

Delivering legal rights: practical problem solving

End of Grant Report January 2020

This report summarises the achievements of the Cerebra Legal Entitlements and Problem-Solving Research Project for the period January 2016 – December 2019. As such it constitutes the end of grant report: Cerebra having generously supported the programme at the School of Law, Leeds University for the last 4 years.

Cerebra and the University have now concluded an agreement for further grant funding, to run from January 2020 to December 2022. For this reason this report looks forward as well as describing the last four years of the programme.

1. Background to the Cerebra Legal Entitlements and Problem-Solving Research (LEaP) project

The laws of the four nations of the UK place enforceable duties on public bodies to provide education, health and social care support for disabled children and their families.

The research evidence suggests that disabled children and their families experience considerable difficulties in accessing these rights and in consequence, in accessing good quality health, social care and educational provision.¹

In 2013 Cerebra funded a pilot programme at Cardiff Law School, overseen by Professor Luke Clements, to identify accessible and effective procedures that could enable disabled children and their families to maximise the benefit of their legal entitlements.

The programme identified a number of commonly occurring problems encountered by families when seeking to access these rights. Utilising undergraduate and postgraduate law student volunteers, the programme also provided tangible evidence that effective mechanisms could be developed to

¹ See for example, S Broach and L Clements *Disabled Children: A Legal Handbook* (Legal Action Group, 2019) paras 1.48 – 1.55.

address a number of these problems and thereby lead to material improvements in the well-being of many disabled children and their families.

In 2014 Cerebra awarded a research grant to Cardiff Law School to develop the programme – entitled the ‘Legal Entitlements Research Project’. Initially the project produced ‘Digests of Opinions’² that detailed the law in relation to specific problems that had been drawn to the attention of the Cerebra in-house research team. The experience gained during the early phase of the research led to the refinement of the programme, with subsequent reports considering generic issues – such as challenges encountered by disabled children and families in accessing ‘short-break’ support.³ The change of emphasis has proved to be of fundamental importance to the programme. Instead of trying to resolve a single problem encountered by a particular family, the approach has been to work closely with the Cerebra in-house research team to identify commonly occurring problems encountered in practice and then to undertake research that identifies:

- the legal entitlements disabled children and families have in the specific area;
- the nature and the extent of the problems that they are encountering;
- a range of responses that can / should be taken to address these problems (which might include, for example, problem solving guides, template letters for families, policy change at Governmental level etc.).

The Cardiff University ‘Legal Entitlements Research Project’ ran for two years, (until 2016). During this period, in addition to the publication of the ‘Digests of Opinions’ and a generic report concerning the provision of short-breaks support⁴ the project also:

- obtained a co-funded Economic and Social Research Council (ESRC) Doctoral Research grant to recruit a researcher to the programme - Derek Tilley (appointed in September 2014);
- obtained an ESRC Impact Acceleration Grant to develop a ‘Problem Solving Toolkit’ and train regional ‘Family Research Ambassadors’; and
- motivated Mencap Cymru to fund a similar project with the Cardiff Law School developing generic tools to address commonly occurring problems encountered by adults with learning difficulties.

In 2016, with Professor Luke Clements’ move to the School of Law at Leeds University, Cerebra transferred the grant support from Cardiff to Leeds University. It was agreed that the Leeds research programme (renamed the Cerebra Legal Entitlements and Problem-Solving (LEaP) Project) would operate along similar lines to that developed at Cardiff. The project would, in particular, build on the close collaborative relationship that it had developed with the Cerebra in-house research team.

In July 2016 Sorcha McCormack (now Dr Sorcha McCormack) joined the Leeds programme as a Research Assistant. In 2018 Sorcha moved to take up a full time lectureship at Leeds Beckett University. In 2019 Dr Ana L Aiello joined the

² Copies of these opinions are accessible at www.cerebra.org.uk/research/university-of-leeds-cerebra-legal-entitlements-and-problem-solving-project/student-research-projects/

³ *ibid.*

⁴ S Howley, B Thorne & L Clements *Local Authority Short Breaks Statements Accessibility and Accuracy* (Cerebra 2016).

programme – also as a Research Assistant. Ana has a substantial and impressive background working for a number of international non-governmental bodies and universities in Spain, Argentina and the UK.

2. Research strands

The LEaP Project is described in greater detail below, but in summary its research strands include: (2.1.) support for the Cerebra in-house research team that has direct contact with families seeking assistance; (2.2.) the provision of generic advice; (2.3.) the development and testing of effective problem-solving approaches for families and their advisers; and (2.4.) the dissemination of its research findings to effect change: change to the systems that cause the problems families commonly experience.

2.1. The ‘individual support’ research strand

The Cerebra in-house research team has developed the expertise to provide guidance and signposting information for families who make contact with Cerebra for support. The Leeds University element of the LEaP Project acts as a back-up resource for cases where additional input/advice is required by the in-house research team. Professor Luke Clements and the LEaP Project Co-ordinator liaise on a regular basis and each month they review the range of questions and problems that the support line has been asked to consider. Individual cases of this kind are of vital importance to the research: they: (1) help flag up commonly occurring problems families are encountering; and (2) enable an assessment to be made of the effectiveness of the problem-solving methodologies developed by the programme.

2.2. The ‘generic advice’ research strand

Where there is evidence that a particular problem is being commonly encountered by families, the Leeds programme seeks to develop a research project that can (among other things): identify the extent of the problem; the nature and source of the problem; mechanisms for addressing the problem; and strategic action that can be taken to bring about systemic change to reduce or remove the causes of the problem.

The succeeding paragraphs contain an outline of the projects undertaken since January 2016. Where possible we collaborate with a local or national organisation who have a particular interest in the specific topic. A notable local non-governmental organisation with which we have partnered on two studies (concerning home adaptations for disabled children) is ‘The Access Committee for Leeds’. In relation to the school transport research project we worked closely with the national charity ‘Contact’ and a 2020 project involves close collaboration with the Disability Law Service (London) and the BBC.

2.2.1. Local authority ‘home to school’ transport policies

A 2017 research study concerning the provision by local authorities of 'home to school transport' illustrates how this strand of the LEaP programme works. The Cerebra in-house research team was contacted by many families who had been denied free 'home-to-school transport' by their local authority. On analysis it appeared that a number of authorities were operating policies that did not properly reflect the relevant law and Central Government guidance.

A team of 12 student researchers analysed the websites of 71 English local authorities to assess the accuracy and accessibility of their information concerning school transport rights. They found that a high proportion of these sites were providing inadequate and/or misleading advice. The resulting report⁵ (as with all the outputs from the LEaP programme) contained a guide to the applicable law and policy; identified the nature of the problem; made suggestions concerning effective approaches to address these problems; identified good practice; highlighted areas where the law / national policy was not being followed; and provided recommendations for improving statutory sector practice.

The report identified the need for local authority websites to be updated to ensure they all contained accurate information; for local authority policies and practice to be reviewed to ensure they complied with the law; and for local authority staff working in this field to have update training to ensure they understood the extent of their legal obligations to families. The report noted that, given the extent of the problem and the likelihood that authorities would be slow (if not resistant) to make these changes – that action had to be taken by the Secretary of State for Education to: (1) update the relevant guidance; and (2) if needs be, to compel recalcitrant authorities to comply with the law and guidance by exercising her 'default' powers under section 497 of the Education Act 1996.

A conference to disseminate the findings of the research report attracted a national audience, including NGOs with similar concerns about the non-provision of school transport support and representatives of local and national government. Shortly thereafter the LEaP team was asked to discuss our concerns with the Department for Education and thereafter revised draft guidance was shared with us, upon which we submitted detailed comments (September 2018). We were hopeful that the resulting guidance would be more accessible, more directive (for example about website information) and would lead to a significant improvement in local authority action in this field. However as at January 2020 (15 months later) the guidance has still not been published – and recent ombudsman reports would suggest that many families are still encountering severe problems with local authority school transport decision making. We must now consider what further steps to take to address this failing. This might include – for example, a follow up report as well as asking for assistance from the Education Select Committee on this question.

What we can learn from the above example, is that the impact of generic reports may often be 'slow burn' – i.e. be measured in years rather than weeks.

⁵ L Clements and S McCormack [Local Authority Home to School On-line Transport Policies: Accessibility and Accuracy](#) (Cerebra 2017).

2.2.2. Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants

The length of time taken for LEaP research to generate a significant impact is evident from a project undertaken in 2016 concerning the costs / benefits of adaptations for children with autism accompanied by behaviour that is significantly challenging.⁶ The research involved a qualitative and quantitative analysis of the experiences of six families who were waiting for or who had recently succeeded in obtaining support for necessary adaptations. 18 pro bono students from the Schools of Law and Media Studies volunteered to take part on the research. The families were identified and supported by our excellent local partner 'The Access Committee for Leeds'.

The report on the research findings demonstrated that substantial cost savings resulted from the payment of a one-off 'Disabled Facilities Grant' (DFG) by a council. The report was welcomed by the Chief Executive of the authority in whose area it was undertaken and in the following year the report was cited at length by a House of Commons Library Briefing Paper.⁷ Later that year it was also cited extensively by a Research Review report commissioned by the Department of Health and Social Care.⁸ The English Government has indicated that action concerning adaptations to address the needs of disabled people will be detailed in a forthcoming social care Green Paper.

2.2.3. Direct payments for disabled children and their families

The Cerebra in-house research team in its contact with families has encountered considerable dissatisfaction with the administration by local authorities of 'Direct Payments': payments made to families to enable them to purchase support services to meet their eligible social care needs. Evidence of this dissatisfaction also surfaced during the 2016 research into the costs / benefits of adaptations for children with autism.⁹ Many families who contributed to the 2016 research explained that although obtaining an adaptation had enabled their disabled children to remain living with them, it had not provided to be 'transformative': other failures by the statutory sector meant that the family was still barely coping. One parent explained that they still felt like they were living on a 'cliff edge'.

A key problem was the fact that the Direct Payments they were being offered were of insufficient value to enable them to purchase sufficient specialist care to enable them to care for their disabled child and also live 'ordinary' lives. The research involved 16 Law School students making Freedom of Information requests to 60 social services authorities in England, about their hourly Direct Payment rates for disabled young people and disabled adults. The final report (which benefitted greatly from expert input by Dr Sarah Woodin) revealed that

⁶ L Clements and S McCormack [Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants](#) (Cerebra 2017).

⁷ House of Commons Library Briefing Paper '[Disabled facilities grants for home adaptations](#)' (July 2018).

⁸ S Mackintosh and others [Disabled Facilities Grant \(DFG\) and Other Adaptations –External Review](#) (2018).

⁹ L Clements and S McCormack [Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants](#) (Cerebra 2017).

(among other things) the rates at which Direct Payments were made were very low (typically at minimum wage rates) and that as a consequence there was in many areas a serious 'market failure' – such that authorities are arguably in breach of their statutory and public law obligations to families with disabled children.

2.2.4. The accessibility of disabled facilities grants application forms

The 2016 research (noted above), concerning the costs / benefits of adaptations for children with autism,¹⁰ identified an additional and important issue concerning the processing of the grants that facilitate these adaptations. The issue concerned 'delay'. The 2016 research identified the need for adaptations to be expedited – to minimise the risk of the disabled child becoming 'Looked After' by the local authority. Although a statutory timetable for the processing of disabled facilities grants (DFGs) exists, it became apparent that some local authorities were not making the application forms available to families – and thereby frustrating the statutory timetable.

The research was assisted by 11 pro bono students who sent Freedom of Information Requests to 54 housing authorities concerning their policies of making application forms available to potential applicants. It revealed (among other things) that almost 50 per cent of housing authorities failed to make copies of their application forms freely available and of those that did, only 7 per cent did so by placing them online.

This research (as with the 2016 DFG research) was cited by a Research Review report commissioned by the Department of Health and Social Care.¹¹ The English Government has indicated that action concerning adaptations to address the needs of disabled people will be detailed in a forthcoming social care Green Paper.

2.2.5. Disability related expenditure and pets care costs

In 2017 the pro bono unit at the School of Law was contacted by a number of people expressing concern about the dilemmas faced by disabled people and their families regarding the impact of local authority charging policies. The problem concerned the difficulty they were experiencing in paying local authority care charges in addition to paying for their basic living costs and the costs of keeping a much loved pet. Hardship of this kind appeared at odds with the many references to the well-being impact of pet ownership by those advocating the advantages of personal budgets. Since there appeared to be no relevant research or formal policy guidance on this issue it was decided that this topic should be investigated by student pro bono volunteers at the School.

The research involved 12 Law School students making Freedom of Information requests to 55 social services authorities in England. In essence these authorities were asked to state whether their community care charging policy

¹⁰ L Clements and S McCormack [*Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants*](#) (Cerebra 2017).

¹¹ S Mackintosh and others [*Disabled Facilities Grant \(DFG\) and Other Adaptations –External Review*](#) (2018).

allowed recipients to retain enough of their income to pay for reasonable expenditure incurred in feeding and maintaining a household pet cat or dog.

The research¹² found that no local authority had a formal policy concerning the disregard of pet ownership expenses and that 89 per cent of authorities indicated that pet care costs would not be taken into account 'in any circumstances'.

2.2.6. The local government and social care ombudsman approach to delay in complaints made by disabled children and their families

In the autumn of 2018 56 School of Law students analysed all the social care reports made by the local government and social care ombudsman (LGSCO) in the preceding 12 months (almost 1,300 reports in total). This research also resulted from evidence gained by the Cerebra in-house research team of the problems families had experienced: of delay in obtaining justice when complaining about local authority failings. This is a major research project on which the LEaP Project has also had financial support from the School of Law to fund research concerning the financial cut backs experienced by the ombudsman as well as *pro bono* research undertaken by the School of Law alumnus (now at the New York bar) concerning the treatment of 'delay' in Constitutional / Supreme Courts as well as by Human Rights Committees.

The report¹³ was launched at a major LEaP Conference held in Leeds in November 2019. It revealed serious (and systemic) failings in the way that a number of English councils investigate children's social service complaints. It noted that in over 60 per cent of the cases where the LGSCO found fault with a council's complaint handling, no recommendation for compensation for the delay was made (despite the average delay (from the initial complaint to the LGSCO's report) being 345 days). In the remainder of cases, where compensation was recommended, the average time amounted to 572 days and the average compensation amounted to 30p per day. As the report concluded, the complaints regime rewarded councils that maintain dysfunctional complaints systems, as the penalties for such poor behaviour are either minimal or non-existent.

2.3. Developing and testing 'what works' techniques

A theme that runs through the entire LEaP research programme is the continuous analysis of the effectiveness of the programme's problem-solving interventions. The insights and understanding that emerge from this iterative process are then used to refine the support approaches given to individuals (and the dissemination materials such as the 'Toolkit' – see below).

The object of this strand of the research programme is to better understand why problems occur concerning the discharge by public bodies of their statutory functions and to identify practical and effective processes by which these

¹² L Clements and S McCormack [Disability related expenditure and pets care costs](#) (Cerebra 2018).

¹³ Luke Clements and A L Aiello [Unacceptable delay: Complaints procedures for disabled children and their families](#) (Cerebra 2019).

problems can be addressed. The aim being to minimise the harm to the well-being of disabled children and their families caused by inappropriate public sector policies and practices.

The programme now has six years of data relating to the advice and support provided to individuals. The research seeks to learn from the experiences of these individuals and thereby to refine the problem-solving techniques and make them more effective.

2.4. Education and dissemination

In 2015, in order to increase awareness of the research findings, an ESRC 'Impact Acceleration' Award was obtained to: (1) develop a 'Toolkit' that summarised the main problem-solving approaches that had emerged from the research; (2) recruit and train eight 'Family Research Ambassadors' to disseminate the research to their wider communities; and (3) hold a series of regional seminars to bring the research findings to as wide an audience as possible.

The resulting publication, the '*Accessing Public Services Toolkit*' (now in its third edition) would appear to have been a great success both in terms of the numbers of printed copies that have been disseminated and the numbers downloaded from the Cerebra website (see page 11 below for data on the dissemination of the Toolkit). In addition Cerebra has received many positive comments from families as to how the Toolkit has enabled them to obtain the support they had been seeking. In 2017 Cerebra was contacted by parents in Scotland and this resulted in the publication of a Scottish version of the Toolkit. Cerebra has also been asked to support regional events to discuss and explain the problem-solving techniques described in the Toolkit. These have taken place in England, Wales and Scotland (see page 11 below for further details).

The LEaP project provides support and advice to the Cerebra in-house research team concerning (among other things) the legal information guides it publishes. In the first months following the project's move to Leeds, this included the commissioning of a guide (written by Sarah Westoby) on the law in Wales concerning the Social Care rights of disabled children and their families (to coincide with the 'coming into force' of the Social Services and Well-being (Wales) Act 2014).

Part of the LEaP project's programme of research dissemination / critical engagement includes the holding of conferences where we publicise our research findings, provide up-to-date and relevant information on the rights of disabled people and their carers, and explore with disabled people's and carers' support organisations practical and effective ways of resolving commonly occurring problems in accessing health, social care and education entitlements. Since January 2016 there have been four such events: 19th January 2016 at Birmingham; 15th April 2016 at Leeds; 12th July 2017 at Leeds; and 19th November 2019 at Leeds.

3. Conclusions

The research undertaken between 2016 – 2019 has been impressive and the findings of direct relevance to all families with disabled children. As noted above, taking these findings forward to bring about systemic / structural change is a major challenge for the LEaP project. While it is clear that changing law and policy takes time – the issue of ‘impact’ is central to the project. It follows that although we take on new research programmes each year, we do not lose sight of the need for practical implementation of the findings of previous research studies.

What the research also makes plain is that families with disabled children don’t have single legal problems. At any one time it is likely that they will have many overlapping problems: problems relating to home adaptations, school transport, social care support, health assessments, equipment and therapies and so on. No sooner has one problem been addressed, than a new one will be encountered, to fill its space. The most that we can hope to achieve through the LEaP project is to remove some of these ‘commonly occurring’ problems.

Appendix 1

Publications

LEaP project publications 2016 – 2019

- The English (third edition) and Scottish (first edition) of the '*Accessing Public Services Toolkit*' to support disabled children and their families who experience difficulties in relation to health, social care or other support services. The English report is written by Professor Luke Clements and the revisions to align the Toolkit with Scottish Law were written by Donna M Morgan;
- *Social Care in Wales A Guide for Parents* (Cerebra 2017) [in Welsh and in English] commissioned by the LEaP project and written by Sarah Westoby;
- *Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants* – Professor Luke Clements and Sorcha McCormack (Cerebra 2017);
- *Local Authority Home to School On-line Transport Policies: Accessibility and Accuracy* – Professor Luke Clements and Sorcha McCormack (Cerebra 2017);
- *Why investing £60k in home adaptations saves public money* – Professor Luke Clements Guardian on-line 26th July 2017;
- *Disability related expenditure and pets care costs* – Professor Luke Clements and Sorcha McCormack (Cerebra 2018);
- *The accessibility of Disabled Facilities Grant application forms in England* – Professor Luke Clements and Sorcha McCormack (Cerebra 2018);
- *The Positive impact of disabled facilities grants* – Professor Luke Clements Legal Action' September 2018 p.7;
- *Direct Payments for Disabled Children and Young People and their Families* – Professor Luke Clements, Dr Sarah Woodin, Sorcha McCormack and Derek Tilley (Cerebra 2019);
- *Unacceptable delay: Complaints procedures for disabled children and their families* – Professor Luke Clements and Dr Ana L Aiello (Cerebra 2019).

Appendix 2

Toolkit data – December 2019

Printed copies

Since the launch of the first Toolkit in February 2016 Cerebra has had 3,740 copies printed.

Website downloads

- English Toolkit: 39,803 downloads;
- Scottish Toolkit: 559 downloads.

Workshops

From June 2016 to December 2019, there have been a total of 84 workshops. At these 84 workshops there have been 908 attendees (an average of 11 per workshop). Of these 84 workshops, 7 have been repeat bookings.

Feedback includes:

- I felt completely informed, empowered and fully confident to confront social services after attending the workshop and reading your excellent Toolkit, thank you so much! I wrote a letter of complaint to my Local Authority and I followed all of your advice to the letter. Within a short timeframe my complaint was successfully upheld, I received an apology and have also (as a result of my letter), been invited to work alongside them to reform their processes for future! I am so grateful to you as I could never have done this before the workshop or without the Toolkit.
- Thank you and for providing the really informative workshop this morning. I think I speak for all that attended these workshops are lifelines for many parents.
- By far the best workshop I been to, the relevance was amazing, delivered in a personable, realistic approach. Much appreciated by those of us that hugely identify with these difficulties!!

Not included in these workshop figures are the presentations that Cerebra has delivered on the Toolkit at events which include:

- Kidz to Adultz Exhibitions:
 - Edinburgh on 14th September 2017;
 - Coventry on the 15th March 2018;
- Tuberous-Sclerosis Society on 9th July 2017;
- Rubinstein Taybi family day on the 15th July 2017 in Birmingham;
- Advocacy Conference, Birmingham on 19th October 2017;
- TSA Scotland Conference on 31st August 2019.

Appendix 3

Cerebra In-house Team

Publications 2016 – 2019

- *Education in Wales Guide* – Derek Tilley, LEaP Senior Development Officer (June 2016);
- *School Transport in England Guide* – Carys Hughes, LEaP Co-ordinator (September 2016);
- *What to do if your child's care package is reduced factsheet* – Cary Hughes, LEaP Co-ordinator (June 2017);
- *What to do if your child isn't getting the social care support s/he needs factsheet* – Carys Hughes, LEaP Co-ordinator (June 2017);
- *School Transport in Wales Guide* – Carys Hughes, LEaP Co-ordinator (November 2017);
- *Carers' Assessments in England factsheet* – Derek Tilley, LEaP Senior Development Officer (January 2018);
- *Carers' Assessments in Wales factsheet* - Derek Tilley, LEaP Senior Development Officer (January 2018);
- *Transition in England factsheet* - Derek Tilley, LEaP Senior Development Officer (January 2018);
- *Transition in Wales factsheet* - Derek Tilley, LEaP Senior Development Officer (January 2018);
- *Disabled Facilities Grant factsheet* - Derek Tilley, LEaP Senior Development Officer (April 2018);
- *Assessment of Continence Needs mythbuster* - Carys Hughes, LEaP Co-ordinator (July 2019);
- *How to complain about social services in England infographic* - Carys Hughes, LEaP Co-ordinator (September 2019);
- *Suite of over 40 template letters to download and use* - Carys Hughes, LEaP Co-ordinator (2016 - 2019);

In-house team successes 2016 – 2019

- In-house team invited to comment on the Department of Education's draft of the revised school transport in England guidance;
- Secured changes to a number of local authority's school transport policies;
- Reported to the Equality and Human Rights Commission on disability discrimination in school transport arrangements in Wales;
- Supported complaints to the Local Government and Social Care Ombudsman and the Public Services Ombudsman;
- Persuaded the Welsh Government to revise its existing guidance on continence products;
- Successfully challenged local continence services' decisions;
- Challenged local authority decisions, resulting in the reinstatement of provision such as school transport and social care support / direct payments.