

Research Specification: Understanding the needs of legal services consumers with learning disabilities

Purpose

Following a scoping exercise the Legal Services Board and the Legal Services Consumer Panel have decided to commission a piece of research, in collaboration with Mencap, focused on people with learning disabilities and exploring their experience of accessing legal advice and their experience of the advice itself. All research will be published externally and freely available to academics, frontline regulators and others.

About the LSB, the LSCP and Mencap

The Legal Services Board has been set up to reform and modernise the legal services market place in the interests of consumers, enhancing quality, ensuring value for money and improving access to justice across England and Wales. The LSB will achieve this pursuing its regulatory objectives and providing regulatory oversight for the eight approved frontline regulators.¹ The Consumer Panel is an independent arm of the Legal Services Board, created to provide high quality, evidenced-based advice to the LSB and others on the consumer interest in the regulation of legal services.

Mencap supports people with a learning disability in the UK and their families and carers. They aim to change laws and improve services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want. Mencap is also one of the largest providers of services, information and advice for people with a learning disability across England, Northern Ireland and Wales.

About learning disability

A learning disability is caused by the way the brain develops before, during or shortly after birth. It is always lifelong and affects someone's intellectual and social development. It used to be called mental handicap but this term is outdated and offensive. Learning disability is NOT a mental illness. The term learning difficulty is often incorrectly used interchangeably with learning disability.

Background

One of the five elements of the Consumer Panel's vision for legal services is a diverse workforce that understands its diverse clients. The Panel's work programme supports this objective through a programme of focused studies on specific groups of consumers who are in vulnerable circumstances when accessing legal services. Our first such study looked at the legal needs and experiences of deaf and hard of hearing people. The research was commissioned in partnership with Action on Hearing Loss and the Solicitors Regulation Authority and provided fresh insight into a vulnerable consumer group. Following the research the Law Society issued two new practice notes for solicitors, one on

¹ The Law Society, General Council of the Bar, Council for Licensed Conveyancers, The Chartered Institute of Legal Executives, The Chartered Institute of Patent Attorneys, The Institute of Trade Mark Attorneys, Association of Law Costs Draftsmen, Master of the Faculties.

providing legal services for people with hearing loss and one on equality and diversity requirements, including making reasonable adjustments. Another area which deserves further investigation, and which we would like to focus on, is that of learning disabilities.

Definitions

Mencap defines a learning disability as “reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.”² Learning disabilities are likely to be present from early childhood and remain constant. A learning disability may be mild, moderate or severe.

There is no definitive record of the number of people with learning disabilities in England but it is estimated at around 1,191,000.³ Up to 40% of people with a learning disability have hearing and/or visual problems that can affect their communication and understanding. Up to 90% of people with a learning disability have problems with communication.⁴

In some cases learning disabilities are classified together with mental health issues under the umbrella term ‘limited mental capacity’.⁵ However, there is an important difference as learning disabilities affect someone for their whole life while mental health issues can instead often affect a person’s abilities at different times during their life but are unlikely to be a ‘static’ condition, and may be overcome with treatment. It is important to note though, that from the perspective of accessing and using legal advice the outcomes of both mental health issues and learning disabilities may be similar– for example the affected person may need adjustments to be made by a legal advisor to help them express their wishes clearly or to understand advice. It should also be noted that learning disabilities and mental health issues can occur together.

Learning disabilities can result in a reduced ability to learn new skills, to cope with everyday demands and to understand complex information. Everyday tasks that people with a learning disability may find difficult include:

- Filling in forms;
- Following instructions/directions;
- Concentrating for long periods;
- Telling the time and understanding or describing time periods;
- Remembering or explaining things;
- Reading, writing and comprehension;
- Managing money and bills;
- Keeping appointments;

² See <http://www.mencap.org.uk/definition%20>.

³ Emerson, Hatton, Robertson, Baines, Evison and Glover, *People with Learning Disabilities in England 2011*, p. i. See also http://www.mentalhealth.org.uk/content/assets/PDF/policy-archive/Mental_health_in_people_with_learning_disabilities.pdf.

⁴ <http://www.scotland.gov.uk/Resource/Doc/346993/0115487.pdf>, p. 17

⁵ See for example National Policing Improvement Agency guidance on *Responding to people with mental ill health or learning disabilities*.

- Using public transport on their own.

The way a learning disability affects someone depends on many things, including the nature of their impairment. Some people have mild or moderate learning disabilities. People in this group are generally included in mainstream education and work towards entering employment. They may need some support in areas of life, but should be able to lead a life like any other person. Other people have severe learning disabilities, or may have a profound and multiple learning disability. People with this level of impairment will face many barriers to their inclusion in society, and are likely to require significant support from the care and support system, as well as family members, to live independently and meet their aspirations in life. People with severe learning disability and profound and multiple learning disability may not have mental capacity to make decisions on some important things in their lives, and may therefore have family members or advocates to support them in decision making, who are empowered to make decisions in their best interests.

The recent abuse scandal at Winterbourne View highlighted the specific needs of people with a learning disability who also have behaviour which challenges, such as self harming, or being aggressive towards others when anxious or not properly supported. This group form an extremely vulnerable group, many of whom have been failed by their local services, and then sent out of area to institutions where they are away from their families, and at a greater risk of abuse.

Finally, there are various reforms currently underway which could impact on those with learning disabilities. The result of these changes is unknown, but some stakeholders have voiced a series of concerns. For example, the Welfare Reform Act will change access to benefits, like Disability Living Allowance, which could lead to reduced levels of benefits, as well as bringing about big changes to income related benefits, through the introduction of Universal Credit. In addition, the 25% cut to local authority budgets in the current Comprehensive Spending Review period is leading to cuts in local services that disabled people rely on, such as Day Centres or transport services.

The Legal Aid, Sentencing and Punishment of Offenders Act will reduce the scope of legal aid in areas of law such as housing, debt and welfare benefits. Concerns have been raised that in the absence of advice vulnerable people will be at a higher risk of being unable to challenge decisions and access justice. In addition, relatively few lawyers specialise in complex and niche areas which may be particularly needed by people with learning disabilities – for example relatively few lawyers specialise in community care law – the number was estimated at less than 60 firms providing such advice in England and Wales in 2009.⁶ Therefore this is a particularly pertinent time to gather information.

Aims and Objectives

The LSB, the LSCP and Mencap are therefore commissioning 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. The research should both aim to summarise and illustrate the experience of those with learning disabilities finding and using legal services but

⁶ See http://www.learningdisabilitywales.org.uk/pdfs/legal_advice.pdf.

also produce clear recommendations that could be used to help the legal profession increase their accessibility to people with learning disabilities.

This research should aim to find out about:

- Barriers to accessing legal advice;
- The circumstances which contribute to people with learning disabilities being vulnerable when purchasing legal services;
- Whether these circumstances result in adverse outcomes when using lawyers, and if so how;
- Whether the legal needs of this particular group are being met;
- If not, what practical steps could be taken by the profession and the regulators to improve access to legal services and avoid adverse outcomes.

Issues and scope

Consumers with learning disabilities may be users of general legal services, for example they may need to have conveyancing carried out if they are buying a home, or they may wish to make a will.

On the other hand, there are specific instances where people with learning disabilities or their carers may particularly require legal advice and assistance such as:

- Accessing the support they are eligible for;
- An argument between two different local authority social services departments over which one is responsible to provide care;⁷
- A carer making sure that their child with a learning disability can attend a mainstream or a specialist school;
- Accessing satisfactory health care.

Previous research has found that people with learning disabilities are more likely than the general population to be victims of crime (including hate crime), and may suffer harassment, bullying or serious violence related to their disability. They may also be extremely vulnerable and suggestible. Therefore this group of people may be more in contact with the police, courts and lawyers than the general population (for example as a witness or a victim of crime) – this provides particular challenges for legal advisors.⁸

Finally, the families or carers of consumers with learning disabilities may have legal needs which are related to the person with the disability. These may centre around the enforcement of rights, for example they may seek legal advice to make sure the person they are caring for moves from childhood into adult life with the right support.

On the other hand they may wish to make a will or set up a trust in a particular way to ensure their family member is cared for after they have passed away. For example a carer may want to make sure the person in question will be able to continue living in the family home.

⁷ See http://www.learningdisabilitywales.org.uk/pdfs/legal_advice.pdf.

⁸ National Policing Improvement Agency guidance on *Responding to people with mental ill health or learning disabilities*.

Consumers of legal advice with learning disabilities may also use an advocate to help with understanding. This could be a family member or friend, a carer or an independent third party. The advocate aids communication, both by making sure that the person understands their rights and the options or courses of action open to them, and to make sure the person is able to express their wishes to the lawyer.

The Civil and Social Justice Survey has found respondents with a long-term illness or disability are somewhat less likely to handle problems alone when compared to the general population.⁹ These respondents were also less likely to know about their rights when compared to other respondents. This untapped demand, whereby consumers may in fact have legal needs but are unaware that they have rights which can be enforced, is a key issue. As part of the research Mencap plan to undertake a quantitative survey of users of their helpline in order to explore this further. The Disability Law Service could also be engaged in this work, which either Mencap or LSB could investigate.

In order to explore the above themes, we are looking to commission qualitative research to explore directly with those with learning disabilities their experiences with legal services. The research should examine, in particular, the following issues in relation to people with learning disabilities:

- What are their legal needs?
- Where do they access legal services? Why do individuals choose a particular law firm/ legal service over other ones, and what are the criteria they look for in making this choice?
- Are there specific circumstances/factors/business practises that make accessing legal services, and obtaining satisfactory outcomes, better or worse? Why?
- What have been the experiences of different individuals?
- Are there common themes in these experiences?
- What changes could improve access to legal services or help avoid adverse outcomes?
- How, if at all, do the above issues differ depending on an individual's type and extent of disability?

Sampling considerations

Given the nature of the information we are seeking we expect the successful researcher to use qualitative research techniques to explore consumers' views. Whilst recognising that the population of potential participants is likely to be fairly small, the researchers should try to incorporate the views of consumers in England and Wales in metropolitan and rural areas as much as possible. We welcome the views of the researcher on the most appropriate sample frame for this research. Family carers should also be included in the research, as they may play a key role in accessing legal services on behalf of the disabled family member they support.

We expect the successful researchers to be able to understand the information and communication support which may be required to help ensure the greatest possible participation, and would welcome views on how this will be delivered and the most appropriate research methods. All tenders should include the costs anticipated for production of accessible materials and any communication or advocacy support needed.

⁹ <http://www.lawforlife.org.uk/data/files/knowledge-capability-and-the-experience-of-rights-problems-lsrc-may-2010-255.pdf>, p. 17.

The Panel, the LSB and Mencap will set up an informal steering group, led by the Consumer Panel, which will provide advice and input throughout the study.

Deliverables

Output

The final output will be an executive summary together with a report, including conclusions on where consumers believe the division between risk and responsibility should lie. The report should be suitable for publication. It is essential that the report and underlying research is sufficiently robust so that the Panel, the LSB and Mencap can use this in discussions with external stakeholders and it can underpin work going forwards. After the final report is agreed, Mencap will support production of an Easy Read accessible version of the report. Both versions of the report will be launched simultaneously.

The LSB will retain ownership of the reports and underlying data, which must be delivered in a publishable format.

Project plan

Tenders should include a project plan and time schedule for the work that identifies the main task and key milestones that will be used to monitor progress. The plan should be accompanied by a resource profile, giving a breakdown of the resources in person days allocated to each task.

Tender Evaluation Criteria

All projects are subject to the LSB's standard terms of contract. Tenders will be evaluated on best value for money and will be assessed on the basis of:

1. Overall cost. Please include appropriate breakdowns;
2. The extent to which tenders are clearly written and meet the specified objectives, present a sound methodology, identifying any potential problems, and proposing suitable solutions;
3. Address outputs and ensure these are in line with requirements and the required timing of the project;
4. Proposed team composition, expertise and management and the organisation's diversity policy;
5. How diversity issues would be addressed in the research.

Duration

The research should commence in January 2013. Tenders should set out dates for completing all key milestones such as information gathering, analysis, synthesis and report writing. The draft report should be submitted by the week commencing 1 April 2013, along with an overview of the findings, which will be presented to the Panel by the research agency. The finalised report is due by 26 April 2013.

Contact

Legal Services Consumer Panel/Legal Services Board Contact Details

For any queries about the research specification contact:

Research: Alex Roy (LSB) 020 7271 0060

Policy team: Harriet Gamper (Consumer Panel) 020 7271 0076

Deadline for submission

**Tenders must be submitted by 4pm on 9 January 2013 to Alex Roy
(alex.roy@legalservicesboard.org.uk)**

Interviews with shortlisted consultants will take place in the week commencing 7 January 2013.

Annex 1: Key documents

Balmer, N., Buck, A., Patel, A., Denvir, C., and Pleasence, P., *Knowledge, Capability and the experience of rights problems*, Plenet/LSRC, March 2010.

Burton, J., *Why people with community support needs sometimes need legal advice*, 2009.

Crown Prosecution Service, *Supporting victims and witnesses with a learning disability*, July 2009.

Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S., Evison, F. and Glover, G., *People with Learning Disabilities in England 2011*, 2011.

Giraud-Saunders, A., *Mental health in people with learning disabilities*, Foundation for people with Learning Disabilities, 2011.

Goldbart, J. And Caton, S., *Communication and people with the most complex needs: what works and why this is essential*, July 2010.

Mencap, *Wills and trusts: leaving money to someone with a learning disability*, undated.

Ministry of Justice, *Court experience of adults with mental health conditions, learning disabilities and limited mental capacity*, Report 2: *Before court*, July 2010.

National Policing Improvement Agency guidance on *Responding to people with mental ill health or learning disabilities*, 2010.