



What happens when people with learning disabilities need advice about the law?

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Executive summary

Access to legal services is an important aspect of both citizenship and the right to justice. Existing evidence suggests that people with learning disabilities face barriers to accessing legal services. This report presents the findings of a short research study commissioned jointly by the Legal Services Board (LSB), the Legal Services Consumer Panel (LSCP) and Mencap designed to explore the experiences of people with learning disabilities when seeking legal assistance. The study aimed to:

- Identify barriers and positive experiences of people with learning disabilities and their families or carers who have used legal services
- Identify barriers which may have prevented people with learning disabilities and their families or carers who needed but did not use legal services
- Identify good and bad practices in working with people with learning disabilities by services which provide legal advice.

The research entailed running 18 focus groups involving a total of 90 people with learning disabilities, conducting 26 interviews with family carers of people with learning disabilities and 9 interviews with legal services professionals.

Key findings of the research are:

- Very few of the people with learning disabilities who took part in the study had initiated contact with a legal service themselves. Most of those who had done so had used Citizens Advice Bureaux or a solicitor known to their family. People with learning disabilities raised numerous issues which could have led to them seeking legal advice. Some of these were ones affecting all citizens: divorce, wills and probate and alleged criminal behaviour. Others were related to being a citizen with learning disabilities: parenting issues, bullying and hate crime and discrimination.
- Family carers also used legal services to make arrangements to secure their disabled relative's future by making wills and trusts. They were more likely than our learning disabled participants to use a legal service on behalf of a relative to challenge decisions or actions made by a public body, to uphold a relative's rights or to use the provisions of the Mental Capacity Act.
- Most people with learning disabilities were unclear about the role of legal services and did not understand when recourse to legal advice might be considered. They relied upon people they trust to know what to do when confronted with a problem. However, these supporters were not always equipped to recognise the need for legal assistance or how to access a service.

- Family carers used websites, helplines and forums provided by national learning disabilities charities, carers' organisations and support groups and networks to get information and advice about legal matters. They valued advice and information given by other family carers who had experienced similar situations to their own.
- Participants in the study reported difficulties in getting specialist advice about those aspects of the law that are particularly relevant to people with learning disabilities, such as community care, welfare rights and public law.
- Law centres and legal aid firms were valued for offering services in these areas but concerns were expressed about the future coverage in the shadow of changes to legal aid and reduced public funding for law centres and Citizens Advice Bureaux.
- The potential outcomes of using a legal service were not well understood by people with learning disabilities, but were better understood by family carers. The positive effects of getting the right legal assistance were said to be relief, improved quality of life and a sense of empowerment.
- The major barriers to getting a legal service were said to be lack of clear pathways to getting the right support, especially for specialist legal services that may not be available locally. Anxiety about the process, fear of consequences arising from taking legal action and the potential costs involved in doing so, especially following changes to legal aid, were all cited as barriers. The lack of accessible advice and information was also an inhibiting factor for people with learning disabilities.
- The research highlighted good practice as including legal services that make adjustments such as producing information in accessible formats, being respectful to learning disabled clients, explaining legal terms in plain language and allowing time for meetings. It was suggested that good practice can be promoted through collaboration between legal services and learning disability and carers' organisations.

Conclusions

The research confirms the findings of previous research that access to legal services for people with learning disabilities remains problematic. The study adds detail and depth to our understanding of the barriers that they face, but also furnishes some of the potential solutions. It highlights the different needs of people with mild learning disabilities and those with more complex disabilities who rely on others to act on their behalf.

Recommendations

The report makes recommendations which centre on:

- Developing accessible information for people with learning disabilities about the purpose of legal services and how they can be used
- Developing information and resources to clarify the routes that family carers and others can take to access specialist legal services on behalf of others

- Strengthening the awareness legal professionals have about learning disabilities through professional training and guidance
- The promotion of collaborative working between legal services and the social care sector.

1. Introduction

Access to legal advice and representation is an important aspect of citizenship and of the rights to justice enshrined in the Human Rights Act and various international conventions. People with learning disabilities may use legal services for the same reasons as any other citizen, but may also require legal advice to deal with issues that are more likely to affect them than other sections of society, for example getting the right level of community care support, challenging an assessment of their health, social or educational needs, or establishing their capacity to make a decision for themselves.

People with learning disabilities are also more likely than the general population to be victims of crime and suffer harassment or bullying because of their disability and therefore come into contact with the police, courts and lawyers. There is evidence to suggest that people with mild learning disabilities are more likely to be in contact with the criminal justice system as offenders (Loucks, 2007). While progress has been made in improving legal support for the victims, witnesses and perpetrators of crime who have a learning disability through the involvement of 'appropriate adults' and application of special measures in court, legal professionals have registered concern about the limitations of these measures (Pleasant et al, 2010).

Adults with learning disabilities who lack capacity to make some or most decisions for themselves are protected by the Mental Capacity Act (Williams et al, 2011). Legal assistance may be required by them, or on their behalf, to challenge an assessment of capacity or best interests decision, to seek authorisation for a deprivation of liberty safeguard, or to apply to the Court of Protection for substitute decision-making powers.

Survey evidence suggests that people with a long-term illness or disability are more likely to need help dealing with legal issues compared to the general population and are less likely to know their rights (Balmer et al, 2010). Family carers have a vital role to play in this respect by ensuring that people with learning disabilities know when to seek legal advice and how best to access legal services. Family carers often support a person with learning disabilities when they have been the victim of a crime, while the Winterbourne View scandal has also drawn attention to the consequences of excluding families from safeguarding the interests of vulnerable adults (Department of Health, 2012; South Gloucestershire Adult Safeguarding Board, 2012).

Although we have a good sense of how the legal system can impact upon the lives of people with learning disabilities and, as a matter of principle, the role that legal services should play in upholding their rights to justice, we have relatively little empirical evidence about what happens in practice when people with learning disabilities seek help with a legal issue. This report presents the findings from a short research study jointly commissioned by the Legal Services Board (LSB), the Legal Services Consumer Panel (LSCP) and Mencap, with the intention of addressing this gap in our knowledge. The study aimed to:

- Identify barriers and positive experiences of people with learning disabilities and their families or carers who have used legal services
- Identify barriers which may have prevented people with learning disabilities and their families or carers who needed but did not use legal services
- Identify good and bad practices in working with people with learning disabilities by services which provide legal advice.

The research was carried out over a period of three months in early 2013. We adopted a qualitative methodology which featured four strands of research:

1. A review of the existing evidence
2. Focus group discussions with people with learning disabilities
3. Telephone interviews with family carers of people with learning disabilities
4. Telephone interviews with legal services professionals.

A full description of the methodology used can be found at appendix 1.

The main focus of the report is upon the experiences of people with learning disabilities who have used a legal service, either directly or through a third party in the form of a family carer. We also sought the opinions of some professionals working in legal services who have worked with this clientele.

The following section establishes a context for the study by describing a review of the existing evidence about people with learning disabilities and their access to legal advice. Subsequent sections provide a summary of the data collected from the three types of informant: people with learning disabilities; family carers of people with learning disabilities and legal professionals. The findings from the study are discussed before we draw out some conclusions.

This independent study was designed to furnish the Legal Services Board and others with a richer understanding of the needs of people with learning disabilities and to generate ideas for practical actions to address those needs. With this in mind recommendations are set out at the end of the report.

2. Reviewing the evidence

The literature review undertaken by the research team provides a rationale for why the research is important to people with learning disabilities, their families, carers and service providers.

2.1 Rationale for the research

The Legal Services Board, the Legal Services Consumer Panel and Mencap commissioned this research to improve their understanding of how consumers with learning disabilities experience legal services, as well as the impact of learning disabilities on obtaining legal advice.

2.2 Access to justice

The notion of *access to justice* has been defined as the ‘right to seek a remedy before a court of law or a tribunal which is constituted by law and which can guarantee independence and impartiality in the application of the law’ (Cojocariu, 2011; 3). Access to justice is therefore taken to be an axiomatic feature of citizenship, yet ‘as long as persons with disabilities face barriers to their participation in the justice system, they will be unable to assume their full responsibilities as members of society or vindicate their rights’ (Ortoleva, 2010/11; 284-286).

For example, The Youth Justice and Criminal Evidence Act 1999 provides special measures to support vulnerable witnesses, including those with learning disabilities, in giving police interviews. Reasonable Adjustments Guidance (HMRC, 2009) states that the ‘core goal’ of the service ‘is to make sure that all citizens, regardless of their differing needs, have access to justice’, and refers to the responsibility to make adjustments for ‘all court users’, including defendants, witnesses, professionals, and members of the public attending court as observers” (Jacobson & Talbot, 2009, p.10).

One of the specific duties of the Legal Services Board is to improve access to justice (LSB, 2012 p.4). The LSB acknowledges the complexity of the concept of access to justice and defines it as follows:

“...the acting out of the rule of law in particular or individual circumstances. The tools to achieve that outcome range from informing the public about their rights, routine transactional legal services and personalised advice, through to action before tribunals and courts. The agents of delivery are wide and, of course, legal professionals are at the heart of this along with many other actors in legal services and the wider justice sector.” (2012, p.5)

The importance of access to justice is stressed by the LSB both in relation to individuals and social institutions. Of particular relevance to the current study is the degree to which people

with learning disabilities who are often marginalised in society are able to access justice through the use of legal advice from either lawyers or other sources. The LSB comments that:

“...legal assistance means more than simply representation in court. It implies help in making people aware of their rights in order to plan their important transactions; indeed at its best it helps people to participate more effectively in the basic private and governmental decisions that affect their lives” (2012, P.14-15).

2.3 The UN Convention on Rights of Persons with Disabilities

The *UN Convention on Rights of Persons with Disabilities* (2006), which was ratified by the UK in 2009, clearly positions people with disabilities as citizens with rights rather than as objects of charity or care (Quinn, 2009) and charges States to take action on the barriers to full inclusion that disable people with impairments. Article 5 of the Convention states specifically the rights of disabled people in relation to the law and their rights to be free from discrimination. Article 5 states:

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

The degree to which people with disabilities ‘are equal before the law’ is to some extent dependent on the accessibility of legal advice and representation when it is needed. Further, equality before the law is an important basis for safeguarding the other rights of persons with disabilities which constitute the Convention. While not focusing specifically on the Convention the research team see this study as making a contribution to the rights of persons with learning disabilities.

2.4 Lack of empirical research

The literature search undertaken by the research team revealed a surprising dearth of information in relation to the issues experienced by people with learning disabilities in accessing legal advice (see section 2 for a summary of the literature). The need for research which is based on the heard voice of people with learning disabilities and their families and

carers is important in examining the degree to which they are equal before the law and the barriers and facilitators in accessing legal services.

2.5 Economic Constraints and changes to legal aid funding

This research is occurring at a time of economic constraint in the UK. This has led to changes in the benefits system for disabled people generally which may lead to concerns by them as to their entitlements. The government cut backs have also directly affected access to legal aid. Of particular and direct relevance to this study are the changes to legal aid. The Legal Aid, Sentencing and Punishment of Offenders Act 2012 (LASPO) came into force on 1st April 2013 after a lengthy parliamentary passage.

The Act introduces cuts to the availability of legal aid for both civil and criminal cases. It removes funding from entire areas of civil law, including: private family law cases, personal injury claims and some clinical negligence cases, some employment and education law cases, immigration cases where the person is not detained and some debt, housing and benefit issues. However, there is provision under Section 10 for funding in 'exceptional' cases where a failure of provision would result in a breach of human rights. The Act also introduces a Crown Court means-testing scheme for criminal cases, which includes the ability for the court to seize assets from convicted criminals to recoup costs of a failed defence, and introduces price competition in the criminal legal aid market.

The Act further restricts legal aid through new eligibility criteria, in which Individuals on 'passport' benefits (Income Support, income-related Employment and Support Allowance, income-based Jobseekers Allowance, guaranteed credit of Pension Credit and Universal Credit) are no longer automatically entitled to legal aid, but will have to satisfy new capital requirements.

The changes imposed by this Act have been criticised on the grounds that they will negatively affect 'the very poorest and most disadvantaged' (House of Lords, 2013). While the Government has stated that the LASPO (2013) may have an adverse impact on civil legal aid clients, especially disabled clients who 'may be disproportionately affected' (Ministry of Justice, 2013, p.150), it has defended the changes by arguing that while legal aid is an "essential part of the justice system...the fact is it is paid for by taxpayers and resources are not limitless" (The Telegraph, 2013). A Ministry of Justice spokeswoman further stated: "Legal aid will continue to be provided to those who most need it, such as where domestic violence is involved, where life or liberty is at stake or people risk losing their home... But in cases like divorce, courts should more often be a last resort, not the first. Evidence shows that mediation is often more successful, cheaper and less acrimonious for all involved." (TheTelegraph, 2013).

While it is too early to assess the effects of these changes to people with learning disabilities the present research will provide some evidence as to how they currently access legal aid and

how they view possible links between government changes to benefits and their access to legal advice.

3. Evidence about access to legal services by people with learning disabilities

This section provides some evidence from previous research and literature about the access to legal services by people with learning disabilities and the documented issues which may lead them to seek such advice.

3.1 Accessing legal advice

A recent analysis of large scale survey data found that vulnerable groups are typically lacking knowledge of rights, are less likely to take action or seek advice when faced with a civil justice problem (Denvier, et al, 2012). Some commentators suggest that the needs of people with learning disabilities in particular are not being met by the legal system and that more should be done to recognise the individual needs of people seeking help (Mackenzie and Watts, 2011). Other researchers argue that lack of access to legal services is in part due to a lack of awareness of the rights of individuals with learning disabilities to get legal advice and the failure of service providers to make appropriate support available to them (Nind and Seale, 2009). Further, research suggests that the stress of involvement with legal issues (Leverton, 2002; Goodall, 2010), time and financial constraints (Hurstfield et al, 2004; Goodall, 2010), difficulties in understanding legal terminology and lack of knowledge by lawyers in working with people with learning disabilities (Johnson et al, 1988) are also inhibiting factors for people with learning disabilities in gaining access to legal advice.

Research carried out in Wales found a number of barriers to people with learning disabilities seeking legal advice. These included a lack of knowledge of legal rights and entitlements, the financial situation of the individual involved, the geographical location of the individual involved and the services they require, the stress and distress caused by talking about problems, the lack of advocacy, especially for those with additional support needs and the 'referral fatigue' involved in finding the right service. As a result of these issues very few people with learning disabilities took legal action or went to court about the unfair treatment they experienced (Lerpiniere and Stalker, 2009).

One study of legal challenges made under the Disability Discrimination Act (1995) found that:

“applicants were more likely to seek advice through sources of free support, such as the Citizens Advice Bureaux, or through their trade unions, legal aid or insurance. They did not have the financial resources to choose who represented them, and some experienced so much difficulty obtaining representation that they ended up representing themselves.” (Hurstfield et al., 2004; 12-13)

These findings are mirrored in a LSB report which found overall only 21% of legal problems faced by individuals were handled by the traditional legal professions¹.

3.2 Issues about which people with learning disabilities may seek legal advice

As with other citizens there are diverse reasons for people with learning disabilities seeking access to legal advice. These include house purchase or tenancy issues, the need to make a will, involvement in illegal activities, divorce or family matters. However there are also issues which relate specifically to people with learning disabilities belonging to an often marginalised group. These issues include parenthood and child protection actions, domestic violence and hate crime, complaints about services and discrimination. Our literature review identified the following legally relevant issues which were experienced by people with learning disabilities their families and carers.

3.2.1 Parenting

It is difficult to identify the number of parents with learning disabilities in England. A national survey of people with learning disabilities found that 1 in 15 of the 2,898 people interviewed had children (Emerson, et al, 2005) and Ward's (2008) extrapolation of these figures suggested there could be 53,000 parents with learning disabilities in England.

The need for legal advice by some parents with learning disabilities arises particularly in relation to State interventions in relation to the care of their children. A study by Masson et al, (2008) found that 12.5% of parents involved in care proceedings had learning difficulties. In one local authority, one sixth of care proceedings involved at least one parent with learning disabilities and in three quarters of these cases the children were removed (Booth and Booth, 2004). This is despite legislation stating that children should be brought up in their own family (The Children Act 1989 Section 17, 1).

There is evidence which indicates that parents with learning disabilities are often unsupported in their involvement with child protection agencies or courts. Cleaver and Nicolson (2005) note that Children's Services do not have the experience required to work with parents with learning disabilities and McConnell and Llewellyn (2000) found that these parents have difficulty instructing a solicitor and are often not advised to seek legal advice by children's services (Tarleton, 2008, p.138).

3.2.2 Domestic Abuse

There is a shortage of research about people with learning disabilities and domestic abuse (Walter-Brice et al 2012), possibly due to the 'double jeopardy' people with learning disabilities face in society regarding their disabled and sexual identities (Scior, 2000). However, Walter-

¹ "Legal Services Benchmarking", BDRC, June 2012

Brice et al (2012) carried out a small scale study exploring the issue of domestic abuse within the intimate relationships of women with learning disabilities. This study found that women with learning disabilities who experienced domestic abuse (physical, sexual, and psychological) generally reported this abuse to the police and social services, but were not given the appropriate support. However, in several cases their children were removed as a result of the abuse being reported.

3.2.3 Hate Crime

Hate crime and bullying have been identified as particularly problematic for people with learning disabilities. For example, Mencap's campaign 'Stand by Me' (2009) revealed that 9 out of 10 people with learning disabilities experience bullying or hate crime, while research conducted by the Equality and Human Rights Commission (Sin et al 2009) identified people with learning disabilities and mental health conditions as the most vulnerable groups in relation to violence and aggression. Furthermore, a study carried out by Gravell (2012) found that 62 of the 67 people interviewed had "experienced some form of harassment, abuse or related crime in the community" (p.1). The incidents reported by Gravell (2012), included verbal and physical attacks as well as financial, emotional and sexual abuse, including rape. These incidents happened both in and around people's own homes, but mainly while they were out in the community, and were carried out by neighbours, local school children and predatory groups who pretended to be friends with people then took advantage of them. In some cases family members, shopkeepers, work colleagues and support workers were also found to be perpetrators.

The individuals in Gravell's study did little when incidents of this nature happened; they felt frightened, ashamed, lonely and disappointed, and often kept quiet (Gravell, 2012). However, some individuals did speak to family members, support workers or the police. For those who did report the incident to the police, they wanted it to be taken seriously.

We were unable to identify any studies which included an account of specific legal advice sought by those who had experienced hate crime or bullying.

3.2.4 Discrimination

People with learning disabilities are more likely to face discrimination than those without a learning disability (Turning Point, 2010), especially in the workplace (Learning Disability Today, 2013). Research carried out by Fevre *et al* (2013) found that 21.2% of employees with a learning disability or mental health condition were victims of physical violence in the workplace, with 44.2% saying they had been insulted and 56.9% reporting being shouted at at work. These findings mirror those presented by the National Autistic Society (2012) which found that more than a third of adults with autism in paid employment had experienced discrimination or bullying in the workplace during their career.

Neither of these studies report any legal remedy being sought by those experiencing discrimination in the workplace, but rather people 'choosing' to leave their employment as a result of their experiences (National Autistic Society, 2012). However, Fevre *et al* (2013) do suggest that the situation could be improved by better advocacy to enable people to get their voices heard when they are experiencing discrimination.

3.2.5 Offending

When someone is an alleged offender the need for legal advice and support through possible court proceedings is important. Several studies have focused on access to justice for people with learning disabilities who are offenders. The Bradley Report (DoH, 2009) suggested that we do not really know how many people with learning disabilities engage with the criminal justice system as offenders or defendants, although the No One Knows programme (Loucks, 2007) estimated that between 20-30% of offenders have a learning disability, and that their disabilities are hidden when they enter the system. The Bradley Report noted that:

"court proceedings are often complicated for anyone who is relatively unfamiliar with the criminal justice system. Many... adults, for example people with learning disabilities and difficulties face particular problems, such as understanding the language used in court and knowing what is expected of them." (DoH, 2009; p.iii)

The difficulties which some people with learning disabilities have had in accessing legal advice which is supportive and accessible can make court appearances more difficult for them (Johnson et al, 1988).

3.2.6 Legal issues for families and carers

While carers and family members may become involved in supporting people with learning disabilities generally through any legal issues they may experience, there are specific concerns which may affect families and carers of people who lack capacity or who have profound and multiple learning disabilities. One of the most evident of these concerns relates to carers planning for the future of the person with learning disabilities, which may result in legal advice being sought to make wills, establish trusts, negotiate with services and/or establish power of attorney (Carney and Keyzer, 2008).

Issues of capacity and service provision are also of paramount concern to many families and carers of people with learning disabilities. The case of the London Borough of Hillingdon v Neary, (2011), while an extreme case, demonstrates some of the legal issues family carers can face. In this landmark case, Steven, a 20 year old man with autism was held in a care home against his and his father's wishes for a year (Neary, 2011). A Deprivation of Liberty order was placed on Steven after he absconded from the care home and took a man's glasses (Neary, 2011). After several months, numerous meetings and with the support of a legal aid solicitor, Mark Neary (Steven's father) took the London borough in which they lived to the Court of Protection and won. The full details of this case are complex and reach far beyond the scope of

this report, but this brief overview highlights the difficult legal issues that can face family carers of people with profound and multiple learning disabilities or who lack capacity.

4. The experiences of people with learning disabilities

This section sets out the findings from an analysis of the data generated by the focus groups with people with learning disabilities. It covers the types of issues that the participants said they sought advice about, the routes they took to getting that advice, the factors that either helped or hindered them in the quest for advice, before presenting their ideas about what constitutes good practice for legal professionals when working with people with learning disabilities. To protect the confidentiality of participants we have used only the regions from which they come to identify quotes.

4.1 Why participants seek legal advice

Our analysis of the focus group discussions highlighted six categories of legal issue that participants had experienced: family matters; property and financial affairs, being accused of something, victims of harmful or abusive behaviour, employment and making a complaint. Each is explored in more depth below. It is worth reflecting here some significant omissions from this list: issues that we had anticipated being raised, as indeed they were, but not as the substance of a legal process, more as the 'background noise' to people's lives. This was particularly true of community care (the support that most of the participants receive to help them to live) and welfare benefits. We consider these omissions in the discussion section later in the report.

4.1.1 Family matters

We had not anticipated that so many of our respondents (10) would be parents with learning disabilities who had experienced problems with local authorities about child care. Some authorities were alleged to be more precipitous than others in initiating child care proceedings and respondents had sought support at different stages in the process and from different sources. All had social workers or other care staff offering a range of help and advice. In one instance an advocate described how she had been asked to support a couple during a meeting at their home to discuss their parenting. She was horrified to find more than 10 professionals in attendance and used her legal training to insist that future meetings be organised in a less oppressive way. With her continued support the couple have maintained their family unit, albeit conscious of the potential legal processes that could threaten that and the constant scrutiny of their parenting. The father spoke of the fear and anxiety about losing his son, borne of the experience of others in similar situations. He told the focus group how he arrives an hour early at the school gates at the end of each day both to demonstrate his commitment as a parent and to ensure that no one else takes the child away.

In the other 9 cases the children were removed from the respondent's care and legal representation was sought either for or by the parents during the process. These respondents appreciated having solicitors and barristers to argue their case but were

bewildered by the assessments, tests and hearings to which they were subject. One participant described her attempt at seeking legal advice when her local authority took her daughter into respite care – a move she interpreted as the prelude to permanent removal:

“They wanted me to sign forms so I felt at that time I needed a solicitor, so, I had no support, so I sort of walked to [local town] to try and find a solicitor that would help me. Eventually found one, but they weren’t very good really so I ended up changing to other solicitors.” (Wales)

Her social worker eventually suggested she contact the local People First group to get help from an advocate. Because the group had received a number of similar referrals, including self-referrals from parents, they were able to help the participant to access the right type of legal support. The group now employs a support worker with a legal background to support parents with learning disabilities. By guiding and interpreting the legal process for parents she has helped them to better understand their rights and expectations. Moreover, her role has shaped the behaviour of both legal professionals and local authority personnel to be more attuned to the needs of those parents.

A number of participants (6) had used solicitors to initiate divorce proceedings, and in some, domestic violence prompted the intervention of the local authority for the purposes of child protection. One mother had been unaware that her husband had been sexually abusing her son:

“My mate said ‘the police will be round to you in the morning’, so I said ‘what for?’ He says ‘what your husband’s done to your son’... when they come round I was still in bed... about half past six and I were down the police station and they took my son away and put him in foster care, and they said he would be there until he was about 18 but he was there till he was 14, in foster care, and I got a solicitor and I got legal aid and eventually I didn’t get him back but my mum and dad got him back and they looked after him and I went round and seen him that way... I divorced [husband] cos social services said I could have either me husband or me son and I chose me son...because of what happened to my son [the solicitors] said that I could get a divorce quicker than normal divorces.” (East Midlands)

Happily the mother and son stayed in close contact throughout this episode and are now living together once again. They also chose to attend the focus group to tell their story.

In two cases women had sought legal assistance to get injunctions against abusive partners. One described to the focus group the denouement to a series of increasingly violent assaults she had suffered at the hands of her ex-husband:

“Me and me son we both left me partner 2009, I was getting name calling off him I was getting injuries and he would injure us in front of the bairn...he got arrested in

front of the bairn...I had to take me son next door to the neighbour until I got back from the hospital cos he'd split me ear, it was hanging off." (North East)

Neighbours, family, the police and social workers all advised her to seek an injunction and a friend explained to her what this meant. She was put in touch with a local solicitor who had experience in working with people with learning disabilities. As she spoke, several other people in the group mentioned that the same solicitor had helped them, including another woman in a similar situation who had sought his advice about an injunction against a partner and ultimately a divorce.

4.1.2 Property and financial affairs

Legal support was commonly experienced in relation to property and financial affairs, although this was rarely initiated by the participant. The biggest single reason for participants coming into contact with a solicitor was either the writing of a will or drawing up a trust by a parent or the process of probate following a parent's death. Participants had a good understanding of the purpose of a will because it is such a common experience.

"Me and my husband went and did our wills on our own (with the solicitor)...well we haven't got any children of our own and if there is any money left over we wanted to make sure that our nieces and nephews on both sides had whatever money was left in the bank." (West Midlands)

However, the extent to which participants were aware of the role of the solicitor or whose interests he or she was representing in these situations varied. In many instances a sibling or other relative had taken the lead in dealing with solicitors and in a few instances this resulted in legal advice being sought by the participant to mount a challenge over a will because a family member had acted against their interests. Again, such challenges were invariably initiated by a third party on the participant's behalf.

It had been a common experience for participants' parents, or their solicitors, to suggest that the person with a learning disability make a will at the same time as the parent. Several recalled a parent prompting them to make a will upon the death of the other parent, while others said that a solicitor or relative had advised them to do so upon becoming the beneficiary of a will following a parent's death.

"My mum and dad were doing theirs and I did mine cos I wanted to do one... I did it on my own also and she [legal advisor] went through it with me and I told her what I wanted to do." (West Midlands)

While a small number of participants had used solicitors during the purchase of a property, it was more common for participants to seek advice about aspects of a tenancy, often from unqualified people (social workers, support workers or advocates) or from Citizens Advice Bureaux (CABx). In one instance, a respondent revealed that:

“I’m a landlord...I do tenancy agreements with the people who’re in there as well...I’m a landlord of my own house and I got people in there, tenants and everything and they sign tenancy agreements as well...I overlook all the property with an agency as well...we work together, they draw up...they go through and make sure we understand.” (Eastern England)

4.1.3 Being accused of something

A small but significant number (7) of participants had required advice and representation because they had either been accused of committing a crime or because they had been threatened with legal action. Most of those accused of committing a crime were held without charge. In the most extreme case a man was arrested on suspicion of rape and murder some years ago. It was 24 hours before a solicitor was instructed to represent him during which time he was questioned by police even though he had told them that he had a learning disability. He recounted how during this time the police claimed to have forensic evidence implicating him and, they said that as they were 99% certain that he was the culprit, that he should make a confession. The solicitor advised him not to admit to anything. Despite being released without charge after 72 hours he lost his job and home in the brief period while he was held and still suffers the effects of the trauma:

“There was a murder...I got pulled in by the police under suspicion of murder and sexual assault and I got locked up for 72 hours. They were gonna go to [City] magistrates to get a further 72 hours and when the 72 hours was up they decided to release me on bail until they do further enquiries. When I were there I were working at [employing agency]... I lost my job, I lost everything. Then it turned out to be it was the carer’s son who actually did the crime. I felt gutted about it, I lost me job, I lost everything... It was [employer] who said ‘look he needs a solicitor present’ and even the solicitor weren’t hopeful cos he didn’t know about people with learning difficulties... [he was a] complete stranger... it was the duty solicitor who, who police has contact number for in case of crime... The solicitor said ‘look if you done it, just admit it. If you haven’t, do not admit to nothing, but police are saying it was you.’... I lost me job through the nature of the crime and they think if he had done this crime I be putting other people in danger, kind of thing. That’s why they decided there are then... and I lost me home cos I used to live in [house provided by the employing agency]... Then I went to live in [name of place]... as a homeless person.”

In two, more recent, cases participants were accused of serious sexual assaults and in both cases the charges were dropped. Three further participants had experience of being arrested and held at a police station. One young man had been detained and assaulted by a group of police officers, for which he received compensation. He chose not to talk about the process of gaining compensation, but told us that the original incident had been sorted out informally with a senior police officer by his father and uncle. This approach was endorsed by other young people from the same community who recounted several incidents where a

resolution had been achieved by family members rather than with recourse to legal advisors. However, any involvement by legal advisors may have been masked from the young people as all agreed that they would always expect older male members of their extended families to manage such situations.

“After the riots...there was like a barrier... that said do not cross...a police officer told me to cross it for five minutes to get some cigarettes next minute I come out and 10 people jumped me...they were CID...they came out of nowhere... throw me in the back of a car and drove off...I was there for a couple of hours...my uncle came with me...I told them what happened and they let me out...I shouldn't have listened to the copper. That's it.” (Yorkshire & Humberside)

A young man with a Caribbean heritage described how he had been accused of stealing money from a handbag in a pub. He was arrested and spent a night in custody before his father and an appropriate adult came to see him the following morning with a solicitor. He appreciated the clarity of the solicitor's advice; by telling the truth he could expect to receive a fine, which is what happened.

Another young man had been arrested by the police on suspicion of arson. He was not clear how a solicitor had been summoned to help him or what her role was, but he felt reassured by her presence throughout the legal process that ensued:

“I got arrested so I had to use a solicitor...I got arrested for setting fires...basically went down the police station got put in a cell the solicitor come got sent to court and the solicitor was there all the way through...I spoke to her [solicitor] on the phone first then when I got in I had to go for an interview then obviously she came in with me and talked me through everything.” (East Midlands)

At the same focus group one of the participants asked for a one-to-one meeting to talk about an incident that had occurred ten years previously when he had been arrested for a serious sexual offence against a child:

“I got arrested for something I didn't do. I had a lodger - I took a friend in to help him out - and when I was out I noticed the police was at the door and they arrested me at me sisters...I got confused, blamed for something I didn't do...I got shoved in the cells...the lodger accused me.” (East Midlands)

He had felt pressured by the police and although he had been released on bail, he had never been formally told that the charges had been dropped or received an apology. As a result he had felt depressed and suicidal from time-to-time. He told us that the reason for attending

the focus group was to find out if he ought to claim compensation for the way he had been treated.²

4.1.4 Victims of harmful or abusive behaviour

A constant theme throughout the fieldwork was the threat of, and actual experience of, harmful behaviour towards people with learning disabilities. Almost all of those taking part could relate at least one incident that had affected them personally and in many cases people lived with ongoing harassment or hostility.

“Three years ago now I had a problem with a mother and her daughter, they going round saying they going to kill me. I told the police this, but they er, they say its still ongoing. But the daughter is threatening, saying she is going to kill me with a knife, that’s why when 4 o’clock comes in the afternoon I lock myself in and I don’t go out till the next day.” (South East)

“In the past, and its actually started happening again, my house is being vandalised again... one night we heard this loud crash and it were half of a house brick through the window...and it’s just started again, I don’t know why...all that happens was we just call the police down several times when it happened...” (West Midlands)

“Somebody stayed at my house and after a while they started to get violent...yeah to me so I had to call the police and I had to call [housing association] to come and help me to get them removed, and that was really hard for me because he just would not budge and I tried it myself so I was so glad to get the law involved and the police.” (Eastern England)

Self-advocacy groups have given the issue of hate crime a high priority and offer practical measures such as keep safe training, safe places schemes, training for criminal justice professionals and acting as reporting centres. Contact with legal services about these issues is rare, however. At most of the sites the police were reckoned to be more responsive now to the issue of hate crime than they had been in the past and we heard several positive experiences of special measures put in place when giving evidence at court, particularly the ability to give evidence via video-link. Respondents appreciated the acknowledgement of their needs in these circumstances.

Participants felt overwhelmingly that there should be a legal remedy to such problems, but were unclear what this might be. There was a good understanding of the nature of hate crime, which perhaps reflects the work undertaken by self-advocacy groups and others, but a relatively poor understanding of how the designation can affect sentencing. Court orders

² During the one-to-one he asked for our advice. We said that we could not give advice, but suggested he talk to someone at the host (self-advocacy) organisation about what to do next. Given his agitated state we asked for his permission to alert the organisation about his need for advice without revealing the substance of the matter.

and eviction notices were mentioned as the consequences of some situations, but we were left with the impression that most participants regarded hate crime primarily as a policy issue, to be addressed by organisations and public bodies rather than by individuals.

4.1.5 Employment

The focus groups threw up several examples of people seeking advice over an issue to do with a job or volunteering, being made redundant, a volunteering opportunity being withdrawn, being paid less than the minimum wage, and in one case claiming payment for unused leave:

“I couldn’t help leaving me job after 11 years cos I like got got ill, but they didn’t then give me like holiday... if you leave or your existing wage or holiday you know your due something innit when you leave, and well they were withholding it this nursing home, um but lucky enough [employment organisation]...managed, threatened the law on them...they must have got scared and quickly gave me my money.” (South West)

In none of these cases was formal legal advice sought. Instead advice was sought and given by employment support workers, advocates and, in one instance, a social worker. It was not possible to assess the validity of this advice but it appears that only modest successes were achieved as a result of it: payments in lieu of annual leave and the offer of alternative volunteering roles. Several participants spoke about jobs they had enjoyed in the past and others about their aspirations for the future, yet where discussion turned to employment it invariably focused on the relationship between paid work and welfare benefits. We were unable to pursue this in as much detail as we wished, but we gained the impression that the apparent unwillingness of participants, or their supporters, to seek legal advice around employment issues, may have been because of an overriding concern not to jeopardise the person’s entitlement to benefits.

4.1.6 Pursuing a complaint

The concept of complaining was familiar to respondents across the sites, although only a few could recall pursuing a complaint and those who had done so relied upon supporters rather than legal professionals. Complaints centred on support services, benefits and housing and the outcomes reported fell evenly between success and failure from their point of view. One told us that several members of staff were sacked as a result of his complaint about abusive practices in a residential home. Another was less successful:

“The staff was really horrible and aggressive to me and really would boss me about...would boss me in an aggressive kind of way, nasty way, and I told all of this to social service but they don’t listen to the client.” (Wales)

Complaints were often initiated with the help of a family member or a support worker, especially where it entailed understanding rules and systems:

“When they have tried to stop my benefits...I’ve complained and done an appeal letter along with my support worker, and the result was they didn’t stop it” (South West)

Others initiated the complaint themselves, especially where the focus of the complaint could be readily identified and pursued.

“I put in a formal complaint to the landlord, to tell him that what were in my bedroom, it were all damp, mouldy and it were just all horrible for me to live there.” (North West)

In this case the initial complaint was ignored so with the help of an advocate she found and engaged a solicitor. The advocate who was also present during the focus group, recalled how the simple expedient of a solicitor’s letter outlining the landlord’s legal obligations resulted in the desired outcome.

Other respondents who had sought legal advice to pursue a complaint were the young man who had been falsely arrested and beaten by police and another man who discovered that his condition had been caused by medical negligence:

“I had to take the old hospital to court...because when I was 15...I had a letter one day and it said on the letter ‘when you was born we fractured your skull we took forceps into your forehead and your brain is damaged for life’... I had to go to court a few years ago I won... I got compensation and I might have won that but tis not going to change the way I am.” (Eastern England)

In both cases the action had been initiated by other people.

4.2 Routes to getting legal support

In each of the groups we explored the routes that participants took to getting legal advice. Our analysis indicates that the route taken was mediated by the type of issue about which people were seeking legal advice. We were able to map three main routes:

1. Direct contact initiated by the person with a learning disability
2. Default contact where engagement with a legal service is inevitable
3. Mediated contact whereby the person with a learning disability relies upon a third party to negotiate the contact with the legal service.

4.2.1 Direct contact

We heard of very few instances where participants had made direct contact with a legal service provider, even when there had been contact with one previously. For one woman it was the lack of anyone to confide in that drove her to approach a solicitor herself:

“I’ve lost me mum you know and I thought I’m gonna have to deal with this me self, pluck up the courage and sort out a divorce.” (Eastern England)

4.2.2 ‘Default’ contact

Default contacts fell into two sub-categories: the first included those formal processes that require the services of a legal professional to complete, such as writing a will or purchasing a house. The second sub-category included those situations where the police had been involved either because the person had been accused of committing a crime, or they had been the victim of, or witness to, a crime.

The experiences of people having these types of default contact varied. A small sample of the participants had been arrested at some point in their lives. In all but one case, a solicitor had come to see them while they were being held at a police station. In more recent cases people talked about the role of an ‘appropriate adult’:

“You might also need a solicitor if you can’t get a police man cos if you’re like in a police station...there was an incident a long time ago...I was taken away...I didn’t do anything, but I got accused of taking money and I had a very bad experience because I got taken to a police station and I got strip searched and I had to stay in a cell...me social worker had to come in because [adoptive parents] had gone on holiday and I was left by myself...yeah there was a solicitor as well because what had happened was the girl who accused me came forward and said I didn’t do anything....he [solicitor] just asked me questions and stuff but I didn’t really understand till me social worker had to explain it him that I were a lady with a learning disability....I was scared and I needed someone...it was just me.” (North East)

Most of the parents with learning disabilities who took part in the study also experienced a form of default contact in the sense that they were engaged with a legal process initiated by a local authority to determine future care arrangements for a child.

4.2.3 Mediated contact

The evidence from the groups gives a clear indication that people with learning disabilities rely heavily on people around them to access legal services. We are able to describe a process involving several steps.

Step one: telling someone about what has happened

In almost all cases the first step towards getting legal advice was for the participant to talk to someone about the issue and take advice about what to do next. Participants reported that at this stage it was important to deal with someone who could be trusted to take their concerns seriously and in whom they had confidence that their interests would be safeguarded. The primary source of this type of support is family.

"It was mostly my brother, he advised me, cos he knew a certain amount [about the law]" (London)

"I did try to get help but the help didn't really come to anything... it was thanks to my sister that the money I had stolen my sister got some of it back for me" (South West)

"Any letters what comes to me what I can't read myself I leave for him [brother]." (North West)

"My dad went to the bus station and complained to them." (North West)

"I told my dad, he went to the police." (Yorkshire & Humberside)

A smaller number mentioned paid supporters, social workers and other health/social care professionals as the first person they spoke to about what had happened. Again their testimony is suffused with sentiments of trust and confidence that the person would know what to do next:

"I reported it to one of the staff [at the day centre]... and she said he wasn't mucking around and it was just taken from there... police were involved, Advocacy for All were involved." (London)

"I've got a nice manager...she'll be on the phone to some people, or she will get me a social worker or social worker they signpost me now." (West Midlands)

"Cos they are like friends instead of staff...if we want to really talk...it depends on what the problem is really." (South East)

"One of the carers where I live... cos I've got nobody else to talk to, so I go to my one who looks after me." (North East)

Given the chosen method for recruiting participants to the study, it was unsurprising that many mentioned self-advocacy and advocacy groups as an important outlet for talking about problems:

"We only have to go and ask [advocates] and they will probably put up on the computer and find out for us just like that." (South East)

"If I have problem now...I would get [advocate's] help...or if there were a letter, I would give it to em to read." (North West)

"I've got an advocate... they help yer speak out for yourself and obviously I mean if you've got any problems you can go to yer advocate and tell em about the problem yer going through." (North East)

“They are not quite ‘legal’... they are an advocacy organisation, but they would know where to go to, they would sign post you...use an advocacy organisation to help you, if my PA’s not about this would be the next port of call.” (East Midlands)

There appears to be no correlation between the strength of the relationships between the participants and their supporters and the likelihood that people will go on to access a legal service. However, precedence appears to be a key factor: as one might expect, people who have used a solicitor are more likely to use one again, self-advocacy organisations that have dealt with an issue are more likely to know how to respond when it arises again.

Step two: making contact with a legal service

Evidence from the focus group discussions suggests that the second stage in the route to getting legal advice is making contact with someone involved in legal services. The two main points of contact are i) through a local solicitor (usually an individual rather than a firm) who has already been used by the person, or their family; or ii) through a Citizens Advice Bureau or a Law Centre. The overall experience of CABx was mixed: we heard several positive stories about CAB workers helping people to sort out problems with debt and with housing. In one instance a woman who had already visited the CAB for advice about a court summons for a credit card debt, returned to get help with an apparent fraud committed against her by a paid carer. On both occasions she was satisfied with the outcome. We were given just a couple of examples of what respondents considered poor outcomes from their dealings with CAB, including someone who went to the CAB with her mother to make a will:

“We thought it was alright until we went to add something to it and found out that the person what did it messed it up - he missed something out... and the document what he gave us we had already signed for and what we took back was invalid because he had missed a certain word or something out.” (North West)

More respondents reported problems making contact with the CAB either because of restricted opening, because telephones were not answered or calls were not returned.

In fewer cases, participants were helped to find a solicitor ‘off-the peg’ either by visiting them directly or searching for them via yellow pages and the internet. For the participants and their supporters who described doing this, the main consideration at this point was the cost of getting support and we heard several accounts of people undertaking lengthy searches before alighting on solicitors who would accept legal aid work or who would agree to work ‘pro bono’. The final category of contact was through duty solicitor schemes, accessed by those under arrest.

Step three: getting specialist legal advice

The third stage in this route to getting a legal service was an onward referral to a specialist resource; a solicitor dealing in a particular aspect of the law, or a barrister. We came across

very few examples where this had happened and invariably where it had, it was to local solicitors (perhaps through a CAB) rather than to larger law firms with a regional or national presence:

“We went to a solicitor [company name]... big in [local town] and they had a lady there who dealt with learning difficulty and disability... and I was so, you know, really pleased about that - I couldn’t believe it.” (London)

We had no examples where a barrister was instructed to defend a participant, although some victims and witnesses did talk about the experience of answering questions in court as witnesses.

4.3 What helps people with learning disabilities get a legal service?

We asked participants to reflect upon the things that had helped them access a legal service. The following list contains the main factors that were highlighted during the group discussion. Many of the factors posited by participants echo their reflections in the previous section, with a particular emphasis upon interpersonal relationships, building trust and confidence and having good information about what legal services do.

4.3.1 Having someone to talk to about the issue

As discussed earlier, participants almost always chose to speak to someone who knew them and they could trust about an issue before sometimes proceeding to access a legal service. For some it was important to deal with the emotions engendered by the issue before addressing the legal ramifications of it:

“They are like friends instead of staff...if we want to really talk...it depends on what the problem is really.” (South East)

“If something goes wrong I get very frustrated and upset and if I speak to them they seems to calm me down.” (West Midlands)

4.3.2 Having support from someone who knows what to do next

Participants were candid about their lack of knowledge of a range of things that affect their lives, some drawing attention to the fact that they need support in many areas, not just sorting out legal issues. For others there was a balancing act to be made between being independent and seeking help. This was especially true for those who had let their finances get out of control and had only reluctantly asked for help when confronted with solicitors’ letters or visits from bailiffs. In such situations it was important that their normal sources of support were able to act swiftly and direct the person to the right legal advice.

“I tend to use (advocates) because they know more things than I know.” (West Midlands)

4.3.3 Knowing where to find legal professionals with the right skills to help

We were struck by how often a good solicitor or CAB worker was known to several members of a group either because they had good interpersonal skills or because they specialised in an area of law that was relevant to people with learning disabilities. This was especially true for those parents concerned about their children being taken into care.

4.3.4 Having someone to help deal with legal professionals

Many participants spoke about the comfort they derived from having someone sit alongside them when dealing with a legal professional, especially an advocate; someone trained to speak up on their behalf. Supporters could help people overcome their anxiety about meeting a new person or being in a strange situation, help them express themselves or tell their story, clarify difficult words and concepts and assist them to follow through the outcomes of the legal advice. Moreover, those taking part in the group discussions were familiar with this type of support and understood the value of it.

“I had someone with me, I couldn’t have done it on me own.” (London)

“It was mostly my brother, he advised me, cos he knew a certain amount but he said there were some bits and pieces he didn’t know, you know and he just needed, cos he came up with me [to the Citizens Advice Bureau].” (London)

4.3.5 The availability of legal aid

Participants were quick to link their satisfaction with a legal professional and the professional’s willingness to do legal aid work. For many, simply getting advice and representation paid for through legal aid represented a good outcome irrespective of the final resolution of the issue.

4.4 Barriers to getting legal support

Many of the factors that participants viewed as barriers to them getting a legal service were the reverse of the factors that they had identified as being helpful. Nevertheless, there was a group of related factors that centred on their and their supporter’s lack of knowledge about the legal system. These included not being aware that there might be a legal remedy for an issue, not understanding what legal advice entails, who might provide it and how they might help them. These are basic ‘gateway’ issues which prevent some people with learning disabilities engaging with the legal system in a positive way.

4.4.1 Lack of knowledge among supporters

We asked participants why they had sought legal advice in the situations outlined earlier. Overwhelmingly it was because someone had suggested that this was the right thing to do: a member of family, a paid supporter or someone from an advocacy or self-advocacy

organisation. Participants also raised other issues – about benefits, changes to services and harassment – but only a few had sought legal advice about them. It was not easy to ascertain why this was the case, but it appears that people in support roles were either unaware of the potential part that legal advice could play or whether it was appropriate. Discussions with supporters and paid staff at the host organisations suggest that people have little experience of public law and were unsure about how legal advice in this area is funded or what local resources exist to pursue it.

4.4.2 Understanding the role of legal services

Knowledge about what solicitors do was limited among participants in the focus groups, and what knowledge people had was invariably taken from direct experience and was conceptualised either functionally – letter-writing, filling in forms, negotiating on the person’s behalf, representation in court – and effectiveness – “they sorted things out for me”. In several groups, the word ‘legal’ was associated with the criminal justice system and the police in particular. Virtually none of the participants distinguished solicitors from other forms of legal advisors, although the CAB had good ‘brand recognition’ in most areas of the country:

“I’ve seen the signs, but I don’t know what people use them for.” (West Midlands)

“I didn’t realise that I could get advice through citizens advice, I thought it was just there for other things like...tenancy agreements and stuff like that...it wasn’t until me brother said ‘we’ve got to get this sorted (name)’ you know, and he said we’ll go to citizens advice bureau and see what they say.” (London)

4.4.3 Fear and anxiety as an inhibitor

Where participants had sought legal advice there were three major factors that inhibited them from accessing it. Firstly, some expressed fear and anxiety about proceeding and the possible ramifications of their actions. A few mentioned physical threats they had received from people they were complaining about, others believed that a service might be withdrawn if they mounted a legal challenge, and concerns were also raised about the attitude of family members towards them taking action. One woman talked about her ambitions to go to University to become a social worker, but that her finances had been managed by the manager of her residential home since the age of 18 when she had got herself into debt. She has never seen a statement of her bank account and is given £2.50 per day to spend. She would like to move away from the home and take control of her finances, pointing out that, “I am 41 and I should be more independent”. Acknowledging her right to challenge this situation, she conceded that she was unlikely to do so because her father believes that the current arrangement is the best way to keep her safe.

4.4.4 Communication

Secondly, participants returned to the theme of communication. Several participants ascribed bad outcomes to poor communication on the part of a legal professional. It was noticeable that those who had contacted solicitors directly were more likely to report feeling intimidated by the use of jargon or technical terms and feel as though they were not in control of the situation.

4.4.5 Costs

Thirdly, participants were deterred by the supposed or the actual costs of engaging a solicitor. In some areas legal aid solicitors were not available locally, law centres had closed or had their funding cut dramatically and Citizens Advice Bureaux could be more or less welcoming to people with learning disabilities and had also experienced cuts to their services. We heard several examples of individuals or support organisations trying a number of solicitors before finding one that took legal aid work or would work on a pro bono basis. Many supporters and self-advocacy organisations were concerned about the impact of further restrictions being placed upon legal aid as the vast majority of people with learning disabilities are too poor to fund legal advice in other ways.

4.5 Identifying good practice

Each group was asked to consider, from their experience, what makes a good legal service. Many of the groups, prompted by the subject matter of the focus group, suggested that more should be done to advertise legal services to people with learning disabilities and the people who support them. This point was sometimes linked to one about making offices more accessible, using clearer signage and easier language to guide people to the right service.

There was near unanimity in focusing upon the interpersonal skills of individual professionals they had dealt with. Key areas where good practice could be developed were: having a respectful attitude; improving communication; and getting things done.

4.5.1 Having a respectful attitude towards people with learning disabilities

This is manifested in people who listen, treating the person as the client by directing conversation at them rather than their supporter, allowing extra time to accommodate the communication needs of the person, and by not being rude or arrogant:

“For a start they need a lot of training for people with learning difficulties and disability, not to be rude and arrogant and just sort of pass you to one side. No jargon words and have patience.” (London)

“...Solicitors are a bit like doctors, they have so much time allotted to a client and they have quite a lot of clients and all I am saying is where they would normally give

somebody say half an hour to three quarters of an hour they should give us an hour because sometimes it's very hard for us, we stammer over some of the words that we want to say, some of the words don't come out the way we want them to come out, and I think if they gave us just that little bit more time we would eventually be able to say what we want to say without having to rely on our support." (West Midlands)

4.5.2 Good communication

More specifically, participants wanted good communication to be emphasised. This could be done by avoiding jargon and long words, using plain language, producing legal materials in easy-read, and explaining things clearly. A number of participants talked appreciatively of legal professionals who had taken the time to check that they had understood the key concepts involved:

"They use a lot of technical jargon...which I hate, therefore we have to teach the lawyers to use proper language." (South East)

"Very patient with me... he wrote everything down... and also he er he sat there and he listened to me." (London)

"He more or less he explained a lot of it to me without some of the jargon that you would get with most. Some solicitors they go through all this jargon and you think 'what are they on about' you know and he did explain a lot of it to me as well." (London)

4.5.3 Competence

Given the lack of knowledge that most participants had about how the legal system works and the role of legal professionals, it was a relief for many to find someone who could deal with the technical aspects of the law and reassure them that their problems would be resolved. Their testimony shows an appreciation for professionals who are able to convey a sense of confidence about the outcomes of a legal process while explaining that process clearly:

"He knew quite a bit about the law and yes and he helped advise me on things like that."(London)

"I explained I couldn't read, couldn't read big words and they put everything down...into easy read for me...The lady does all my paperwork for me." (West Midlands)

Participants, including those without direct experience of using a legal service, believed that good practice for legal professionals in dealing with people with learning disabilities are the same as for the other professionals they deal with. Several groups talked about training that the host organisation had undertaken with the police, health workers and social work

students and went on to suggest that similar training should be offered to legal professionals. Several also suggested that self-advocacy organisations could help legal services produce accessible information.

5. The experiences of family carers

This section sets out the findings from the 26 interviews carried out with family carers. It covers the main issues that family carers sought legal advice about, their motivations in seeking advice, the routes they took to get a service, the challenges they faced and the examples of good practice revealed during their journey.

5.1 Issues requiring legal advice

Our 26 respondents spoke about a range of issues about which they had sought advice from a legal service provider. All had used a legal service for reasons unrelated to their role as a family carer of someone with a learning disability and so had an understanding of the function of legal services when seeking advice that was related to that role. The issues prompting them to seek a legal service fell into three broad categories we have labelled as 'anticipatory', 'assertive' and 'protective' actions. A detailed analysis of the telephone interviews suggests that even where family carers had not sought legal advice for an issue falling under one these categories, the groupings still resonated with their concerns as carers. This gives us confidence that the categorisation is a valid one.

5.1.1 Anticipatory actions

Anticipatory issues are all about planning for a relative's future by writing a will, setting up a trust, gaining deputyship under the Mental Capacity Act or donating a power of attorney to someone to protect that relative's interests. For many this was prompted by an increasing sense of their own mortality, linked to age or their experience of death in the family. The fact of a testamentary beneficiary's disability meant that engaging a solicitor was essential to 'doing it right'.

"And we had discussed with him in some detail the arrangements we needed to make for our daughter given her capacity. We have two other sons, so we wanted to make sure that was done correctly. The last couple of years I've been executor and administrator for two of my relatives that died."

However, 'doing it right' was not straightforward for a number of our respondents. We were offered several examples of legal professionals not understanding the specific requirements of dealing with someone who lacks capacity. Others highlighted the need for family carers to monitor future plans because of the changing circumstances of those involved and the potential cost implications that may flow from that.

"[We] arranged with this person about writing the will and discretionary trust fund, people with disabled children, and it cost me about 1000 pounds to set it up, and then things have changed again with him as well, and people have changed, the guardian, the trustee has changed again, so of course now the law has changed, cost me another 1000 pound to upgrade... And I went, and found out the will I have is useless."

Knowledge about, and attitudes to the Mental Capacity Act varied markedly within our sample of family carers. Still a relatively new piece of legislation (only fully implemented in 2009) many were unfamiliar with the detail of the Act or the place it gives to family carers to be involved in decision-making for a relative who lacks capacity. One commented that:

“... a lot of carers do not know about the Mental Capacity Act, what the implications are if they either don't have power of attorney or deputyship, and that is very very concerning to me when I hear people who have never heard about deputyships, about power of attorney, don't know what the Mental Capacity Act says, and actually don't realise that when they have an adult they look after legally they no longer have a foot to stand on, other than within the guidelines. The guidelines clearly say family carers should be consulted. But what the guidelines say and what the law says may not be the same. And that gives agencies wriggle room. I'm sorry if I'm sounding cynical.”

While a third of our respondents had actively used the provisions of the Mental Capacity Act, most had done so seeking deputyship either for property and financial affairs or for health and welfare. The complexities of the process meant that all had engaged a legal professional to act on their behalf and this led to a number of complaints about the cost that was entailed, especially by those whose application for health and welfare deputyships were not granted by the Court of Protection.

5.1.2 Assertive actions

Assertive actions by family carers included using legal processes to establish a relative's eligibility for publicly funded services, perhaps in relation to 'statementing' for a child or young adult, or an assessment of needs for an adult. Family carers also acted assertively to challenge the level of provision (including services and/or funding) offered to a relative or proposed changes to provision, such as a proposed move to a new residential placement or the closure of a day centre.

“Right, that was to help my second son again over DLA. Because, we had been given the mobility side, and then it was reviewed and he lost it, I needed help to appeal. Anyhow, that is why we went [to firm of solicitors], I got a lot of help from them, and they were very helpful.”

“I took [son] along to him and he was incredibly helpful and he said no you have a case here, they can't just reduce it without an assessment or anything, you know... it was bonkers...”

Another important route to assertive action for a small number of family carers was the Mental Capacity Act which they had used to contest a best interest decisions made by someone on behalf of their relative, or to assert their right to be consulted about such

decisions. Using a legal service in these cases was rare because, it seems, such disputes are often resolved before legal advice is required.

5.1.3 Responsive actions

A number of family carers consulted a legal adviser to address the quality of care received by a relative, including responding to harmful acts against them. None of the family carers mentioned Deprivation of Liberty Safeguards as an issue, but one did mount a legal challenge to her son's exclusion from a facility because of his behaviour. More common were allegations of poor practice against staff or a failure of a service to follow established procedures. In one instance, for example, a family engaged a solicitor to seek compensation for an injury suffered by a relative using a service:

"[Local authority] really pushed it as an issue of a rogue member of staff. And I know the trainer who trains, and he told me that this particular respite centre cancelled their training shortly before this incident happened. So the staff are not trained and that is something I could sue for in a case. But the whole duty of care and partnership with parents and schools and others was just totally absent."

Another family used a legal service to establish a relative's right to a particular treatment in what the family considered an emergency:

"[Healthcare professionals] were all denying the need for her to go into hospital, saying she needs to go into a proper autism placement, and you know, it wasn't the medication and just any excuse to keep her out of hospital, and she was just going down and down and down... so we took legal action with the same solicitor to get her into hospital, and got into hospital which was funded without prejudice by the PCT..."

A few family carers spoke about historical cases of negligence or ill-treatment that had either recently come to light, or about which they now felt able to take action.

"She was entitled to legal aid at one stage, and we were able to investigate at that stage. We needed to find out for our other two children what really happened to her, because that has caused a lot of problems with siblings and they don't know why their sister or brother is damaged. We didn't get any compensation or anything, but we were able to clarify that it wasn't a genetic problem, that there was real damage at birth."

5.2 Motivations for seeking legal advice

In addition to addressing particular issues, family carers spoke about the more general motivations for seeking legal advice. These centred two major concerns. Firstly, that their relatives are especially vulnerable to decisions and actions that are either unfair or unjust and by engaging a legal service they can prevent such situations arising or put things right once they have happened:

“People with learning disabilities are bottom of the pile, so it’s our job to make sure it’s not the case for [daughter].”

“I want things to be just, fair and appropriate.”

The second, related, motivation is a desire to ensure that a relative’s interests will be protected once the family carer is no longer able to fulfil the role themselves:

“We want a future for our children... the government need to support parents to support their disabled children.”

“We lie awake in bed at night, fearful for our children.”

“What happens when we are not here, and for those who do not have the financial wherewithal?”

Unsurprisingly, a number of our respondents talked about how they had come to appreciate the potential of using legal services to achieve a desired outcome. This may have happened gradually, through a process of attrition, perhaps because they had tried other routes unsuccessfully. Others experienced a more rapid enlightenment, usually in response to a crisis.

“I mean I can look back and realise many many times in his life before I caught on that we had a right to have legal representation. [Son] needed it so often in his life, and it was only lately that I caught on that we could actually have it. And that’s when things went very very badly...”

A consequence of this is that the family carers in the study were much more ready to seek legal advice despite some of the significant barriers they faced in doing so (discussed below).

We were struck by how many family carers believed that “legal services are not for people like us”, that they are beyond the reach of everyday people. Some associated the use of a legal service as the province of “people with a sense of entitlement”, pointing out the paucity of ‘no-strings attached’ information for the types of legal support sought by family carers and the fact that most law practices are for-profit businesses. Interestingly, one family spoke about their reluctance to pursue a case with other families, even though they had been advised this was required to achieve the best outcome, because it would mean putting them all through “the pain of a joint action”.

5.3 Routes to getting a legal service

Family carers were asked to talk about how they managed to access a legal service. Our analysis revealed three salient aspects to their testimony. Firstly, that most family carers had ‘shopped around’, often undertaking research on their own behalf before finding the

right type of support. Secondly, the main gateways to getting the right support are other families, carer support groups and networks, and national learning disability charities. Thirdly, family carers become focussed on getting specialist support at an early stage in their journey to getting legal advice.

5.3.1 Shopping around

For most of the family carers we spoke to, the journey to getting legal advice began with research into the issue at hand. Our respondents reported no shortage of information about most matters on the internet which helped them understand the options available to them. One described finding out about deputyship online:

“I did a bit of work in the internet and looked up government website that give court of protection stuff, and that explains how to do it. And from the words there you’d think what we want to do is possible. We realised it was a complicated case, and we obviously needed advice.”

Another carer illustrated both the value and the limits of this type of approach when he needed help after his daughter had been accused of attacking someone:

“It was only someone that shared the community care article on Facebook and twitter and I thought oh my God that is like [daughter]... I do use a lot of research find out what’s on the net, speak to parents and organizations like Mencap and they really help with that and wording... the politically correct wording you would use. So that helped, it’s helped me get together what is needed, but not get the result, because [local authority] just ignore it. That’s why you need to bring down the full weight of the law.”

Finding someone to provide specific advice was more problematic. National charities’ and government websites were cited as good places to search for specialist legal services. For example, one family carer wanted to find help challenging a local authority decision, but preferred to consult with someone with experience of working with autism:

“...we’re floundering in an area I don’t know much about... so I rang round some of the national charities... I tried to say would you take this on as a matter of principal, because there are wider issues here than just our own situation... I’ve gone on to a number of charities. I fully understand that most charities don’t retain lawyers. The National Autistic Societies website has a lot of lawyers listed and I’ve gone through those and some of them say that they’re family lawyers, some say they have experience of taking on local authorities...”

5.3.2 The gateways to getting the right support

National charities do provide an important source of specialist help: Mencap, the National Autistic Society, the Challenging Behaviour Foundation, the Disability Law Service, Princess Royal Trust for Carers (now The Carers Trust) and Contact-A-Family were all suggested as

organisations that could direct families to legal practitioners with appropriate knowledge and experience. Mencap was cited repeatedly by participants as being a 'first port of call' for dealing with problems that arise, but the fact that all of these charities kept lists of legal services to back up their other resources was particularly appreciated by family carers. They also valued the opportunity to speak with experts through telephone helplines.

Forums, social media and email groups were also a good source of information because they provide recommendations based on consumer feedback:

"... I can't remember who recommended them to me... It is probably another parent on the Challenging Behaviour Foundation; you know we keep in touch, parents on Facebook, parents on twitter, and we send anonymous emails around the organization. We send it to the network email address, and we try to find things out there, we say 'we are trying to find a solicitor that has experience on this, if anyone has had a good experience please suggest one'..."

Advice about where to seek help from other family carers was valued above all others. Many respondents spoke of the importance of having trust in the sources of information and the primacy of advice based upon personal experiences to which they could relate. This meant that groups representing the interests of people with learning disabilities or carers were high on the list of trusted sources, while official channels were sometimes viewed with suspicion or scepticism. Interestingly the CABx fell somewhere in between, with several suggesting they lacked independence because of their reliance on local authority funding, while others prized CABx for being independent. One even mentioned a Bureau that:

"... is known as the CAB for carers... I would say they stand out as a very good example of that, when you have more input locally of people with disabilities or carers, you know representation of people with disabilities."

5.3.4 Accessing a specialist service

Many family carers raised questions about the capacity of local legal services to address their needs. Family carers drew attention to an apparent shortage of solicitors dealing in public law, community care and mental capacity, citing examples of law practices withdrawing from these areas of practice. At a time when social and health care decisions are more contestable (especially in the context of 'personalisation' and Continuing Health Care funding) family carers want to be confident about acting on behalf of a relative who is affected, and that legal advice will be available to assist them. Another problem that family carers spoke about was getting passed down to junior staff in a law practice when they felt they needed to deal with someone with more experience.

A few respondents had used a Law Centre and appreciated their focus upon those areas of law that were relevant to family carers. More than half of our respondents talked about their experiences of using a CAB to seek help with a problem, with mixed results. Several

complained about the difficulty of making contact with a CAB (discussed in more detail later) while others questioned their level of expertise to deal with issues like supported living, the needs of people with learning disabilities, or complex benefits issues.

“Well we tried the CAB, which I think is absolutely useless... this is not to criticize the people at CAB, simply because they are under resourced, but when you do manage to see or speak to someone, clearly this is not something they dealt with very often. The people you speak to are volunteers, ex accountant or whatever, and they never come across a mental disability before, so all they do is do the research which I could have done myself. From that point of view, CAB is a waste of time.”

“But citizens advice, they just looked at me as if I was insane, they didn’t understand what I was talking about, and I said it was supported living and they didn’t know what it was... They didn’t appreciate the difficulties at all I don’t think...”

“We went to the local CAB and the very local one gave us a whole piece of information, the lady herself was totally flummoxed at the situation. She could only come up with a document about ESA [Employment Support Allowance] which actually was totally confusing.”

While the overall tenor of the family carer perspective on CABx was critical, many respondents were keen to qualify their remarks with references to what they believed was poor resourcing rather than individual failings. Moreover, respondents also reported good outcomes for more straightforward issues:

“We had an issue with the working tax credit and citizens advice were really helpful.”

The real issue about CABx for respondents was less their inability to offer specialist advice and more their inability to provide a pathway to such advice. Beyond the national and online sources mentioned above, the main way of accessing specialist advice was through local carers groups, either directly from recommendations by other carers, or as a result of a presentation by a legal professional:

“We went to the solicitors of the lady who came to our local carers group and talked about the mental capacity act, because she seemed to know what she was talking about. So we felt based upon her knowledge that was a good place to start for that need.”

Where ‘expert’ lawyers were required for specialist actions contact invariably happened over the phone and via email when most preferred to deal with professionals face-to-face. One family carer pointed out that while specialist advice could be expensive, it could also be quick, and so prove cost-effective in the long run.

5.4 Outcomes

Family carers spoke about the outcomes they had achieved through using a legal service. They articulated an overwhelming sense of satisfaction with the outcomes of the intervention of a legal service on their behalf. Interestingly, few dwelt upon the material aspects of successful outcomes, preferring instead to focus upon the impact upon their family's quality of life and their own sense of empowerment. Two carers summed up the observations on the value of legal advice for families:

"Those that have gone that [legal] route, I have to say almost 100 percent of them have been really happy and very pleased that they made that decision and they went that route. I've only heard of one family who weren't entirely happy and found the whole process traumatic. To be honest I don't know whether that was because that family were under particular strain and were finding the whole thing traumatic anyway and adding solicitors into the mix..."

"I have to say the vast majority have come away from the whole thing very positively ... I only wish more of them would, but unfortunately I think that is the way it is, many of them are just. I think they are afraid."

Several described feelings of relief after long periods of struggle attempting to resolve an issue in other ways:

"I hadn't got anywhere really, so this was really a last resort to just try and get something sorted out. And I was astounded when the solicitor said she thought she might be able to do something for me, because it never occurred to me that you could consult a solicitor, unless it was something really definite, you know what I mean?"

"[Taking legal advice]... has been 'the only way we've been able to get any joy or any action.'"

"I see it as positive; I'm in more a positive position than other parents in my position - I mean other people that have people with complex learning disabilities, because we've actually won litigation. We have a better quality of life. I have the opportunity to put something back into society."

Often the intervention of a legal professional could make a difference in a very short space of time:

"It was very forceful action, very to the point, one page letter. With me, I could spend months wiring off to all sort of people trying to get help and getting promises and nobody delivering me... with her, one page letter, she seemed to just overnight literally, she sorted it you know, very impressive.. Really really impressive, so yeah it worked..."

And several respondents regretted not having sought legal advice at an earlier stage. One had been in dispute with his local authority:

"...but at the time I kept buying into thinking that the social workers would get their act together, and believing them... Oh yes, because me going on about a certain act, doesn't apparently have much weight. But when a barrister goes on about an act, [local authority] have to get out the senior solicitor and you have a logical sensible game of chess."

Solicitors could usefully escalate a situation. One family carer reflected that there are times when a resolution interview, for example, won't do and "you want your day in court" in order to get across your message about changing poor practices. Others lacked faith in complaints processes:

"I am concerned and I don't want to make it a formal complaint, because I know what will happen, will go down the 30 days route, and in the end I get an answer which is bland at the best, and the word apologise in many places – 'I'm sorry you were upset by this'."

And escalating an issue in this way could result in a wider benefit:

"Do I want to hurt them? I want it to be better for every parent."

However, one carer noted that an individual victory did not necessarily lead to better outcomes for people in a similar situation because:

"...when you have legal representation you tend to win because [local authority] know they cannot face what will happen if it went to court. And the court might say what about the others... which I hope they might."

Unsurprisingly, much of the testimony of family carers was suffused with contemplation of a relative's capacity, either over the question of that person's ability to litigate or as the substance of the legal action. A number of family carers had sought legal advice in pursuit of substitute decision-making powers on behalf of a relative under the Mental Capacity Act 2005. Some described the authority ascribed to a deputy as very helpful because it provided the family with an 'official role' in the life of an adult who lack capacity to manage their own affairs. There was a general view however, that deputyships are expensive to obtain and maintain. The option of 'do-it-yourself' deputyship was considered, but many found the process daunting and so felt that engaging a legal service professional was a better way of managing it.

Family carers articulated a number of concerns and problems about the way that the Mental Capacity Act works and how legal professionals had helped them negotiate this particular system, including the Court of Protection. One had found the Court reluctant to grant deputyship for health and welfare issues to parents, steering them towards a best

interests process on a decision by decision basis. They noted that the Court wanted to promote consensus and collaboration and assumed that all sides to a decision would act in good faith. However, some felt dissatisfaction with the way best interests meetings had been conducted and believed that the local authority legal team and commissioners didn't understand the MCA. This generated frustration for family carers who felt that being unable to be a relative's 'voice' amounted to rejection of their role and a judgement upon them. Legal professionals could help to mitigate the stress of these situations by giving family carers good advice about the best way to proceed. For example, one valued the advice to the effect that her instinct to 'go to law' was likely to result in losing the case unless the family allowed a best interests process run its full course.

5.5 Barriers to getting a service

Our respondents were asked to reflect upon the barriers they had encountered, if any, in their search for legal advice. Previous sections have highlighted the problems family carers experienced in charting a route to the right kind of advice both in terms of areas of law and in dealing with people with learning disabilities. In addition, respondents identified three further major barriers which, it is alleged, may prevent family carers setting out on the journey at all: ignorance among family carers about their rights and the rights of learning disabled people, fear of the consequences of pursuing legal remedies, and concerns about the costs of professional legal services.

5.5.1 Ignorance about rights

As has been mentioned before, a number of family carers spoke of a process of coming to understand that they and their family had rights to legal advice when confronted with the sorts of problems that people with learning disabilities encounter. They described a cultural 'veil of ignorance' about rights that hung over the social care field in general so that individuals are left to work out the system by themselves:

"Nobody said anything to me - only friends and the network - no professionals or service told me what to do. They kept it so vague. There's nothing about rights, nobody mentions rights, not even in their new leaflet. Nothing about rights."

The implication in this remark, that such ignorance is nurtured by public authorities, was one that was taken up by a number of respondents. Some were incredulous that agencies they had entrusted with the care of a relative, and with whom they had previously enjoyed a good relationship, would conceal information and advice from them at a time of need:

"... you are thinking, I am accessing social services; they should know, they should be following the bill of human rights, they should be following MENCAP, they should be following the government guidelines. I shouldn't be spending a load of money for a barrister to tell them, it should be a phone call. And I would say this goes against the bill

of human rights and I don't want to write, but apparently me saying that wasn't enough."

5.5.2 Fear

A number of our respondents spoke of fear as the primary emotion engendered by the prospect of initiating a legal process. This had two dimensions: fear about compromising existing services (where there is a dispute with a service provide or public agency) and fear about the stress that the process cause for the family:

"There is a fear that if they pick up the phone and speak to solicitors, they will make matters worse, and I've actually had that comment from more than one family, in a particular borough, and it's not this one, it was another borough, the family actually said that if I rock the boat I could end up with less than what I'm getting to support my son. And when you try to explain, that's not actually how the system works, a local authority can't say, "oh they're causing difficulty, lets reduce what they have".. It doesn't work like that."

Respondents recognised fear as a powerful inhibitor of action, not just in relation to legal issues, and felt that as with the 'veil of ignorance' outlined above, needed to be addressed as a broader cultural issue within the social care field.

5.5.3 Costs

A major consideration for family carers seeking a legal service was cost. Many recalled not knowing whether they or their relative would be entitled to legal aid and many expressed fears that this will get worse with changes to legal aid, with people already counting themselves out because of the media coverage. Particular issues were mentioned in relation to applying for legal aid for a relative who lacks capacity to litigate or who is unable to apply on their own behalf. Proving a lack of capacity could be problematic, while gathering evidence of a person's financial situation can be a lengthy and time consuming process. Some family carers did not proceed because legal aid was not available for certain types of action - to assist in using the Ombudsman, for example, while in another case it was unclear to the family carers whether or when a minor is entitled to legal aid.

5.6 Carers' views of what is required for legal professionals to work effectively

Family carers were able to offer a perspective on what legal services professionals need to work effectively with family carers of people with learning disabilities. Some had come across lawyers who had personal experience of a family member with some form of disability and these were judged to have greater commitment and understanding of the needs of this clientele. More generally, lawyers needed a mixture of appropriate training, relevant experience, skills and knowledge. Some suggested it was also vital for professionals

working in this field to be motivated by a social conscience. Others expressed a concern that some solicitors appeared to be 'out of their depth' when dealing with people with learning disabilities, suggesting they need training in these specialist areas, and for this to be regularly updated.

Honesty, 'straight talking' and realism were qualities in legal professionals appreciated by family carers, some of whom felt jaded by years of obfuscation and false promises from people in authority. One lamented that she had "lost all faith in the veracity of legal services, social services, and local government." It was therefore refreshing to deal with a legal professional who:

"... did tell me from the beginning she couldn't guarantee what the outcome would be, but she would try and help in any way she could.. And I think that is under circumstances, that is fair enough... I am quite happy with that and it definitely helped me personally with the confidence and I think it helped the local authority know it as well... because they were very obstructive at the beginning..."

For others, experience is a prerequisite for effective practice:

"[I was] always very very grateful and satisfied that there was help and that I could call them, because not only does it do the job - you still have to work your socks off - but you're not doing it alone and in ignorance. So support for the family of the person is huge... you get appropriate legal help with someone who knows the ropes... I don't know how you get that sort of expertise when you haven't got it... I think it must be down to skills training knowledge and being a particular kind of person who is determined to do good work, and knowing how to work with that."

6. The views of legal professionals

This section summarises the interviews we conducted with 9 legal services professionals. The interviews were unstructured, but we did ask participants to comment upon the types of legal issue that people with learning disabilities bring to them, how their services are accessed and what good practice in working with this clientele looks like.

6.1 Legal issues affecting people with learning disabilities

From this small sample of legal practitioners we heard of a range of issues about which people with learning disabilities or their families had sought advice. Because most of those we spoke to specialised in a certain area of law, their experiences reflected this. However, it was possible to discern some common themes.

Mental capacity formed a backdrop to the practice of all participants even if the substance of the advice sought had not been about the Mental Capacity Act. Some areas of the law were believed to be underused by people with learning disabilities: community care, public law and welfare benefits. Other areas, such as family law, seemed to affect people with milder learning disabilities (and especially parents with learning disabilities) compared to people with more profound disabilities. There was unanimity that people with learning disabilities and, to a lesser extent, family carers lacked knowledge about their rights and how to use the law to assert those rights.

Our respondents also expressed frustration at the apparent lack of confidence displayed by their clients about achieving successful outcomes through a legal process. As lawyers, success could be defined as ensuring that an accused person was properly represented and that due process was followed. Several spoke about the empowering effect of taking legal advice as well as the tangible benefits of winning a case or reversing a decision made by a public body. However, there was also a recognition that fear of the legal system acted a strong disincentive to people coming forward to seek advice.

6.2 The professional / client relationship

A number of the legal professionals we spoke with, but especially those with more specialist roles, rarely have direct contact with people with learning disabilities themselves. For those who have had direct contact, the biggest challenge was in the lack of understanding of the needs of people with learning disabilities, and the need to develop appropriate communication tools. One explained that it was essential to explain information in simple, small pieces of information and in stages rather than in big chunks of information. Additionally, the jargon of the legal system is very technical and hard to understand for any lay person, so solicitors needed to invest time in adjusting their thinking and practice.

“The impression I get and I think that this applies to myself as well as to other professionals is that we don’t have a big understanding of what it means to have

learning difficulties and consequently, you could communicate as much information as you want but if the person is not picking up on that information then it is a complete waste of a conversation". (Solicitor)

The manager of a law centre agreed, but also recognised that she and her colleagues were in a relatively privileged position to adjust their practice to cater for the needs of a diverse clientele:

"We will try to adapt our service in whatever way possible... Our interviews are not necessarily straightforward because lots of our clients have barriers; so if we have to explain something in a different way, or draw some picture, then that is what we will do. Because our service is free... our case workers do not feel constrained to work within a set timescale. So if it takes longer, it takes longer... we don't ask our staff to work in a particular way, but we do expect them to find the best way to work with a client, whatever the barriers are. Our funding arrangements mean that our grant from the local authority (which is very generous) subsidises our legal aid work. This is vital because so many of our clients have additional issues that make it difficult to work with them – chaotic lifestyles, perhaps – which means that they may miss appointments and so on."

There was agreement among the professionals that all their learning disabled clients required support from someone in addition to a legal professional to help them negotiate a legal process. For most of the lawyers their main point of contact is a family carer. In some situations establishing who their client is can be problematic and legal professionals were conscious of their obligation to determine the competence of a client with learning disabilities to litigate. Several talked about the potential for conflicting interests where family and other carers were involved. Yet even where this was the case, our respondents recognised the value to their clients of someone other than a legal professional to assist them through the process:

"This applies to everyone, but for person with learning disabilities even more so. After you've left an interview with the lawyer it's really good if there is somebody you can say to; 'is that what they really said?' 'What did that mean?' Seeing a solicitor is a bit like going to the doctor, it's quite scary really. So to have someone who can reassure you and answer questions afterwards makes the whole transaction much more likely to be a positive one." (Solicitor)

6.3 Routes to getting the right support

All of the legal professionals we spoke to emphasised the importance of having a good triaging system in place for ensuring that when people with learning disabilities first engage with legal services they are directed to a professional with the right skills and experience to help them. Within larger firms and law centres this may be an internal process:

“At the first in-depth conversation we want someone who is quite experienced. So someone may come in with a presenting issue that is about debt, but the solicitor who deals with that will work holistically and pick up on other issues, such as community care, and book the person in with the team that deals with that.”

The manager of a Law Centre suggested that the part of the purpose of triaging was to identify issues that were not immediately apparent to the client. This was especially true of certain areas of the law, such as community care:

“Because it [community care] is an amorphous area of law, a lot of people don’t get it, so our solicitor does pretty much all of the first interviews... There are some areas of law where people know there is an issue - you know if you are seeking asylum, you know if you are about to be evicted, you know if bailiffs are at your door, you know if you’ve just lost your job – but for some things we do people don’t know their rights and community care is a good example. Some people go to get a service and get told by whoever they ask – social services, or whoever – well you are not entitled, or this is all you can have. They will accept that because they don’t know they have some rights around that. It is an area of work we find it difficult to make people aware of their rights, so for that reason we work with a whole range of organisations who help us spot problems and bring people to us.”

She stressed the value of law firms, law centres and CABs working in partnership with other agencies to improve knowledge about people’s rights about community care, public law and welfare benefits, and to open up pathways to the right legal advice.

Others also noted the difficulty for family carers finding the right kind of specialist support. One barrister was critical of the role of local firms of solicitors when dealing with people with learning disabilities wanting to challenge a public body because of their reluctance to refer clients on to specialists. He explained that this was simply a matter of economics with solicitors seeking to retain such business for themselves. He suggested that families in particular are better advised to use support organisations and national charities such as Mencap and the Challenging Behaviour Foundation as their first port of call.

Several of the professionals we spoke to worked for large law firms which support many departments. Dealing with people with learning disabilities on a regular basis they were sometimes called upon by colleagues for advice about how to work with people with learning disabilities.

6.4 Working in partnership

Partnership working between lawyers and people in support roles was seen as an effective way of promoting access to legal services for people with learning disabilities. Three activities were mentioned by the legal professionals taking part in the study. Firstly, a number of them provided training and open advice sessions to family carers, usually

through local groups or national networks. All felt this was an extremely effective way of alerting a key set of supporters to the possibilities and practicalities of seeking legal advice and keeping them aware of the issues affecting this client group.

Secondly, firms and law centres had collaborated with learning disability organisations to produce information and resources specifically for people with learning disabilities:

“In terms of awareness-raising, something we did that I am quite proud of, we had some funding from the equalities and human rights commission where we collaborated on making people with learning disabilities more aware of the HRA and the rights it gave them... Our senior solicitor here specialises in employment and discrimination – not just in employment but in goods and services as well – and she did some work with a person with a learning disability and their carer to explain to them about the HRA and the basic rights its gives to people. They converted this into a session for people with learning disabilities. It was really good and my only regret is that we didn’t get it filmed!”

Thirdly, some suggested that more lawyers undertake outreach work, making formal arrangements with local groups to make sure they are aware and can easily access a service on behalf of people they are working with. As one explained, “they are spotting the problems and hand-holding the person in to us”.

6.5 Funding and resources

All of the legal professionals we spoke to expressed concerns about the potential impact of cuts to legal aid funding and local support for CABx and law centres upon groups, like people with learning disabilities, who already struggle to access appropriate legal advice. One described the effect that the changes from the 1st April would have in family law, for example, after which legal aid for divorce and disputes about children will no longer be available:

“I think it is going to have a real detrimental effect, because ultimately people will not be able to resolve their differences, and they won’t have access to legal advice which would be able to help them resolve their difference. And I think it is just going to be a dreadful time for families, with the children and parents in the middle of all these disputes”.

The manager of a law centre described “a new dimension” to the law centre movement now that as many as half charge for some types of advice because of the vulnerability of existing sources of funding. She also noted that while all law centres share an ethos, they vary considerably in size from the largest which employs 30 people, including 10 solicitors, to 2 solicitors, the minimum required to qualify as a law centre. And because centres have developed as separate entities, provision is not evenly distributed across the country. One consequence is that the largest centre covers 9 areas of law while the smallest cover only 2. More significantly for this study, it means that smaller centres are less likely to specialise in

working with people with learning disabilities or undertake the sort of project work that the larger ones have done to address this gap.

Allied to this were concerns that the areas of law that most affect people with learning disabilities, such as public law, community care law and welfare benefits, were underfunded, undervalued and underused within the legal system. One barrister pointed out that this was particularly pertinent to people with learning disabilities since a significant proportion (he estimated 30-40%) were probably not receiving their full entitlement to public funding. He talked of his own frustration at not being able to bring more challenges to court to establish case law because in a majority of cases the public body settled ahead of a full judicial review. This had the effect, he argued, of limiting the exposure of people with learning disabilities and their supporters to the potential benefits of seeking a legal remedy, especially when confronted with tightening eligibility criteria.

7. Discussion

The data gathered during this study provides us with a detailed insight into the experiences of people with learning disabilities from three distinct perspectives. The data are intended to represent the perspective of two sections of the learning disabled population. Participants in the focus groups were people with mild learning disabilities who were able to advocate for themselves, sometimes with support, for the purposes of contributing to the research. Some had jobs, most were living independently and many received low levels of public support. This compared with the experience of family carers and legal professionals who were mostly representing people with more profound and complex needs and therefore larger packages of public funding and support. This discussion explores how these perspectives sit alongside one another, pointing up the differences, and also important commonalities.

7.1 Understanding the law

The types of issue about which the participants in the focus groups have contact with legal services tends to be where that contact is inevitable or unavoidable: – at one end of the spectrum this will be about routine, formal processes whereby a solicitor will be involved, such as making a will, a tenancy agreement, conveyancing etc. At the other end of the spectrum, people with learning disabilities come into contact with a legal service because something dramatic has happened and the police become involved – they are either accused of something and a duty solicitor or an appropriate adult will be involved, or they have been the victim or witness of a crime whereby special measures may be invoked. The fieldwork showed the particular impact that legal processes can have upon parents with learning disabilities and the importance of having good legal representation in child care proceedings. Some local initiatives have recognised the need for better access to legal services for this group by developing specialist support for parents to legal representation. At a broader level, the criminal justice system has responded proactively to the needs of people with learning disabilities when they deal with the police and the courts.

One possible consequence of these experiences is that where they have a view at all, people's understanding of the nature of legal services is polarised. Those areas of law that lay somewhere in between - where legal services may be used proactively to challenge an action or decision, or to assert a right - are rarely taken up by this group.

This contrasts markedly with the experience of family carers whose concerns clustered around those areas of the law where our focus group participants were less active. Their purpose in using a legal service was about asserting rights, accessing resources and challenging decisions. Of course these issues are also of concern to our focus group participants. During our discussions with the host organisations we became very aware that groups had been dealing with community care provision and changes to welfare benefits as political issues that should be addressed at a political level, perhaps through campaigning.

One worker noted that while subjects such as changes to welfare and eligibility for community care services issues were being raised by their members, they were presented as aspects of someone's life to be endured rather than challenged.

We would therefore draw attention to different perceptions about the purpose of legal services and the outcomes that people can expect to achieve. For our focus group participants the primary meaning of 'the law' is the criminal code and the primary actors are the police, court-based lawyers and the judiciary. Broader concepts of 'legal professionals' and 'legal services' were not understood and they struggled to define the more concrete ideas of what a solicitor does, or what could be achieved by using one, beyond the specific role that solicitors had played when they had sought advice in the past.

For family carers, concepts of the law and understanding the role of legal professionals was less of a problem than finding the right people to help them with an issue. It is apparent that some family carers simply do not appreciate that legal services are structured into different areas of law, while those that do may not understand how to get hold of specialist advice. In the vast majority of cases the route to getting such advice was brokered via a learning disability or carer intermediary such as a national charity, local support group or fellow carer.

7.2 Developing support

Both sets of respondents highlighted their needs for information and support to improve their access to legal services. However, the substance of these needs differed. Our focus group participants lacked knowledge about the essentials of i) the scope of the law and how it affects their lives, and ii) the nature of legal service provision - what is a legal professional, what they do, the sorts of issues that they can help with and the difference that a legal service can make. There was unanimous support for accessible information of this type to be made widely available across the learning disability field.

Armed with this information, how might people with learning disabilities seek out a legal service? Our fieldwork paints a very clear picture of the extent to which those people with learning disabilities who live more independent lives rely upon the people they turn to when something goes wrong. These people – relatives, paid supporters, social workers and self-advocacy groups in particular – need to understand how the law affects people with learning disabilities, how to signpost them to get legal assistance and, where necessary, to support them to navigate the legal systems. This suggests that efforts to promote practical assistance to this section of the learning disabled population are best targeted at these people in support roles.

Some groups require dedicated support to help them through particular legal processes, notably parents with learning disabilities involved in child care proceedings and offenders, victims and witnesses when dealing with the criminal justice system. Support for the parents involved in this study seemed to be especially patchy.

Family carers' needs for information fall into a different realm. There is little evidence that family carers lack information about the role of legal services generally, although there is an apparent need for better understanding of the benefits to be derived from using a legal service and the sorts of outcomes that can be achieved within the particular contexts that our respondents have described. Family carers are often adept at researching issues for themselves and seeking out advice about the best way to proceed, but can be reticent about pursuing a legal remedy because of anxieties about the costs of doing so and the potential consequences for themselves or their relative. The most productive channels for family carers to access specialist help and advice are national learning disability charities, carers support organisations and forums and networks where they can communicate with family carers in similar situations.

The study suggests that further support and information for family carers needs to concentrate upon the promotion of legal advice as an option in resolving disputes alongside practical resources for locating specialist services and outlining the costs involved. Most importantly, support and resources are likely to be most effective where they are produced by trusted organisations and are grounded in the real experiences of family carers.

7.3 Capacity of legal services to respond

While much of the fieldwork for this study explored the demand for legal services by people with learning disabilities, it also addressed issues of the capacity of legal services to meet the needs of this clientele. There was unanimity across all respondents that this is lacking in three important respects: firstly, in the necessary adjustments to practice when working with people with learning disabilities; secondly, in the availability of legal services covering those areas of the law most likely to affect people with learning disabilities; and thirdly, in the affordability of services.

The fieldwork illuminated the need for training and awareness among legal professionals generally about the needs of people with learning disabilities when they are seeking advice and representation. There are indications that the Mental Capacity Act provides a framework for this to happen where the client (person with learning disabilities) may lack capacity to litigate. It also means that more people with learning disabilities, or someone acting on their behalf, are using a legal service to deal with issues of capacity.

The study suggests that legal services rarely make adjustments to their practice to ensure that people with learning disabilities are able to access them, yet provides evidence of what good practice looks like, based partly on participants' experience of using legal services, but also through their dealings with other professionals. This includes making information available in accessible formats, avoiding jargon, explaining technical points of the law in plain language and allowing extra time for consultations.

People with learning disabilities and family carers appreciate the role of CABx in dealing with routine legal issues, but they are less well equipped to meet the needs of people for more specialised advice. Law centres do address the areas of law that are of particular concern to family carers and are well placed to meet the needs of people with learning disabilities because of their funding arrangements. Partnership working between legal service providers and representative organisations and outreach work by specialist lawyers offer productive ways to make direct connections to this clientele.

The research reveals the importance of cost in determining the willingness and ability of people with learning disabilities to pursue legal action. There are significant fears about the existing capacity of local legal services to meet the needs of people within this group, especially in relation to legal aid work, and about the implications of reductions in both legal aid and the funding of CABx and law centres for future legal support to people with learning disabilities.

8. Conclusions

This study sought to explore the views of people with learning disabilities, family carers and legal professionals about the access of people with learning disabilities to legal services. Additionally we obtained the views of experts in the field of learning disabilities and from a range of organisations in support roles, particularly self-advocacy organisations. The participants provided a significant dataset from which we have extracted key themes and issues affecting people with learning disabilities when they seek assistance from a legal service. The study has contributed to our knowledge about access to legal services in two ways. Firstly it has reinforced the findings of earlier research in relation to the issues and experiences of people with learning disabilities and those who support them. Secondly it has added to our knowledge by providing a more focused and nuanced account of these experiences and has enabled us to explore the differences and the similarities between the experiences of people with mild learning disabilities and those with more profound disabilities who are supported by families/carers. This section of the report provides a summary of these findings and relates them to previous research.

8.1 Access to justice and equality before the law

The importance of having access to justice and the need for people with a learning disability to have equality before the law has been recognised in the mandate of the LSB to improve access to justice, by writers who have linked this to rights and responsibilities of citizenship (Ortoleva, 2010/11) and in the UN Convention on rights of persons with disabilities (UN, 2006). It has become clear from this study that for both people with mild learning disabilities and families/carers of those with more profound learning disabilities access to legal advice when it is needed remains problematic.

A number of factors contribute to this situation. It became clear from the focus group discussions with people with learning disabilities that they sometimes did not see their experiences as rights issues or as requiring legal advice. Although bullying and hate crime have increased over the past two years and were raised by a number of participants, these issues were not always reported and tended to be accepted as part of their lives. A similar response was found in relation to discrimination experiences in employment. When an issue was defined as requiring advice people turned firstly to family for support and then to either self-advocacy organisations or the CABx. Their decision as to whether or not to seek legal advice was then shaped by the support from these organisations.

Some participants in our focus groups were very unclear about what lawyers did and were confused about the appropriateness of seeking their advice for issues about which they were concerned.

Fear of losing current benefits or services, the possible cost and stress of seeking legal advice were factors which deterred by people with learning disabilities and families/carers

from seeking legal redress. Similar findings were obtained in previous studies (Leverton, 2002; Hurstfield et al, 2004; .Goodall, 2010). However, in this study some families/carers found that these fears were unfounded and that legal advice could provide a remedy that was fast and served to reduce their anxieties about the issue.

Seeking legal advice seemed to be an action of last resort dependent on the perceived seriousness of the issue, for example potential loss of children by parents with learning disabilities or alleged involvement in a criminal offence. Public law issues relating to discrimination, to queries about poor practice by professionals or appeals in relation to entitlements were more likely to be accepted as a part of everyday living or lead to advice being sought from self-advocacy organisations or a CAB.

8.2 The issues

Many of the issues that were raised by people with learning disabilities and family carers were ones that had been identified by previous research. The despair of some parents with learning disabilities about the actual or potential loss of their children was a powerful issue in some groups and the difficulties that parents confront in relation to negotiating with children's services and the legal system on this issue have been reported in earlier research (McConnell and Llewellyn, 2000; Tarleton, 2008). The problematic nature of bullying and hate crime was widely reported in the focus groups and for some people was leading to restricted lives and experienced high levels of stress because of it. While some people reported incidents to the police, others continued to live with threats and harassment. Little constructive action appeared to be taken on this issue even when it was reported. Similarly incidents of discrimination or what was seen to be unfair dismissal tended to be accepted by those who experienced them without recourse to legal advice, supporting other earlier research evidence (National Autistic Society, 2012).

Some people spoke of being accused of crimes and of experiences with police which at times had long term negative effects on their lives. When duty solicitors became involved in these situations much depended on their skill and knowledge in working with people with learning disabilities. At times the intervention was helpful but at other times the person with learning disabilities found it difficult to relate to the legal professional. The need for training and support for legal professionals in this situation was seen to be important by participants in the study.

Family carers reported a range of issues many of which had to do with concerns about services or benefits. While many of these people reported positive outcomes from accessing legal advice, finding the right person sometimes involved both time and resourcefulness.

8.3 The gatekeepers

It became clear from this study that self-advocacy organisations, carers networks and the CABx were important gatekeepers in relation to either facilitating or inhibiting access to legal services. Some people with learning disabilities commented that they had only realised that an issue could have legal implications after becoming a member of a self-advocacy organisation. Some self-advocacy groups had become knowledgeable both about referrals to legal services or about the issues raised by their members because of the frequency with which they occurred, for example one self-advocacy organisation had a number of members who were parents and had become knowledgeable about the issue and also knew the legal professionals most able to help with it.

Similarly carers networks for some family members provided a source of information about legal professionals who were particularly skilled in problems which they were experiencing. CABx while perceived as variable in their capacity to respond to some issues were an important first port of call for many people with learning disabilities who were dependent on the advice that they gave. The cut backs to this service and the limited time that staff have to deal with often complex issues in a clear way are of concern given the high dependence of people with learning disabilities on this service.

These organisations could benefit from information that was written in accessible language and which could be used with people with learning disabilities to clarify the role of legal professionals and to identify the issues with which they could offer advice. Similarly making known to legal professionals the role and the contact details of such organisations could provide support for them in working with people with learning disabilities.

Repeatedly in focus groups participants raised the issue of having clear information about the legal services in their local area and the need to know who they could go to with particular issues and problems.

8.4 Legal access in a time of economic constraint

There was considerable confusion and anxiety by people with learning disabilities in relation to recent changes in benefit entitlements and access to legal services. People were unsure about whether they would be eligible for free legal aid and under what circumstances this would be given. This anxiety was heightened by concerns about the effect of benefit changes. The provision of clear and accessible information about government changes and their effects to relevant organisations such as self-advocacy organisations and CABs is needed.

8.5 Legal professionals working with people with learning disabilities

The findings from this study revealed that some lawyers were skilled in working with people with learning disabilities and adapted their practice to meet the needs of their clients. Using

plain language, treating the person with respect and being honest about the possible consequences of taking action were valued by participants in the study. However there were also examples given of where lawyers could not be understood, appeared uninterested or were not able to make a more appropriate referral. In part this seemed to depend on the amount of experience that the lawyer had in working with this group. This was a particular issue in small firms where there was less specialisation and where for example the Mental Capacity Act was not understood. Some legal professionals indicated that they were anxious about working with people with learning disabilities and were uncertain about the issues involved. There is therefore a need for clear advice to lawyers about how to work with people with learning disabilities.

8.6 Conclusion

This study reaffirmed and increased our knowledge of the experiences of people with learning disabilities and their families or carers. The accounts given by participants were powerful and sometimes distressing. There is a need for clear sign posting in terms of understanding what lawyers do, what issues can be taken to them for advice. This kind of knowledge should be available to the gatekeeping organisations and also to lawyers who may have people with learning disabilities or their families/carers as clients.

9. Recommendations for action

9.1 Recommendations for legal services

9.1.1 Good practice guidance. There is clear need for some good practice advice and guidance for solicitors and other legal service professionals. This should emphasise the importance of producing easy-to-read materials explaining how to people with learning disabilities can access their service, what it offers, the costs of using the service, likely outcomes and the adjustments made to accommodate people with intellectual impairments and other disabilities.

9.1.2 Working in partnership. Guidance for legal services about working with local support groups for people with learning disabilities and family carers, as well as health and social care agencies, to gain a better understanding about the issues that people with learning disabilities face and the types of help they might require. These contacts will also be useful for establishing points of support when dealing with clients with learning disabilities and for getting advice about producing accessible information.

9.1.3 Training and professional education. Training and professional education for legal professionals should be reviewed to establish whether and how good practice in working with clients with disabilities is included in curricula. The special interest group Lawyers for Learning Disabilities should be promoted to legal professionals and invited to assist in the implementation of these recommendations.

9.2 Recommendations for learning disability agencies

9.2.1 Accessible information. Accessible information should be produced for people with learning disabilities to explain how legal services work, the types of issues that they can seek help with, and how they can access legal advice. We note for example that many people attending the focus groups appreciated our short film about the study for its clarity and use of practical examples.

9.2.2 Advice and guidance. Advice and guidance should be produced to help supporters of people with learning disabilities understand how to guide people with learning disabilities to access legal services. As a minimum this should be distributed to all self-advocacy and advocacy organisations, health and social care agencies and national charities.

9.3 Other recommendations

9.3.1 Further research. Research needs to be conducted into the impact of recent changes to legal aid to assess the impact upon people with learning disabilities and their ability to access justice.

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Appendix 1: methodology

The overall purpose of the study has been to gain a better understanding of what happens when people with learning disabilities need to use a legal service. Two factors guided the development of the chosen methodology; the need to explore in some depth the experiences of the research participants and the short timescale available to complete the research (3 months). In addition, we considered the different perspectives that would illuminate the overall purpose and how those might best be captured during the fieldwork. Finally, we took account of the resources available to complete the study and the requirements of procedures, such as ethical review, over which we would have limited control.

These practical considerations, allied to precedence and good research practice, mean that we adopted a qualitative methodology which featured four strands of research:

1. A review of the existing evidence
2. Focus group discussions with people with learning disabilities
3. Telephone interviews with family carers of people with learning disabilities
4. Telephone interviews with legal services professionals.

Prior to the commencement of the fieldwork, the proposed methodology and project documentation were submitted for ethical review by the Research Ethics Committee of the School for Policy Studies at the University of Bristol. Ethical approval for the study was granted on 27th February.

Focus group discussions with people with learning disabilities

In designing the fieldwork we were conscious of the need to ensure that the direct testimony of people with learning disabilities was prioritised over mediated accounts of their experiences of using legal services. In doing so, we recognised that group settings were likely to not only generate significant numbers of participants within the timescale, but also provide a 'safe space' in which they could talk about their experiences. In addition there exists an extensive network of self-advocacy and advocacy organisations across England and Wales that are used to facilitating groups and provide a line of communication to a significant sample of the learning disabled population. To ensure a good geographical spread and an approximate balance between rural and urban areas, we invited one or two self-advocacy or advocacy organisations from each of the English regions and two from Wales to recruit participants on our behalf. We offered a facilitation fee to each host organisation in recognition of their assistance and to cover the costs of room hire, refreshments and travel for participants.

To assist the recruitment process and to ensure that potential participants were properly informed about the purpose of the study we produced a short film explaining the nature of

the research and how it was to be carried out. The film can be view [here](#)³. We also supplied the host organisations with an accessible information sheet about the project (a copy is attached as appendix 2). At the start of each focus group discussion we played the film, went through the information sheet and asked participants to complete and sign a consent form, with assistance where that was required (the consent form is at appendix 3).

The focus group fieldwork was conducted over a 5 week period and engaged a total of 90 participants in 18 separate focus group discussions (see Table 1 below). While the object of the exercise was not to generate a representative sample of adults with learning disabilities, we felt it was important to ensure a rough typicality in terms of geographical spread since we hypothesised that this might affect both the legal issue that people experience, but also the legal services that are available to them. Despite repeated efforts to recruit host organisations from Inner London, we were able to only work at one fieldwork site there.

The under-representation in London and the South East, in terms of the estimated population of people with learning disabilities was mitigated by a good response elsewhere, particularly from other metropolitan sites.

Table 1: summary of focus group fieldwork

Region	% of 'likely true' learning disabled population ⁴	Characteristics of fieldwork site	Focus groups	Participants
Eastern England	10.54	Largely rural	2	10
East Midlands	8.20	Urban	1	10
London	14.41	Metropolitan	1	4
North East	4.76	Metropolitan	1	12
North West	12.68	Metropolitan	2	6
South East	15.43	Urban	2	9
South West	9.57	Urban	2	10
West Midlands	9.93	Urban	2	11
Yorkshire And The Humber	9.71	Metropolitan	2	9
Wales	4.77	Largely rural	2	7
National carers with learning disabilities group	n/a	n/a	1	2
England & Wales	100.00		18	90

We did not collect full demographic details of participants but we did ask one host organisation to recruit proactively from local black and minority ethnic communities; 5 of 6

³ <http://www.youtube.com/watch?v=oJZ1cK93vFk&feature=youtu.be>

⁴ Source: *Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England* by Eric Emerson & Chris Hatton, Institute for Health Research, Lancaster University 2/6/2004

participants at the subsequent focus group were from these backgrounds. Overall 9 (10%) of the participants were from black and minority ethnic communities. The focus groups contained slightly more women than men and a preponderance of people aged between 30 and 50 years. It is also worth noting that most of the people attending the focus groups were at the margins of eligibility for community care support, or were receiving relatively small packages of support.

All participants were able to advocate for themselves with only minimal assistance to understand the discussion or to express themselves. An indication of this may be gleaned from the fact that we had prepared a comprehensive communication pack of images to augment spoken questions, but found that we did not need to use them. This was largely due to the presence of at least one supporter – usually from the host organisation – who was able to assist participants as required. These supporters also provided invaluable contextual information about local issues and the resources available to people with learning disabilities seeking legal advice.

Permission was sought from each group to record their discussion with the assurance that the recording would only be used by the research team for the purposes of analysis and that any quotes taken from the recording would be anonymised in such a way that individuals could not be identified. All of the groups agreed to their discussion being recorded. In addition, participants were offered the opportunity to speak to a member of the research team separately to talk about something they did not wish to share with the group; 6 people chose to do this, 4 to talk about being in trouble with the police and 2 about sensitive personal issues.

The focussed discussions followed a topic guide that introduced broad themes to the groups: the issues about which they had sought advice and the outcomes, the routes they had taken (or not taken) to getting advice, the things that helped and that had hindered them along the way, and finally what could be changed to make access for people with learning disabilities better. We found that this simple design worked well and was applied consistently throughout the fieldwork period. A copy of the guide is at appendix 4.

Our original intention had been to run separate groups at each site for people with experience of using a legal service and those without such experiences. In practice this proved impossible for logistical reasons and also because the vast majority of those agreeing to participate in the research did so because they had some experiences to share. However, while only a very few participants (about 5%) were unable to recount an issue about which they **could** have sought legal advice, most groups did contain a mixture of people with and without experience of using a legal service and approximately 80% of the participants had used some form of legal service in the past.

Interviews with family carers

The second strand of research was designed to capture the views of family carers. We supposed, rightly, that the focus groups would generate data about the experiences of people with milder forms of learning disability, living more or less independent lives in the community. We also knew from existing evidence and our own knowledge of the field that family carers often take the lead in accessing a range of professional services for people with more profound and complex learning disabilities with larger packages of support.

Within the resource and time constraints of the study, we determined that an open recruitment policy with the offer of participation through a telephone interview would be the most cost-effective way of gathering this data. We therefore posted an invitation to take part on online forums and through family carer networks.

This strand of the research was led by one member of the research team to ensure consistency in data collection. We aimed to recruit up to 30 family carers with a view to generating a large enough dataset to analyse for significant patterns and themes; by the end of the study we had conducted 26 interviews with family carers, all parents of an adult with learning disabilities. The interview schedule is set out at appendix 5.

Interviews with legal services professionals

The final strand of the research tapped into the views and opinions of legal professionals. This strand was altered significantly from what was proposed at the start of the project where we had intended mapping local legal services as part of our fieldwork strategy. Initial attempts at doing so indicated that this was likely to be a time-consuming and ultimately fruitless exercise as the few who responded had no dealings with people with learning disabilities. The methodology was amended to identify professionals with regional and national specialist roles (specialists in large law firms and barristers) who could provide us with insights into working with people with learning disabilities; and secondly, by approaching legal professionals mentioned during the focussed group discussions. We therefore carried out telephone interviews with 6 professionals in the former category and 3 professionals with local roles.

Data management and analysis







All of the data collected during the study has been stored safely on the University's system. A rolling programme of analysis was instituted as data arrived to make best use of the time available. Focus group recordings were reviewed and coded for key themes. Selective quotations were taken to illustrate themes. Each of the telephone interviews with family carers has been transcribed and similarly coded for key themes. Secondary analysis of these data was carried out by a second member of the research team to check for consistency and to identify patterns in the responses.

Appendix 2: Information sheet

What happens when you need advice about the law?

Information about our research








	<p>This research is finding out what happens when people with learning disabilities need to use “legal services”.</p>
	<p>A legal service will help you to use the law.</p>
	<p>You might need help making sure something is done properly.</p>
	<p>For example, getting a tenancy agreement.</p>
	<p>You might want to make a complaint about a service...</p>
	<p>Or you might need help if someone has broken the law and it affects you...</p>

	<p>For example, you feel you lost your job unfairly.</p>
	<p>People who work in legal services can give you advice about the law.</p>
	<p>There are many types of legal service</p>
	<p>including solicitors...</p>
	<p>Law Centres and</p>
	<p>The Citizen's Advice Bureau</p>




What we are going to do

	<p>We will speak to people with learning disabilities who need help to use the law.</p>
	<p>People who used a legal service</p>
	<p>And people who did not use a legal service</p>
	<p>We want to know what happened to them.</p>

How you can help

	<p>Have you needed help to use the law?</p>
	<p>If so you can help by coming to a meeting and telling us what happened</p>
	<p>We will make a note of what people say at the meeting</p>
	<p>And put them in a report for other people to read</p>
	<p>But we won't use people's names in the report</p>
	<p>The money for this research came from the Legal Services Board</p>
	<p>You can also watch a film about this research by clicking here (http://www.youtube.com/watch?v=oJZ1cK93vFk&feature=youtu.be)</p>

More Information








	If you want to know more, contact Paul Swift
	0117 9294365 / 07740 946564
	<u>paulswift.research@gmail.com</u>

Appendix 3: consent form

What happens when people with learning disabilities need advice about the law?

A research study by the Norah Fry Research Centre

Consent form

		Tick
	I have seen the film about the study	<input type="checkbox"/>
	I have read the information sheet	<input type="checkbox"/>
	I understand the information about this study and would like to take part	<input type="checkbox"/>
	I agree that the researcher can record what I say, but I can ask for the recorder to be switched off at any time	<input type="checkbox"/>
	The researcher will keep the record of what I say in a safe place	<input type="checkbox"/>
	I understand that the researcher will write a report, but will not use my name in it	<input type="checkbox"/>
	I can change my mind about taking part at any time	<input type="checkbox"/>

Name (please print)



Your telephone number



Your email address



Signed

Appendix 4: focus group guide for facilitators

What happens when you need advice about the law?

A research study by the Norah Fry Research Centre

Focus Group Guide

Before the session

One week before the focus groups are due to run, contact the host organisation and check:

- That they have received all the information and this has been shared with potential participants.
- Timings – start and end times, also mention that we will arrive an hour before the start time to set up.
- Parking arrangements, if any.
- Who from the organisation will be there on the day to greet us and that there will be someone there to call upon in case of any problems.
- Numbers of people confirmed as coming to each group and any special requirements (translation services, wheelchair access, hearing loop etc).
- **Ask them to prepare a list of names, which they can give us on the day, along with the key issue that each person is likely to discuss (if this is known).**
- Set up of the room – TV and DVD player (if available), flipchart board and sheets.
- Refreshments.
- We are expecting them to sort any travel arrangements and pay people's expenses – this is included in the £500 fee.
- The organisation should invoice us after the event – give them a SAE to return this.

Day before:

- Check that all the resources and equipment are ready to go – laminated photosymbol sheets, accessible information sheets, consent forms, focus group guide, laptop, DVD, audio recorder and microphone (and spare batteries), flipchart paper and pens.
- Check that we have right address, directions and travel documents.

On the day:

- Arrive an hour before the scheduled start to introduce ourselves and set up the room.
- Assess the room and arrange seating.
- Check all the equipment.
- **Talk to the host about the people who are coming – what are the issues that they are bringing with them.**
- Meet and greet as people arrive.

Welcome

Introduce self and the scribe and then welcomes participants to the focus group discussion.

Say the discussion will last about 60 minutes and people should say if they want to stop and take a break at any time.

Ask each person to say their name and where they live. Scribe writes names on flipchart.

Explaining the research

Say that we are going to show the film which says what the study is all about. Some of them will have seen this before, so we are showing it to remind them.

If the film does not work or we do not have the means to show it, give a short explanation:

- Research means gathering information that helps answer an important question.
- In this case the question is; what happens when people with learning disabilities need to get advice about the law?
- Gives examples: getting a tenancy, making a complaint, losing a job unfairly
- We want to find out if people get advice when these things happen.
- And who they get advice from.
- We will write down what people say and put it in a report.
- The report will go to the people who asked us to do the research.
- They will use it to make it easier for people with learning disabilities to get advice about the law.

Show everyone the consent form and give them a copy of the information sheet. Go through it step by step.

How the discussion will work

Explain that you (the facilitator) will be asking people questions. *There are no right or wrong answers; we just want to hear what you have to say.*


We will ask everyone to say something, but it is OK not to talk if you don't want to.

You may not want to talk about something if it is painful or too personal – that is fine.

The facilitator explains that the scribe will be recording the session and writing down the main points.

Say that we would like to record the discussion (show the audio recorder) so that we don't get things wrong. But we will not be including anyone's name in the report.

Issues that might lead to participants seeking advice about the law

<p>Route 1 (where we already have good information about the issue that each person is bringing)</p>	<p>Route 2 (where we do not yet know what the issues are)</p>	
<p>Introduce this theme: <i>Sometimes people have a problem and then needed help to sort it out – like Julian in the film. We’d like to see if you have had any problems and how they were sorted out.</i></p>	<p>Introduce this theme: <i>Sometimes people have a problem and then needed to help to sort it out – like Julian in the film. We’d like to see if you have had any problems and how they were sorted out.</i></p>	
<p><i>Let’s start with this problem...</i> Show appropriate photosymbol to the group. Confirm with the relevant individual that this has happened to them. Ask them to tell the group what the problem was.</p>	<p><i>Here are some problems...</i> Show photosymbols for three issues and describe each in turn. Ask if anyone has had that problem. If so, ask them to tell the group what the problem was</p>	
		
<p><i>Who did you talk to about this?</i> Prompt for details about the person and their status</p>		
<p>(Legal adviser)</p>	<p>(Non legal adviser)</p>	
<p><i>Tell us what happened when you saw them</i></p>	<p><i>What did they do?</i></p>	
<p><i>What did you like about them?</i></p>	<p>(Problem resolved)</p>	<p>(Referred to legal adviser)</p>
<p><i>What happened about the problem?</i></p>	<p><i>Tell us how the problem was resolved</i></p>	<p><i>Tell us what happened when you saw them</i></p>
<p><i>How happy were you with that?</i></p>	<p><i>How happy were you with that?</i></p>	<p><i>What did you like about them?</i></p>
		<p><i>What happened about the problem?</i></p>
		<p><i>How happy were you with that?</i></p>

General

Let's think about what makes a good [legal professional]...

(List and prompts)

What could be done in a better way?

Ending

Thank everyone for their time.

Explain that we will be writing a report and the Legal Services Board will be using it to make sorting out problems easier.

Appendix 5: interview schedule for telephone interviews with family carers

What happens when people with learning disabilities need advice about the law?

A research study by the Norah Fry Research Centre

Legal service provider telephone interview schedule

Introduction

Thank the person for agreeing to take part in the research and explain that the interview will last for between 30 and 45 minutes.

Background to the study

Check that the respondent has read the information sheet. Give a brief resume of the background to the study:

- The research has been commissioned by the Legal Services Board. The Board is responsible for regulating legal services in England & Wales.
- The Board has a duty to ensure that the interests of people who use legal services influence its work.
- They have asked us to find out about the experiences of people with learning disabilities when they need legal advice.
- We are looking at the issues that people with learning disabilities need advice about, how easy it is to get the right advice and what could be done to make it more accessible.
- The Legal Services Board will use our report to make legal services more accessible for people with learning disabilities.

How we are doing the research

Explain briefly that we are collecting information in several ways:

- From groups of people with learning disabilities.
- Individual interviews, like this one.
- Telephone interviews with family carers.
- Telephone interviews with people who provide legal services.

About the interview

We would like to record the interview using a digital audio recorder. The recording will be transcribed but any names, including the respondent's and the person they are talking about, will be left out. If we something that the respondent says as a quote in the final report, we would not identify them. Check that the respondent is happy for the interview to be recorded. Reassure them that they can stop the interview at any time.

Information to be gathered during interview

- Respondent's situation (relationship to family member with a learning disability)

- Relative's situation (support arrangements, involvement of respondent in the relative's life)
- Respondent's own experience of seeking and using legal advice generally (frequency, issues about which advice sought, where advice sought, satisfaction with outcomes)
- Respondent's experience of seeking legal advice as a family carer (frequency, issues about which advice sought, where advice sought, satisfaction with outcomes, extent to which experience differed from the generic)
- Respondent's experience of seeking legal advice on behalf of a learning disabled (frequency, issues about which advice sought, where advice sought, satisfaction with outcomes, how relative was involved, extent to which experience differed from the generic and for a carer issue)
- Summary of good legal advice, what could be done better and impediments to good access (for example, costs).
- Any other comments the respondent would like to make

Closing remarks

Thank the respondent and ask if they would like to receive a copy of the final report.