping for food and doing household tasks. Although the support received is very limited, the family themselves have been reluctant to accept support in the past. They feel wary of inviting social workers into their home as a result of the perceived criticism of their parenting skills.

The family has been working with Equal Say for just over a year. The referral was initially made by Fred's social worker. Fred was very keen to have an advocate although Mary was less keen initially. After she observed the support that Fred was receiving however she warmed to the idea and now has an advocate of her own. The main role of the advocate has been to support Mary to attend meetings. She also assisted her to seek legal representation. Mary has recently become much more receptive to receiving support to help her deal with her son Andrew. She is interested in trying parenting classes, although it is unclear whether appropriate classes are available in the local area.

Rachel

Rachel is a woman in her 40s who lives on her own in her own tenancy. She has two children, neither of whom presently live with her. She has one daughter in her early 20s who has left the family home and one son aged 16 who has been accommodated by the social work department since 2006. Rachel currently does not know where her son is living. It appears as though Rachel's son also has a learning disability. Rachel appears socially isolated with the only reported social contact being with her daughter.

Rachel was married for 22 years to an abusive alcoholic husband. He died in 2006 before her son went into care. Rachel reports that her husband died in prison where he was sent for assaulting her. Rachel's son was accommodated in 2006 due to his increasingly violent behaviour towards her, although this was not something Rachel herself complained about to anyone.

Rachel feels that she is being prevented from seeing her son by the social work department. She reports that she has had no contact from the social work department about her son in over two years and has not at any time been asked to attend a children's hearing. Rachel states that she has had no contact from her son since he became accommodated. It is unknown whether Rachel still has her parental rights. Equal Say became involved with Rachel following a referral from her housing provider. An advocate was identified for Rachel, however for a variety of reasons they have not been able to begin working with her, she therefore did not have an advocate at the time of the interview.

The situation is very confused because of the lack of an advocate for Rachel and her general lack of clarity over the situation with regard to her son. It is therefore difficult to be definitive about Rachel's circumstances. She finds written material difficult and did not appear to remember time frames particularly well. For example she talked about not seeing her daughter regularly and then was reminded by the Equal Say coordinator that in fact she had seen her daughter some two weeks prior to the interview. The Equal Say coordinator has developed a good relationship with Rachel although she had not acted as an advocate for her at the time of the interview. There appear to be no other supports in place for Rachel. Rachel is currently living in poor housing conditions and would benefit from some support to help her with day to day living.

Sandra

Sandra is 34 years old. She currently has one son who is almost two years old. Sandra lives alone in a flat that is fairly new and well decorated. Sandra does not live with her son Mark who is currently living with foster parents. She has never lived with her son as he was removed from her care shortly after birth.

Concerns about Sandra's ability to parent were raised prior to the birth of her son. Sandra attended parenting classes where some concern was raised about her ability to learn the skills required to be an adequate parent. As a result a referral was made to social work and child protection proceedings were undertaken. Upon his birth, Mark was very seriously ill. He had a heart condition and a very low birth weight. He had to undergo open heart surgery after which a case conference was held and an application was made to formally remove Mark from Sandra's care.

Sandra has a partner, Harry who also has a learning disability. They met when they were at school together and have been a couple for many years. Although they do not currently live together – Harry lives at home with his parents – they have a stable relationship and have plans to marry at a later stage. Sandra also has a good relationship with her father who she sees regularly. He provides her with support both practically and emotionally and was extremely upset at the loss of his grandson. Sandra's mother died two years previously. Sandra has two sisters both of whom live in England. As a result of this she does not get to see them on a regular basis.

Sandra does not have a social worker. She receives support from her housing provider. This support is made available to her twice a week and assists her with practical tasks such as shopping, paying bills and cleaning her home. This support is somewhat unsatisfactory as it is provided by a team of people. This has meant that Sandra has not been able to build up a relationship with any particular member of staff.

Sandra currently has contact visits with Harry on a twice weekly basis. These contact visits originally took place at a contact centre but this was felt to be an unsuitable environment for Sandra and the visits now take place in her own home.

Sandra has been receiving advocacy support from Equal Say for almost two years. She was originally referred to Equal Say after concerns were first raised by the midwife. All of her support has been provided by the advocacy co-ordinator in recognition of the on-going and complex nature of her case. The main role of the

advocate has been to ensure that Sandra's views are represented at the various meetings she has to attend with regard to her son. Prior to the involvement of Equal Say, case conferences were held without Sandra's knowledge. Equal Say has also supported Sandra to secure legal representation.

Angela

Angela is a thirty nine year old lady who currently lives alone. She has two sons aged 11 and 13 who have recently been accommodated by the local authority. Angela's previous partner and father of her two sons is currently in prison and there are concerns about the risk to Angela's sons when he is released from prison at a later time.

Angela's initial referral to Equal Say did not centre on child protection issues. At the time of referral, Angela and her partner had hoped to marry and the referral related to providing her with the support she needed to do this. The wedding did not take place and Angela and her partner are no longer together. Very quickly, issues with Angela's housing situation deteriorated. Angela and her sons were the only tenants remaining in a block of flats that were about to be demolished. The local housing association was unable to re-house the family in suitable accommodation and social work became involved.

A number of grounds for concern were raised relating to the unsuitable housing and other issues of neglect. There were also concerns about Angela's ability to assess risk and protect her children from harm. The children are now being looked after by the Local Authority. Angela hopes that her children will return to live with her after she is re-housed.

Angela has a care manager who recently arranged for Angela to receive some support with practical tasks such as cooking, cleaning, shopping and paying household bills. It is also hoped that this support will assist Angela to develop her parenting skills, although it is not clear whether such an intervention would be funded by the Adult Learning Disabilities Team or Children and Families Social Work.

Since working with Equal Say, Angela has started to attend childrens' panel meetings to discuss her children's future. Prior to the involvement of Equal Say she was not invited for fear that the meetings would upset her. In addition she has recently started seeing a psychologist to help her work through some difficult issues that occurred during her own childhood.

3. KEY THEMES FROM THE LITERATURE

Parents with learning disabilities are properly seen not as a different kind of parent but as a more vulnerable one

Mickelson (1949)

3.1 Overview

The above quote gives a useful starting point to look at the literature by considering whether or not this perspective has changed over time. There is a general perception amongst policy makers, practitioners and academics that there is not enough research that looks at the experiences of parents with disabilities including those with learning disabilities, nor is it sufficiently targeted to be of use to individual groups. There is however a growing awareness of parents with a learning disability as a neglected area of research, particularly with regard to the experience of fathers. Despite this growing awareness, there is perceived to be a significant gap in the available literature. However some key themes can be acknowledged and these are summarised below. It is important to note that what follows is a comprehensive summary of the key themes emerging from the literature. It is not intended to be taken as a systematic review of the literature.

3.2 Numbers of parents with learning disabilities

Overall the number of parents with learning disabilities has increased, perhaps due to normalization principles and policy developments such as *The same as you*, although estimates suggest that they represent less than 1% of the population. However exact figures for the number of parents with learning disabilities are not known. Booth and Booth (2000) suggested that although there are an acknowledged 2.1 million parents with disabilities in the UK the exact number of parents with learning disabilities is largely unknown. The recent national survey of adults with learning disabilities in England found that 1 in 15 of those interviewed had children, 48% of these parents were not looking after their own children (Emerson et al, 2005).

It should be further acknowledged however that parents with learning disabilities are not a homogenous group and that there are wide variations in characteristics and circumstances. Experiences of child-rearing and parenthood do show a number of similarities in that they tend to mirror the experiences of other at risk groups.

3.3 Care System, Abuse, Neglect and Disadvantage

In work carried out by Booth and Booth (2004) it was noted that parents with learning disabilities are over-represented within the child protection system. Despite the small numbers one in six Local Authority Care applications concerned parents with a learning disability. Parents with a learning disability were more likely to have their children removed. In Booth and Booth's study, almost 40% of parents were not living with their children.

The majority of the children removed were taken into care or fostered rather than being adopted. Interestingly, nine out of 10 parents with learning disabilities who lived with relatives had their children with them as compared to four out of ten mothers living in their own households (Booth and Booth 2004). This demonstrates the value of family support and is discussed in more detail below.

Concerns about people with learning disabilities who are parents generally relate to inadequate parenting not abuse, in essence, neglect by omission. Concern over neglect has centred on performing household tasks, attending to a child's physical needs, providing love and affection and stimulating the child intellectually (Booth and Booth 2004). Parental competence is often situationally determined and socially constructed. Problems therefore for parents with learning disabilities tend to be around social isolation, poor housing, harassment, victimization and poverty rather than parenting skills per se. Problems experienced by parents with learning disabilities are often viewed in terms of the learning disability itself and the cognitive impact rather than wider factors such as the parents own childhood experience for example, not having experience of 'ordinary family life'. Consequently there is often a lack of a holistic approach taken to assessment of need and subsequently support for the parent. In addition the focus of the assessment is often centred on the needs of the child rather than the needs of the parents.

The literature also suggests that as many parents with learning disabilities are single mothers, there is evidence of men with difficulties themselves e.g. learning disability, unstable mental health or a forensic history approaching mothers with learning disabilities to form relationships (Booth and Booth 2002).

Further work by Booth and Booth (2002) which drew on data from three previous studies found that despite conventional wisdom that says that mothers with learning disabilities often establish relationships with men who abuse them, the evidence is not there to present such a blanket assessment. There appears to be a high incidence of unemployment, disability, divorce and separation, abuse, drug and alcohol misuse and child removal amongst male parents with learning disabilities. However most of the men in Booth and Booth's study were supportive of their families and less than one quarter were abusive. Of those who were abusive, a significant number only became so when other stressors were in place, for example the removal of a child or ill health. There is a significant impact on practice from these findings including recognising the importance of engaging with men in families where one or both parents have learning disabilities.

In addition to the above Accardo and Whitman (1990) found an increased risk of abuse occurring when parents with learning disabilities had children with higher intellectual ability than their own. It is noted that parents with learning disabilities also find it increasingly difficult to cope as their child grows up. Studies also show that they have less chance of successful parenting where the child has severe or complex needs. However it should be noted that purposeful abuse by mothers with learning disabilities is rare and is more likely to be associated with their partners. Tymchuk (1992).

As family size increases so does the risk of abuse and neglect (Tucker and Johnson 1989). When more children arrive the focus of support and protection is aimed at the children rather than at supporting the parenting and consequently concerns over parenting increase.

Most of the children of parents with learning disabilities are brought into care or accommodated due to neglect, mainly due to a concern over the lack of parenting skills, failure to learn or to appreciate the need for change. In half of all cases a parents' learning disability was specifically cited as a factor in the neglect of a child (Booth, Booth and McConnell, 2005b). There is little evidence to suggest that supports were put in place to best meet these needs or to combat disadvantage.

Concerns about parents with learning disabilities include the following.

- Any children will be disabled – evidence suggests that when one parent has a learning disability 15% of all children may have a disability. This increases to as much as 40% when both parents have a learning disability. This is in sharp contrast to 1% when neither parent has a learning disability (Reed and Reed 1965). Caution should be expressed here as this figure may now be out of date.
- They'll have too many children – there is some evidence that the numbers of children born to parents with a learning disability are slightly higher than the average.
- They'll be inadequate parents – the evidence does support this, however the nature of the evidence is questionable. Some parents with learning disabilities can and do provide adequate parenting.
- They cannot learn to be adequate or good enough parents – research suggests that parents with learning disabilities can learn to be good enough parents.

(Sheerin F 1998)

3.4 Support for parenting

The literature highlights the importance of social networks in supporting people with learning disabilities in particular in enhancing their quality of life, (see for example, Sheppard, 1994). Stenfert Kroese et al (2002) in a study of 15 mothers with learning disabilities reported that significant associations were found between the number of reported social contacts and positive affect, the recentness of reported social contacts and self-esteem, and the lack of self-esteem and the reported burdens of parenting. They also found that very few non-family members were part of the support networks. Of 102 social contacts reported in the study, only 29 were non-family members, just less than a third. It could be argued therefore that the psychological effects of social networks impact on the parenting ability of the individual.

Lack of support and social isolation can impact significantly on adults' abilities to cope. Having support from someone without a learning disability can be one of the single most important factors influencing the ability of parents to manage. In some studies, for example Llewellyn (1995), many parents with learning disabilities were single parents and one third of those in this study could identify no other significant adult in their life and were not aware of other parents with learning disabilities.

Successful outcomes are often linked to the presence of family members, for example a grandmother or aunt who is available for support and/or advice.

It is noted that support may be as important a factor as the learning disability itself in successful parenting. It is suggested that successful support includes:

- provision of easy information and adapted resources for parents
- advocacy and self-advocacy support to parents which builds on their existing skills and abilities, praises their successes and promotes their social integration
- interventions that build on parents' strengths and promote children's resilience while following and developing good practice. These interventions should be provided in the parent's home using the actual equipment the parent will use
- helping parents to overcome the wider issues in their lives such as debt, poor housing and harassment
- support for women and men experiencing violent relationships
- support for fathers (whose needs have generally been overlooked)

(CHANGE 2005, McGaw and Newman 2005, Tarleton et al 2006)

The support available to parents with learning disabilities can often be short term in response to a crisis that has brought them into contact with services, rather than long-term preventative and support work. Concern over short term support is that it creates a cycle or revolving door whereby once support reduces concerns it is removed or reduced and concerns then re-emerge. (Tarleton 2006). In addition it has been noted that social workers working with children of parents with a learning disability often provide input on the basis of the child's needs rather than the needs of the family as a whole which also leads to short term input.

It should also be noted Booth and Booth (2004), Booth et al (2005 a and b) and McConnell and Llewellyn (2000) highlight that parents with learning disabilities often do not want to work or co-operate with children's services because their competence to protect their child's welfare is under scrutiny with an assumed baseline of incompetence.

The literature suggests that parents with a learning disability think that children's services:

- do not understand them
- do not listen to them
- expect them to fail
- do not give them clear messages about what is expected of them
- treat them differently from other parents who need support
- use their need for support, or any difficulties with their child, against them as evidence that they are unable to parent
- use their previous history of having children removed, when they have not been provided with adequate support, against them
- provide no support once their children have been removed from them

(Tarleton 2006)

Statutory proceedings are very harrowing and can be lonely. The processes involved often go unexplained to parents with learning disabilities and they tend to have a difficult relationship with solicitors, are often not advised to use them or there is a challenge to their competence to instruct.

Adequate support services are crucial in helping parents to overcome their limitations when the best predictor of neglect 'appears' to be the absence of suitable societal and family supports (Tymchuk 1992). In addition, the attitude of those delivering the support is the most important factor contributing to the success or failure of a parent with learning disabilities (Tymchuk et al 1990).

Five key features of good practice in working with parents with learning disabilities

- Accessible information and communication
- Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways.
- Support designed to meet the needs of parents and children based on assessments of their strengths and needs
- Long-term support where necessary
- Access to independent advocacy

(Department of health, Department for Education and Skills 2007)

3.5 Advocacy

The literature clearly emphasises the importance of advocacy and self-advocacy for parents with a learning disability (e.g. Booth and Booth 1999).

Advocacy and self-advocacy is promoted in the literature (Booth and Booth 2004) as playing an important role in ensuring that parents are not disempowered and that their voice is heard during the upsetting and legally complex child protection process.

A study carried out for Mencap (2007) suggests that advocates should be independent of support services supporting parents, have a person centred non-judgemental style and be honest. Details of the role that advocates should play during child protection proceedings are provided in this study.

Booth and Booth (1999) in a study of advocacy support provided to parents with learning disabilities using a specific model of parenting and support, showed that:

- Although individually parents felt very supported by the service, advocates were aware that they did not assist in changing the circumstances that the individuals lived in, e.g. poverty, abuse.

- They did not change environmental factors but did make professionals see individuals differently and ensured they got better/different types of support. Advocacy could challenge individual bad practice but not systems as a whole.
- Advocates are often caught between the scale of the problem and the unavailability of appropriate services and this can wear them out.
- Advocacy groups should be seen as an extension of one to one advocacy support rather than in place of it.

3.5 *Joint Working*

A range of services are available UK wide:

The emerging concept 'parenting with support' promotes better parenting and aims to provide pro-active, flexible, preventative support, through co-ordinated multi-agency working, and within the current policy guidance.'

(MENCAP 2007)

This positive approach is however not taken everywhere and is generally limited to those areas where the number of cases has increased and/or individual professionals have a particular interest. As with other areas of partnership working, where co-ordination between services is not effective and there is a general lack of awareness of other's roles and responsibilities, this impacts on taking a pro-active approach to providing support to parents with learning disabilities.

It is suggested that a barrier to the provision of effective parental training and support is the blurring of responsibilities between children and adult services. As previously indicated children's services tend to focus on children's needs and welfare including child protection issues, whilst adult services focus on the provision of personal services to adults with learning disabilities. The needs of parents with learning disabilities therefore often fall between the needs of both services. A consequence of this blurring of responsibility may be that as a result of high eligibility criteria, needs are often only identified and assessed when a crisis is reached and there is a potential issue of child protection.

Some adult services feel that parents with learning disabilities should be seen by children's services particularly where there is court work involved, an area that adult social workers are often not trained in and do not feel comfortable with. (Booth and Booth 2004, Tarleton et al 2006)

Conversely, children's social workers often do not have significant experience of working with people with learning disabilities, can hold stereotypical views of parents with learning disabilities and don't make good use of specialist support that is available.

The literature suggests that barriers to joint working include:

- the apparent lack of skill among professionals for assessing and supporting parents with learning disabilities

- entrenched attitudes about the responsibilities of respective services towards children and adults.

(SCIE 2005)

3.6 Training

Parent training and education programmes are available for parents with learning disabilities although it is not clear how widespread these programmes are in the UK.

Feldman (1994) notes that parent education programmes generally focus on developing the skills of problem solving and decision-making. He further notes that training can be effective and virtually all mothers can be helped to improve their parenting with training.

Parent training programmes for parents with learning disabilities focus on childcare, child safety, and these home based programmes do demonstrate some success and are preferred to 'centre-based programmes as a form of education. (SCIE 2005).

4. FINDINGS

4.1 Statistics/Referrals

The statistics detailed below were provided by Equal Say in July 2008. These provide details of referrals received between April 2002 and 2005 and then from April 2005 to March 2008 a period of six years in total.

During 2002 to 2005 there were 11 referrals for support for parents with learning disabilities. Referrals were primarily from social work in both the north and south west of Glasgow. The majority of those referred were living in two parent households with the primary reason for referral being for advocacy around the issue of child protection.

Referrals for the period April 2002 – March 2005, by Quarterly Periods

Period	1	2	3	4	5	6	7	8	9	10	11	12	TOTAL
Total	15	21	15	28	21	26	24	25	28	26	18	19	266
Number	0	0	1	1	0	1	2	0	1	2	1	2	11
Parents													
LD													

Of the 11 referrals involving parents with a learning disability, all information as at point of referral:

Source of Referral

self	Service provider	Social work	Family/friend	Health care worker	Other Advocacy service
1	0	9	1	0	0

Area Parent lives in:

Glasgow: North	4
	0
West	
	2
East	
South East	0
South West	5
East	0
Renfrewshire	
East	0
Dunbartonshire	

Age Range

Ages were not routinely recorded; therefore no accurate information is available.

No. of children at point of referral

Mother expecting first child	1	2	3	4	5	6	Not informed
	4	2	2	0	1	1	0

Housing situation of parent referred

Temporary accommodation	0
Secure tenancy	6
Traveller	0
Living with family	1
Not recorded	4

Family situation

Single parent	2
Living with partner who is parent to all children	6
Living with partner who is parent to some of the children	0
Living with partner who is not parent of children	0
Single and children living with other parent	0
Not recorded	3

No. of referrals where child protection procedures are main reason for referral: 10

None had other additional referring issues.

For the one referral where child protection procedures were not the main reason for referral, the parent had her child living with her and the child's father was at home. She had family support close by. The reason for the referral was around housing.

Of the other 10 referrals:

All children at home with parent	2
All children in care	6
Some children in care, some at home	1
All children in care of other parent or another relative	0
Some children in care of other parent or another relative, some	0

at home	
Unborn child	1
Not known	0

Between 2005 and 2008 as can be seen from the statistics, Equal Say has provided an advocacy service to 20 of the 30 referrals over the last three years. The focus of this advocacy is dependent upon the needs of the individuals at the time of referral. It should be noted that the number of referrals have not increased significantly over the period under consideration but rather they have remained steady, averaging two per quarter. They have however increased significantly from the previous three year period from 11 to 30, more than doubling.

Referrals are primarily from one social work team within the North of Glasgow, providing almost half of the referrals over the last three years. There is therefore clearly a role to be played in raising the profile of this service user group within the social work service generally and more broadly within the voluntary sector.

Age ranges of those referred were fairly widespread between those under 25 and 55, although a third were aged between 36 and 45 with a further 27% of parents with unrecorded ages.

There was an even split of almost 50% each between those who were single parents and those living with a partner at the time of referral. This is in contrast to the previous three-year figure where the majority of referrals were in two person households. Of the 30 referrals, 80% were made because of child protection issues. This figure is slightly lower than in the first three year period where 90% of referrals were for child protection issues.

Referrals Received April 05 – March 08, by Quarterly Periods

Period	1	2	3	4	5	6	7	8	9	10	11	12	Total
Total	19	51	39	29	33	50	49	33	64	47	35	34	501
Number Parents with LD	1	4	3	1	4	3	3	1	5	3	2	0	30

Of the 30 referrals involving parents with a learning disability, all information as at point of referral:

Source of Referral

self	Service provider	Social work	Family/friend	Health care worker	Other Advocacy service
4	4	15	2	3	2

Area Parent lives in:

Glasgow: North	13
West	2

East	3
South East	3
South West	7
East Renfrewshire	2
East Dunbartonshire	0

Age Range

25 or under	26-35	36-45	46-55	Not Disclosed
6	10	4	2	8

No. of children at point of referral

Mother expecting first child	1	2	3	4	5	6	Not informed
2	10	9	3	1	2	1	2

Housing situation of parent referred

Temporary accommodation	3
Secure tenancy	15
Traveller	1
Living with family	1
Not recorded	10

Family situation

Single parent	11
Living with partner who is parent to all children	10
Living with partner who is parent to some of the children	0
Living with partner who is not parent of children	1
Single and children living with other parent	1
Not recorded	7

No. of referrals where child protection procedures are main reason for referral: 24

Of these 24,

Additional Referring issues included:

Benefits/finances	1
Other legal issues	1

Adult Protection	1
Social isolation	3
Housing	5
Other family issues	4

Of the six referrals where child protection procedures were not the main reason for referral, all parents had their children with them at home, apart from one parent who was single and living in temporary accommodation. She had made an informal arrangement with a relative to look after one of her two children.

Of the other 24 referrals:

All children at home with parent	4
All children in care	9
Some children in care, some at home	3
All children in care of other parent or another relative	4
Some children in care of other parent or another relative, some at home	0
Unborn child	2
Not known	2

Referral Outcome

Advocacy Provided	19
No further action taken	11

Of the 11 referrals where no further action was taken, the reasons for this were as follows:

Person did not want advocacy	3
Person moved away	2
Other people already advocating	2
Not prioritised	2
Reason not recorded	2

Of the 19 referrals where advocacy has been provided, the following has been provided:

Direct Advocacy	5
Crisis Advocacy	5
Citizen Advocacy	3
Crisis Advocacy, then citizen advocacy	2
Combination of crisis and direct advocacy	3
Added to working list	1

Direct advocacy is when advocacy is provided by a member of staff. This will be issue based and normally short term.

Crisis advocacy is when a volunteer is supported by a member of staff to get to know and represent one person about a specific issue. It is usually short term, but can become long term, depending on whether the advocate and partner choose to continue their advocacy relationship.

Citizen advocacy is when a volunteer is supported to get to know and represent one person in a long-term, unpaid and independent relationship. The advocate and partner will together decide which issues to tackle and how long their partnership will last. When recruiting a citizen advocate for someone, the member of staff will get to know the person to identify what type of person would make a suitable citizen advocate for them and then try to recruit the right person through networking. At this stage the person is considered to be on the working list of the Advocacy Coordinator

4.2 Findings from interviews and survey

The findings presented below provide a detailed picture of the experiences of parenting with a learning disability. They also highlight the impact which advocacy can have on the lives of parents. They are based largely on the interviews with parents and their advocates. The findings are presented as key themes and are illustrated with quotes and examples where relevant.

4.2.1 Service demand

Before looking in detail at the experiences of individuals, it is important to look at the picture more generally, as illustrated by the survey. This reinforces the view that service providers know very little about the experiences of parents with a learning disability, other than those in specialist provisions such as the Parents and Children Together Teams (PACT) and learning disability teams. Aside from the specialist teams, those who completed the survey were able to say very little about parents with a learning disability and what their needs might be. Few service providers, again other than the specialist teams, were able to provide information on the number of parents with learning disabilities that they worked with mainly because their systems were not able to provide it or because they did not work with parents with learning disabilities. A further challenge with identifying parents with learning disabilities supported by services noted by a number of respondents was that often they worked with individuals that they suspected of having a learning disability but who did not have a formal diagnosis.

Many respondents were also unaware of the support services available for parents with a learning disability. For example a number of providers were unaware of the work carried out by Equal Say on behalf of parents. Overall, those out-with specialist teams felt they would, in the first instance, seek support from social work either through children and families or learning disability services.

While the survey was unable to conclusively demonstrate large increases in the number of parents with learning disabilities, it did demonstrate the need for support for service providers in terms of awareness raising around the particular needs of parents with learning disability alongside providing information about the support services available to assist parents in their parenting role. In addition it provided

detail of the kind of supports agency staff felt should be available. For example, one respondent noted a need for addiction staff specializing in learning disability and mental health. However it is important to note that those specialist services who responded had noted an increase in numbers of referrals which they attributed to two major factors.

- More young people with learning disabilities having positive health and social opportunities
- Growing awareness of the need for support for parents with a learning disability.

There were a number of service supports currently being utilized, primarily by the specialist teams and these included:

- Social workers from children and families
- Social workers from community care and specialist learning disability services
- Health visitors
- Family support workers
- Nursery nurses
- Community nurses
- Clinical psychologist
- Speech and language therapists
- Consultants
- Advocates
- Occupational therapists

We have examples of parents getting support from OTs, psychology, home support service, the PACT team and our own social workers as well as advocates..... So there is support around, I think the challenge sometimes is it can be seen as being too late – depending on what's happening with the child protection process

Social worker in learning disability service

What becomes clear from the above evidence is that there has been an increase in demand for specialist services to support parents with learning disabilities. However this finding should be treated with caution given the small-scale return on the survey questionnaire. It has also highlighted the number of services currently providing various levels of input to parents with learning disabilities, although perhaps limited to those gaining access to specialist services. More work is required to ascertain the number of parents with learning disabilities within the city and the range of services available to support them.

4.2.2 Complexity of individual situations

For the five research participants, issues around parenting provided the most immediate and urgent need for advocacy. The pen pictures above show that the parents faced extremely challenging and complex circumstances in relation to parenting but their lives more generally can be characterized by the disadvantage that they faced in a number of areas. The five parents lived in relatively disadvantaged parts of the city in fairly poor housing conditions where poverty was

part of their everyday existence. In two of the five cases, referrals to Equal Say were not made in relation to parenting specifically but were as a result of issues in relation to other aspects of disadvantage such as problems with housing. In Angela's case for example, the referral was made as a result of problems with the local housing association failing to provide adequate alternative housing for her.

For four of the five respondents, problems with housing were significant. For Mary, problems with neighbours that resulted in the eventual physical assault of her husband led to the family having to be re-housed. In Catherine's case, she lived in a high-rise flat where she experienced social isolation. Alongside, poor housing the five research participants had also experienced difficulties in terms of accessing appropriate services and support for example in the areas of education and employment. In addition, three of the five participants had some experience of abuse - Catherine had lived with a partner who had a previous history of abuse, as did Angela. Rachel also had experienced abuse from her previous partner and also from her son.

For all five parents, issues around parenting quickly took priority and intervention by Equal Say focused on supporting parents with a range of child protection issues. It has been highlighted in the literature review that despite the relatively small number of parents with a learning disability, they are over-represented in the child protection system. They are more likely to be involved in the system as a result of concerns over neglect as opposed to active abuse of their child or children as the following quote illustrates:

Its never come into question that she is a bad or parent or that she doesn't care about Andrew?...maybe she just doesn't have the toolkit that other parents have...you know about sanctions and rewards that kind of thing...

Professional advocate

This was the case with the five parents who participated in the research. For all parents there were a number of concerns around neglect. The specific nature of these concerns depended very much on the age of the child/ children and the families' particular circumstances, but common themes related to poor living conditions and concerns over parents' ability to provide the child with clean clothes and nutritious meals. For parents of younger children, the grounds for concern were likely to relate to the child's failure to thrive.

For parents of older children, concerns often related to poor attendance at school. Concerns were particularly apparent if the child did not have a learning disability. As children without learning disabilities get older, their intellectual capabilities often outstrip that of their parents. The following quotes illustrate the grounds for referral in relation to these concerns.

At the moment the main issue is his non-attendance at school...what Mary is saying is that she is trying her best to get him up and out his bed in the mornings...he is turning night into day...what's missing is someone to give Mary and Fred better parenting skills around negotiating.

Professional advocate

One of the grounds for referral was that Steven is now outstripping his mother in terms of capacity...he is reading mail he shouldn't be reading...they stopped sending the mail to Angela to protect the children...but Steven should be getting the support of a young carer...having a 13 year old at home could be a really important help to Angela...I don't know him well but he is a nice boy...

Professional advocate

In addition, there was concern about the ability of parents' to protect their children from harm. This was particularly evident for two parents whose previous partners had been schedule one offenders.

Depending on the timing of referral to Equal Say, the advocacy intervention was likely to be long term; parents required a significant amount of support to guide them through the child protection process. The complexity was exacerbated for parents with more than one child. Three of the parents who took part in the research had more than one child. This resulted in separate child protection proceedings with the associated meetings, professionals and paperwork for each child. In three of the five cases individuals' had initially been matched with a crisis advocate or volunteer advocate in order to assist them. However, in all cases it quickly became apparent that the case was of a complex nature and likely to be on-going over a lengthy period. This meant that advocacy coordinators often had to provide the support required. This will be discussed in greater detail later in the report.

The complexity of the cases under consideration may have an impact when considering the model of advocacy that could be most effective. In four of the cases the advocacy was provided by a professional advocate.

It's not just attending the meetings, its sitting down with the reports, going through them with a fine-tooth comb, planning, preparation, the writing up of anything that Catherine would want to say and has said, the discussion around whether and who speaks, how we do time out if we need time out, how we communicate in the meetings together, all those things get done every time so if you are dealing with two children with different social workers and different hearings it becomes extremely complex and time consuming.....I've had at various times four mums with between them 20 children, imagine what that's like to manage.

Professional Advocate

In one week we had a permanency review for one child on the Wednesday morning, a permanency review for the other child on the Thursday morning, contact for both children followed by a panel on the Thursday afternoon – it gets very difficult to manage.'

Professional Advocate

4.2.3 Support for individuals and the early identification of support needs

Evidence from all of the sources within this study suggest that in general intervention to support parents with a learning disability comes too late when it is a question of supporting parents through the child protection process rather than supporting them to develop their parenting skills. Indeed, the grounds for referral highlighted above are often of a nature where early intervention may have prevented, for example, the removal of children from the parental home.

The survey was unable to provide a fully comprehensive picture of the level and kind of support that is available to parents. The in-depth interviews showed that those parents who took part in the research had limited support. Apart from the support of their advocate, four of the five parents had limited support from their housing provider. This support was usually made available once or twice each week for around one hour. It usually comprised of help with housework, paying bills and shopping. While limited it might be that support of this nature where appropriately targeted may assist parents with their parenting role.

Evidence from the interviews suggests that the support that was available for parents was often not appropriate to meet their needs. For example, Catherine had access to a parent support group, however she was the only person in attendance who did not have their child with them and she felt disempowered within that setting. There is little evidence from the research to suggest that specialist support for parents with learning disabilities is available in Scotland. The research suggested that mainstream services often do not meet the needs of parents with a learning disability adequately. In Angela's case for example, Direct and Care Services (DACs) were commissioned to provide support to Angela in relation to the provision of nutritious meals for her sons. However, rather than teaching Angela about how to provide a healthy diet for her sons, they regarded providing the ingredients and making the meals as their responsibility disempowering Angela further. This is illustrated by the following quote from Angela's advocate:

Some services are totally inappropriate like DACs...what DACs does is dis-empower people...they were cooking the boys a meal rather than letting Angela know what a healthy meal was...we're in charge of the kitchen now...we'll make the kids dinner

Professional advocate

The importance of early intervention is clear. For many parents with a learning disability support from the early stages of pregnancy has been shown to be beneficial (see literature review). However, that support must be provided by professionals with an understanding of the particular issues faced by parents with a learning disability. In Sandra's case for example, the special needs in pregnancy midwife felt ill-equipped to deal with Sandra's particular needs. This is illustrated by the following quote from her advocate:

The midwife who was taking parenting classes felt a bit out of her depth and didn't know whether she had the skills to help Sandra...held her hands up and said she didn't know whether she was doing the right thing...that led to

the question if the professionals who are doing this don't have the right skills then who does

Professional advocate

Interestingly, none of the sample group had their own social worker. Social work services tended to focus on the needs of the child rather than the needs of the parent. This was particularly the case when child protection proceedings were underway. This finding is supported by the literature outlined above which presents a revolving door of support whereby parents get support through a crisis only to have that support withdrawn. Concerns then re-emerge promoting more significant measures to be taken.

It is clear that the research participants, aside from their advocates, had very limited support that was often not appropriate to meet their particular needs. It was possible from both the survey and the interviews to identify the *type* and *level* of support that respondents felt would be particularly helpful. A number of survey respondents noted that *'there is a need for longer term support for parents focused on the parenting role'*. The type of work suggested as appropriate from the survey returns included:

- Assisting with parents' understanding of children's basic needs, including hygiene
- Practical support with daily living
- Practical support with parenting tasks, including boundaries and the establishment of routines
- Advocacy

Intervention at an earlier stage, for example during pregnancy was noted as being beneficial in terms of prevention work for parents with a learning disability. A number of survey respondents noted that, in their experience, one major problem with regard to accessing services and support for parents with learning disabilities was that they had often attended mainstream school and had no formal diagnosis of learning disability and consequently were not eligible for support from learning disability services. In a similar vein, the high eligibility criteria for particular services meant that parents with learning disabilities might not come into contact with services until a crisis point was reached. There appeared to be very little scope for preventative work (see also SCIE, 2005).

4.2.4 Availability of accessible information

A common theme running throughout the research relates to the availability or otherwise of accessible information to assist parents with learning disabilities in their parenting role. As mentioned above, mainstream service providers often feel ill-equipped to support parents with a learning disability adequately. Likewise, many of the standard information packs and training materials in use are not accessible. A number of examples of creative work to provide accessible information for parents with a learning disability were identified during the course of the literature review. It was not clear whether any of the participants had been able to access any of this information. In England and Wales, the Department of Health have developed a training pack for parents with learning disabilities entitled *You and your baby*. This is

a practical handbook which parents can have at home to read. The British Institute for Learning Disabilities has also produced a number of publications which cover topics such as what it is like to be a parent, the need for children to have healthy food and so on. There is no central responsibility for ensuring these publications are distributed to parents with a learning disability however and so they tend to be available on an ad hoc basis.

For the parents who took part in the research there was some evidence of attempts to make information available in an accessible format. In Sandra's case for example, her psychologist had displayed pictorial reminders around the home to prompt Sandra as to when she should be carrying out particular tasks such as feeding or changing Mark. Whilst this only had limited success in Sandra's case, it is an example of innovative practice. It would appear that this work was done to the individual practitioner however rather than being a result of standard protocols or procedures.

Sandra also received a manual to assist her with her parenting skills. However as her advocate pointed out:

They put together a manual for Sandra but she can't use it...it just didn't work...but I couldn't use it either. I mean if I had a screaming baby the last thing I would want to be doing is saying oh I better look up page 17 in the manual to see what I am meant to be doing here

Professional advocate

4.2.4 Experience of the child protection system

With regard to accessible information within the child protection system more specifically, the main concern for individuals who participated in the research related to the amount of complex material that was sent to them prior to meetings. Often this material was sent at very short notice which left individuals and their advocates with very little time to prepare. Advocates who were questioned stated clearly that a significant part of their role involved assisting parents to prepare for meetings. They had to spend time working with parents, often through very legalistic paperwork to assist them to prepare their own response.

Professionals will say she can be very monosyllabic but she will chat away when she gets to know you...at panels she didn't get a chance to build up relationships with people...so I would spend some time helping her prepare what she wanted to say...if you didn't do that she wouldn't say much.

Professional advocate

This task was often made difficult as papers were often made available at extremely short notice. There were also examples of papers being distributed during meetings with parents being expected to respond to these without prior notice. Overall, advocates agreed with parents in their view that very little adjustment had been made to make meetings accessible to parents with a learning disability as the following quotes suggest:

The meetings have been very business like which isn't very helpful for Angela...she has had to leave the meeting to go outside and take a break...they haven't done anything to facilitate her understanding of the meeting...if anything it has been the opposite... the care manager has been the exception...she has briefed me on what she thought I should be doing

Professional advocate

The CP hearings...she gets very upset, she doesn't understand them...I don't have much criticism of the CP process...the panel hearings themselves have been as supportive as they could be...she has been able to talk to panel members and it has worked for her...things like paperwork, its not very clear and simple to read...I don't get copies of the paperwork I have to rely on her to let me know but I don't know when she got it...I think she could be supported better with that...

Professional advocate

The whole system isn't geared up for parents with a learning disability...even the children's panel meetings...the week before you get this whole lot of papers and your supposed to decipher it...its rare for the social worker to go out and talk them through it...they aren't given any idea how to interact in the meeting...there is very little support given in that way...I think the biggest thing is support to keep the children in the family home but the process you have to go through to get to that is also very inaccessible

Professional advocate

Overall, within the child protection system the parents who participated in the research felt there was a general lack of information about what was happening and what each part of the process meant. There appeared to be a lack of reasonable adjustments in order to make the meetings and other procedures more accessible and "user-friendly". Difficulties were also reported in terms of securing legal representation for parents. There are very few lawyers available to provide support to parents with a learning disability. One of the major problems is that legal aid is not available to enable lawyers to attend children's panel meetings. Parents have no legal representation at these formal meetings as a result. In addition, very few lawyers appear to be familiar with the particular issues faced by parents with a learning disability and communication appeared to be a particular difficulty:

She asked me questions...I couldn't understand...I told my advocate but I had to speak for myself... I don't know...I didn't know what she was talking about...my head was sore and my stomach was sore

Angela

There are of course exceptions to this. One lawyer in particular was in the process of raising an action against the children's reporter in the Court of Session to argue that her client's lack of legal representation in the children's' panel meetings was against her human rights.

4.2.6 *Appropriate assessment*

Alongside their experiences of the child protection system, three of the parents who participated in the research had been subject to an assessment of their parenting skills. Evidence from the interviews and from the wider literature suggests that assessment of parenting often focuses negatively on what people cannot do rather than on what they can. Little account appears to be taken of the difficulties in understanding standard assessment procedures that people with learning disabilities might have. In addition standard assessment tools are not always adapted to take account of learning disability. In Sandra's case for example, an assessment of her communication needs was carried out. This assessment was then ignored in future parenting assessments:

there has been an issue with communication...the reports weren't done according to the assessment which said don't use long and difficult words....try and use pictures...none of that was done...every letter and report meant nothing to Sandra...we tried to put it in a format that Sandra understood while at the same time saying, you know under the Disability Discrimination Act Sandra has a right to get things communicated to her in a way she understands...

The research did identify some examples of good practice however. Equal Say has worked with a social worker who is based in England who carries out parenting assessments using a specially adapted assessment tool. In addition there is a specialist assessment tool available from the Norah Fry Centre which could be utilized in the first instance if it were acceptable. Cornwall NHS Trust has also developed a tool called Learning Curves: The assessment of parents with a learning disability. More recently the Scottish Consortium for Learning Disabilities have run a conference on assessing parents with learning disabilities to identify further examples of good practice.

Parents who had experienced assessment of their parenting skills found this an extremely traumatic experience. One example was identified where the parent was not aware that she was being assessed. In other cases, the continual assessment of their parenting skills has resulted in parents feeling unable to be spontaneous or relaxed with their children. This not only has a negative impact on the relationship between mother and child but can have negative consequences for the outcome of the assessment. The quotes below highlight the difficulties faced by parents in trying to demonstrate their parenting skills in often unnatural, artificial conditions:

The report states that she has no empathy for her children and one of the examples they gave was that when the baby was climbing up on a chair and Catherine told her 'no' to get down, the baby started crying and Catherine did not pick her up and hug her. Catherine saw that as rewarding bad behaviour and that she was setting boundaries for her daughter. However social work staff saw this as her not rewarding her for doing what she was told

Catherine was aware that she was doing things “properly” and tried to adapt her behaviour accordingly.

They said that I don't set boundaries...I don't structure and stuff like that...but the things I was doing right was I was following Lauren about...she was still at the stage where she was getting used to walking so I was following her in case she fell to make sure she didn't get hurt and stuff like that...that's one of the good things I was doing...one of the things they said I wasn't doing well was showing emotion, like giving kisses and cuddles and things like that...that's one of the things I thought I was getting better at after they told me but they said that I wasn't...but I thought wait a minute, I have been...I was saying hi and kissing her and telling her how pretty she was...the first couple of times I went and I felt awkward and I didn't like it but you get used to it

Catherine

In Sandra's case, the assessment of her parenting skills had taken place over a number of months. The assessment involved assessing various aspects of her parenting. There have been a number of difficulties, mainly arising from the fact that the assessment has taken place in a contact centre where the equipment was unfamiliar to her and unsuitable to her needs. For example, she was asked to place Mark on a table and take him out of his chair. “The table was almost as tall as she is”. Most recently, it has involved testing whether the skills she has learned are transferable to different settings:

They are looking at the skills Sandra has and if these can be transferable to other situations. She is being assessed in six weekly blocks...feeding and clothing...keeping Mark safe...are the skills transferable...they are taking her to new places and new environments...I feel it is dreadfully unfair on her...they took her to a museum and then criticised Sandra when Mark touched the artefacts in the museum...yet they told her to let him out the buggy

Professional Advocate

4.2.7 Joint working, eligibility criteria and funding

It is clear that further work is required in terms of providing accessible information to parents with a learning disability. Likewise, it would appear that there is a lack of information available to professionals to support parents with learning disabilities, particularly for those out-with area learning disability teams (ALDT's). Discussions with ALDT team members indicated that there was limited knowledge of the needs of this group and that at times there was an acknowledged assumption of incompetence which needed to be challenged. Staff felt that they needed additional resources in order to do this.

All of the participants in the study had difficult relationships with the social work department. This can be attributed to a large extent to the perceived criticism of

their parenting role. It appeared that children and families social workers had a limited understanding of the particular needs of parents with a learning disability. It was acknowledged by parents and their advocates that children and families social workers were not necessarily unsympathetic to the needs of parents; however the needs of the child once the child protection process is initiated do appear to dominate every aspect of the process thereafter. Interviews with representatives from adult learning disability teams suggested that they found it difficult to challenge the views or decisions made by their colleagues from children and families teams, whose views they felt carried more weight.

In order to alleviate some of these difficulties further joint work and support would be helpful. There appears to be a lack of clarity over who should pay for this support and how this would be accessed. In the sample within this study there were examples of individuals who, despite long standing contact with the social work department had access to no support services for themselves, other than the advocate from Equal Say. There is no evidence that despite the need for support around parenting that this was offered to any of those within the sample group however it is not clear why this is the case. In one example the parent had been offered some support with cooking skills for a short period of time before the funding ran out.

One potential barrier to the provision of support to parents with a learning disability relates to funding and the high eligibility criteria imposed by Local Authorities to determine who receives services from them. Parents with a learning disability, particularly those who might have attended mainstream school or who had no real need for service intervention in the past often find themselves ineligible for services. Indeed, only two of the participants in the current study have a social worker or care manager of their own. Eligibility criteria create a barrier to early intervention and make it difficult for staff to carry out any kind of preventative work. Given the need for early intervention and on-going support for parents with a learning disability outlined throughout this report, this creates significant difficulties. As highlighted above, intervention often takes place when crisis point is reached. This can result in further child protection measures such as the accommodation of children being the end result.

Agency staff that completed the survey identified that effective inter-agency procedures and protocols would be helpful to aid in the early identification of support needs. Effective multi-agency working is viewed as vital. Health, social work, education and housing services should work together in order to ensure that people are given consistent messages about parenting within an agreed framework of assessment and support. Advocates have an important role to play in assisting parents to access support at as early a stage as possible.

4.2.9 Advocacy

There is evidence from the interviews that advocacy performed a number of key roles. These relate to:

- information translation
- keeping parents informed
- assisting parents to have their voices heard

- empowering parents to challenge decisions which they have previously viewed as being set in stone

However as with other supports there is evidence that advocacy comes at a point where crisis has been reached instead of supporting individuals at an early stage. Evidence from the interviews shows that often advocates first role was to ensure parents were represented at meetings to discuss their children. Prior to the involvement of advocates there was evidence to suggest that meetings were being held without parents being in attendance:

The main problem was her relationship with social work and services. They didn't invite her to meetings because they didn't want to upset her. We insisted they invite her, which they agreed to...when we first went I felt intimidated by them...the PTL was there and it was chaired by the operations manager...she made it clear at the outset that I had my place at the meeting but I would be invited when to speak...it was very hostile...It has got better...I can't help feeling that my presence is making it work in that way

Professional advocate

There was another meeting coming up...I got in touch with children and families to say Sandra had a right to attend these meetings to hear what people are saying about her and to get information...she knew right away that taking away the baby was the agenda...

Professional advocate

After assisting with any initial crisis situation, the role of the advocate has then involved supporting parents to attend meetings, providing support for parents to prepare for meetings by assisting them to understand any related paperwork and supporting parents to access other support, such as securing legal representation. By taking on these roles advocates have been highly valued by parents with a learning disability. In particular they feel that their views are taken more seriously and that they have been given a "voice". The following quotes from parents who have taken part in the research are particularly illustrative:

Every time I go to the panel he comes with me...he sticks up for me...he speaks for me...I get stuck on stuff and he says for me what I mean

He keeps the papers for me and reads them with me...I keep them as well...that's important to have

He talks to me about what happened in the past and all that...he asks me how are things...

He's the only one I trust...I told him he is the only one I trust...I don't trust anyone else I trust him...he helps me to speak...If I've got a problem he will speak to me...he will do that...that's why I trust him...I can talk to him about things and he will take it back to people who want to know about me

She helps me with the panel meetings...she knows lawyer friends so she phones them up and says are they allowed to do this...she's helpful

She asks me how I am doing and stuff like that...she helps me...she knows me and we have a laugh about people...we had a laugh on Tuesday before the panel meeting

Definitely...I like her [advocate]...she is doing a fantastic job...I don't think she should be doing anything different really

The quotes clearly illustrate that enabling parents with learning disabilities to have a voice is one of the most important functions of the advocacy role. The research has demonstrated a number of successful outcomes in relation to this. Parents felt that for the first time their views were being taken seriously and there were clear examples of people being included in processes from which they had previously been excluded. One of the most positive outcomes for individuals in having advocacy support was that they felt that at least their voices were being heard. For one parent being able to see her words reflected in the notes of a meeting was very powerful. She stated that this made her feel that at last her voice was being heard and that her children would have evidence that she fought to care for them. Advocates were able to support parents to become active participants in decisions that were being made about their children's' future, as the following quote suggests:

Before I got involved...she just wouldn't turn up to meetings...so at least she is getting to meetings and being a part of them...and it's the same with the lawyer...if I hadn't been there I don't think she would have gone to see the lawyer...its managed to remove the grounds for referral that she was particularly unhappy about...I hope that...its not my place to judge her...but I hope she feels like she has had someone listening to her and speaking on her behalf rather than telling her what she should be doing

Professional Advocate

However further work in this area is needed and advocates can also provide an important educational role in terms of assisting other professionals to take the views of people with learning disabilities more seriously. The following quote is particularly poignant:

I actually sat in a meeting with her, with the children's social worker and he said "right I'm putting together this report for the panel and obviously we want to put your views and opinions in as well, we're interested in what you've got to say, so what would you like to say". He sat with his pen next to his pad and she was talking and I was looking at his pen and it didn't move and I looked at his pen and I looked at Catherine and I looked at him and I thought I don't believe this – he didn't write anything she said down.

Professional advocate

The quotes above from parents with a learning disability also suggest that advocates perform an important social function in the lives of people with learning disabilities.

It can be seen from the literature that people with learning disabilities generally lack social networks to provide them with support and company and often face social isolation. Indeed, it is not unusual for parents with a learning disability to face multiple disadvantages, which often add to the challenges they face in parenting their children. The impact of this complex interaction of issues for advocates cannot be underestimated. Advocates reported finding it very challenging to support parents with the processes of child protection, much less with the other issues within their lives. Therefore it is perhaps unsurprising that the focus of advocacy for the majority of those interviewed was around the child protection process. A consequence of this is that one of the key functions of the advocacy co-ordinator which is to match people with learning disabilities with citizen advocates has had to, in some cases, take a back seat. Obviously dealing with crisis situations, particularly those in relation to child protection has to take priority but the important role that citizen advocates can potentially play in terms of helping people access support and make connections in their local communities may suffer as a result.

Advocates who participated in the research clearly felt the pressure which their roles brought. They had to deal with cases which were at times harrowing and traumatic and were aware that other aspects of their workload were not receiving their full attention:

My caseload at the moment is the worst it has ever been...I am at the stage where I have had to start a waiting list for referrals...my role originally was to recruit volunteers but what has happened is that we have been taking more complex cases which are more time consuming...it was originally thought it would be discrete pieces of work but it hasn't worked out that way...while I am doing this I am not finding an advocate for her...it's a conflict I have to manage

Professional Advocate

Advocates faced a number of barriers in terms of their ability to do their job effectively. There was evidence from the research of occasional hostility towards the advocate from other professionals. In a similar vein there appeared to be a misunderstanding around the role of the advocate. Advocates spoke of social work "putting a black mark against someone" if they chose not to accept the services from an advocate. Likewise, advocates spoke of being asked to do particular tasks after attending meetings with social workers or other professionals which were not part of their role:

We should be completely independent from social work...I mean sometimes you get a good social worker who you build a relationship with but sometimes at meetings you'll get social workers who start to hand tasks down to you, like could you go and see the lawyer...you know that's not what advocacy is about...there is widespread misunderstanding

Professional advocate

Advocates were able to identify a number of factors that enabled them to do their jobs effectively. In particular, they valued the informal support that they received from colleagues and any training they had received in relation to the child protection system and relevant legislation. There was recognition that very little appropriate training materials were available, again demonstrating the need for further work in this area.

5. CONCLUSIONS AND RECOMMENDATIONS

5.1 Conclusions

While this is a small scale pilot study, it is interesting to note that the key themes identified in the literature resonate to a great extent with the experiences of the parents with learning disability who participated in this study. Parents were likely to face disadvantage in a number of areas. These included income, social networks, housing and employment. Parents also faced a number of particular challenges in relation to their parenting role. In addition, there is evidence that they are disproportionately represented in the child protection system.

A particular challenge for this study has been the lack of reliable data on the numbers of parents with learning disabilities in the UK and more specifically in Glasgow. As the literature highlights, very little is known about the number of parents currently in receipt of services, much less so those who are not in receipt of services.

While it was not possible to conclusively demonstrate large increases in the number of parents with learning disabilities, it is important to note that those specialist services that participated in this study had noted an increase in the number of referrals. The study demonstrated a clear need for support for service providers in terms of awareness-raising around the particular needs of parents with a learning disability alongside providing information about the support services available to assist parents in their parenting role.

The foregoing report provides extensive detail about the experiences of parents with learning disabilities both from within the literature and the interviews. In particular, the report highlights the importance of advocacy as a support mechanism for this group of parents. It was possible to identify a range of successful outcomes that can be achieved with the support of an advocate. While evidence suggests that advocacy cannot effect systemic change, the research shows that it can highlight and challenge individual bad practice and ensure that the voices of parents with learning disabilities are heard. This was viewed as extremely valuable by those who participated in the study.

The research clearly demonstrates the complexity of situations within which parents with learning disabilities find themselves. Consequently advocates working with this particular group deal with a wide variety of issues, often requiring long term involvement. This in turn has implications for the model of advocacy best utilised. It can be particularly challenging for volunteer advocates to have the capacity and expertise to support parents with learning disabilities through the complex and often legalistic processes and frameworks of the child protection system. Advocacy co-ordinators, by taking on the role of professional advocate, find themselves – due to the complexity and long term nature of the cases – less able to develop and support citizen advocates to match with individuals. As a result, the research suggests that where there are a complex interaction of issues involving parents with a learning disability perhaps the most effective model of advocacy would involve work with a professional advocate. However, it is important to note that parents with a learning disability also face challenges in a number of other areas outlined above. Citizen advocacy has an important role to play in the lives of these individuals in terms of

making community links and building social networks. This is envisaged as being complementary to the work of the professional advocate.

It is incredibly difficult to measure outcomes in this area as a successful outcome may not always result in a child being returned immediately to the family home and indeed, in some cases, this may not always be appropriate. However, all of the parents who participated in this study were able to identify successful outcomes from their involvement in the advocacy service provided by Equal Say. These related to feelings of empowerment, being heard, understanding processes of child protection and providing support in relation to daily living. Although one can only hypothesise, it is likely that without the support of an advocate, the parents who took part in the study would continue to find themselves being excluded from the processes and procedures that concern them around the child protection system. In other words their voices would remain unheard. Advocacy can play an important part in levelling the playing field for parents with a learning disability who previously described themselves as being discriminated against by a system which does not recognise their particular needs or situations.

5.2 General Recommendations

1. There should be an increase in focused professional advocacy available on a long term basis for parents with a learning disability.
2. It is essential to raise awareness among professionals working in the health and social care field of the particular issues faced by parents with a learning disability.
3. It is necessary to establish clear protocols for effective joint working to ensure that the needs of both parents and their children are met and that parents needs do not fall between the gap of service provision.
4. Whilst ambitious, in order to accurately assess need and consequently demand, it is essential that a scoping exercise to identify the number of parents with a learning disability is undertaken.
5. A mapping exercise should be conducted to establish current service provision, how it is accessed and levels of use.
6. It would be helpful to build on the existing work that has been carried out as part of this research in terms of identifying good practice. This would be particularly helpful at a local level.

REFERENCES

- Accardo P and Whitman B (1990) Children of mentally retarded parents. In *American Journal of Diseases of Children* 144 69-70
- Booth T and Booth W (1993) Parents with learning disabilities: Lessons for practitioners. In *British Journal of Social Work* 23 459-480
- Booth T and Booth W (1996) Parental competence and parents with learning difficulties. In *Health and Social Care in the Community* 2 (3)
- Booth T & Booth W (1999) Parents together: action research and advocacy support for parents with learning disabilities. In *Health and Social Care in the Community* 7(6) 464-474
- Booth T and Booth W (2000) Against the odds: growing up with parents who have learning disabilities. In *Mental Retardation* 38(1) 1-14
- Booth T and Booth W (2002) Men in the lives of Mothers with Intellectual Disabilities. In *Journal of Applied Research in Intellectual Disabilities* 15 187-199
- Booth T and Booth W (2004) *Parents with learning difficulties: Child Protection and the Courts. A report to the Nuffield Foundation on Grant No CPF/00151/G* Sheffield University, Department of Sociological Studies, www.supportedparenting.com/projects/NuffieldReport.pdf
- Booth T, Booth W and McConnell D (2005a) Care proceedings and parents with learning difficulties: comparative prevalence and outcomes in an English and Australian Court Sample. In *Child and Family Social Work* 10 (4) 353-360
- Booth T, Booth W and McConnell D (2005b) The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. In *Journal of Applied Research in Intellectual Disabilities* 18 7-17
- CHANGE (2005) *Report of National Gathering of Parents with Learning Disabilities*. CHANGE
- Department for Education and Skills (2007) *Good Practice Guidance on Working with parents with a learning disability*. DOH: London. http://www.changepeople.co.uk/Libraries/Local/547/Docs/working_with_parents_wit_h_ld1.pdf
- Emerson, E et al, 2005, Adults with learning difficulties in England 2003/4, www.ic.nhs.uk/pubs/learndiff2004
- Llewellyn G (1995) Relationships and social support: views of parents with mental retardation/intellectual disability. In *Mental Retardation* 7(1) 64-77

Llewellyn G and McConnell D (2002) Home-based programmes for parents with intellectual disabilities: lessons from practice. In *Journal of Applied Research in Intellectual Disabilities* 15 341-353

MacIntyre, G. (2008) *Learning disability and social inclusion*. Edinburgh: Dunedin Academic Press

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

Mencap (2007) *Providing the right support for parents with a learning disability* Norah Fry Research Centre: University of Bristol.

Murphy G and Feldman MA (2002) Parents with intellectual disabilities. In *Journal of Applied Research in Intellectual Disabilities* 15, 281-284

Olsen R and Clarke H (2003) *Parenting and Disability: Disabled Parents Experiences of Raising Children*. The Policy Press

Steinfert Kroese B, Hussain H, Clifford C and Ahmed N (2002) Social Support Networks and Psychological Well-being of Mothers with Intellectual Disabilities. In *Journal of Applied Research in Intellectual Disabilities* 15 324-340

Sheerin F (1998) Parents with learning disabilities: a review of the literature. In *Journal of Advanced Nursing*. 28(1) 126-133

Sheppard M (1994) Child Care, Social Support and maternal depression: a review and application of findings. In *British Journal of Social Work* 24 287-310

Tarleton B Ward L and Howarth J (2006) *Finding the right support. A review of issues and positive practice in supporting parents with learning difficulties and their children*. Baring Foundation: London

Tucker M B and Johnson O (1989) Competence promoting vs competence inhibiting social support for mentally retarded mothers. In *Human organisation* 48 (2) 95-107

Tymchuck A, Andron L and Tymchuck M (1990) Training mothers with mental handicaps to understand behavioural and developmental principles. In *Mental Handicap Research* 3 (1) 51-59

Tymchuck A (1992) Predicting adequacy of parenting by people with mental retardation. In *Child Abuse and Neglect* 16(2) 165-178