

**Centre for Law & Social Justice  
The School of Law  
Leeds University**

**Legal Entitlements and Problem-  
Solving (LEaP) Project**

**Delivering legal rights through practical problem solving**

**Annual Report for 2024**



## The Cerebra LEaP Leeds Research team

### **Professor Luke Clements, Cerebra Professor of Law**



In 2016 Luke joined the School of Law at Leeds University as the Cerebra Professor of Law & Social Justice.

Luke practised as a solicitor between 1981 and 2021, and has extensive experience of advising disabled people and their carers concerning the rights to social welfare support; he has written widely concerning these rights and provided advice to a number of independent, charitable and public bodies.

### **Dr Ana Laura Aiello Cerebra Doctoral Researcher**



In 2019 Dr Ana Laura Aiello joined the Cerebra LEaP research team at Leeds. Ana studied law and human rights in Argentina, Spain and in the UK (obtaining her PhD at Leeds University). She has worked for a number of international NGOs (including Amnesty International, Disability Rights International and CHANGE) and at universities in Argentina, Spain and the UK. Ana has a sister with learning disabilities and experience of co-working with disabled people in an accessible & inclusive way.

## The Cerebra LEaP in-house research team

### **Beverley Hitchcock**

Beverley is the Acting Head of Research and Information at Cerebra where she additionally coordinates (among other things) the development of the 'Accessing Public Services Toolkit' and the dissemination workshops that consider the Toolkit throughout England, Wales and Scotland (discussed below).



### **Carys Hughes**

Carys is the Cerebra LEaP project co-ordinator. Carys is the Leeds programme's link with the Cerebra in-house research team. Her expertise is pivotal in responding to requests for specialist advice and then identifying commonly occurring problems on which the LEaP team can undertake in depth research.



### **Derek Tilley**

Derek is the Senior Development Officer with the Cerebra in-house research team. Derek's research concerns the barriers that disabled children and their families experience in accessing their legal entitlements to education, health and social care services.



**John Furlong**

John is the Cerebra LEaP project Information and Support Officer. He undertakes case work, workshops and fulfils a policy role within the team. He previously worked as a paralegal in the education department of a legal aid law firm, has volunteered for an SEN charity and campaigned to improve access to education and social care for children with disabilities



**Student researchers**

The LEaP project has again benefitted from the research expertise of our *pro bono* student volunteers – numbering 50 in 2024 and to whom we are most grateful. They will all be named in the research publication that they are helping to produce.

**Particular thanks are due to:**

Dr Alison Tarrant of the School of Law and Politics, Cardiff University, Dr Peter Baker Senior Lecturer of the Tizard Centre, University of Kent, Vivien Cooper OBE of the Challenging Behaviour Foundation, Lucy Fullard of the Parent and Carer Alliance, Donna Kelso of the Staffordshire Parent Carer Voice, Priya Panchal of the Disability Law Service and Fletchers, solicitors.

## Annual Report 2024

### Cerebra Legal Entitlements and Problem-Solving Project

#### Summary of achievements in 2024

1. The collaboration between the LEaP Project team at the School of Law, Leeds University and the Cerebra in-house research team has continued, with the Leeds team:
  - (a) providing expert input concerning specific challenges encountered by families in accessing their legal entitlements;
  - (b) helping to identify commonly occurring problems on which in-depth research can be undertaken at Leeds; and
  - (c) designing and then undertaking in-depth research on a commonly occurring problem: analysing the findings to identify implementation measures and good practice lessons that can reduce the prevalence / impact of these problems.
2. Editing and submitting for publication an edited book '[Understanding Parent Blame: Institutional Failure and Complex Trauma](#)' Luke Clements and Ana Laura Aiello (eds) to be published in 2025 by Policy Press.
3. Finalising the research findings concerning the availability and adequacy of paediatric continence containment products (commenced in autumn 2023) to be published in 2025 by Cerebra.
4. The commencement of a research programme concerning the Systems Generated Trauma experienced by disabled children and their families (including convening a conference at Leeds on this topic).
5. The LEaP Project teams at the School of Law, Leeds University and Cerebra have continued, where practical opportunities arise, to take action to implement the recommendations that have been made in earlier LEaP research reports.

These achievements are considered in more detail in the pages that follow.

## **Annual Report 2024**

### **Legal Entitlements and Problem-Solving (LEaP) Project**

**LEaP is an innovative problem-solving project that helps families of children with brain conditions cope with the legal barriers they face.**

#### **Background**

The laws of the four nations of the UK place enforceable duties on public bodies to provide a range of social welfare supports 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.

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

The pilot research identified a number of commonly occurring problems encountered by disabled children and their families when seeking to access their statutory entitlements. It also provided tangible evidence that effective mechanisms could be developed to address a number of these problems and thereby lead to material improvements in the wellbeing of many disabled children and their families.

In 2014 Cerebra awarded research funding to the project including the endowment of a Cerebra Chair in Law and Luke Clements became the first Law Professor to be awarded a prestigious Cerebra Chair. In January 2016 the research programme moved from Cardiff to the School of Law at Leeds University.

The LEaP project currently comprises three relatively distinct (but interconnected) components, which can be broadly described as:

- (1) research involving individual advice and support;
- (2) research of a specific nature concerning a commonly encountered legal problem (and the dissemination of the research findings); and
- (3) research concerning the practical application of emerging theories of problem solving and 'resilience building' (and the dissemination of the research findings).

#### **1. The 'individual advice and support' research strand**

Since the inception of the LEaP research programme, the Cerebra in-house research team has developed deep expertise in dealing with the vast majority of 'commonly occurring' problems without the need for these to be referred to the Leeds University team. On the rare occasions that it receives referrals on which additional input/advice is required then these are discussed with the Leeds team.

Individual referrals are of vital importance to the research, since the advice that is provided to families incorporates the problem-solving methodologies developed by the programme. This process has identified 'legal confidence' as one of the important elements that enable disabled children and their

families to develop resilience and the ability to persevere with the multiple challenges they face in obtaining their statutory entitlements to health, social care and educational support. This in turn requires that there be a range of high quality, up-to-date and accessible guides to the law. In addition to supporting the development and publication of the *Cerebra* guides, the LEaP Project has provided support for the enlargement of the *Cerebra* '[Template Letters](#)' library – which is one of the best UK based resources of its kind for families seeking to secure access to their legal rights to support.

## 2. Specific research concerning 'commonly encountered problems'.

Analysis of the requests for advice received by the *Cerebra* in-house research team identifies commonly occurring legal problems encountered by families. These problems inform and direct in-depth research by the Leeds LEaP team – with a view to ascertaining their nature and prevalence and the legal context out of which they arise. The purpose of the research is to develop innovative ways of resolving such problems at 'root' – so that (ideally) they cease to be encountered by individual families.

The Leeds team develops a research programme designed to capture relevant data that can be critically analysed in order to better understand the legal/policy causes of the problem, its impact on families and how best the specific 'system' can be changed to reduce (or ideally eradicate) its incidence. The Leeds team is fortunate to be assisted by student volunteers in its initial analysis of the research data.

The involvement and expertise of our *pro bono* student volunteers is not only invaluable for the LEaP programme (in facilitating the collection of a significant 'data set') - it is also considered by the students themselves to be a hugely enriching experience. In this context, students refer not only to the research skills they acquire during the programme but also to the personal insights they gain from witnessing – first-hand – the challenges families experience when trying to access their legal entitlements – and of being able to see the inspirational work undertaken by *Cerebra*. Appendix 3 to this report includes a selection of feedback comments received from the students in December 2024.

During 2024 the Leeds Research Team has researched two such problems.

### 1. The availability and adequacy of paediatric continence containment products in England, Scotland and Wales

The initial data gathering phase of the research study, which commenced in October 2023, was undertaken by 49 *pro bono* student volunteers and has been described in the previous Annual Report.

During 2024 the Leeds research team analysed the data obtained from: (a) a *Cerebra* on-line survey of parent carers (anonymised); (b) Freedom of Information Requests to (among others) all NHS Integrated Care Boards / Health Boards in England, Wales and Scotland; and (c) desktop research of the websites of NHS Integrated Care Boards and Health Boards'. The analysis also considered data provided by the Parent and Carer Alliance, namely: (a) the responses (anonymised) to an online survey the Alliance had initiated on this issue; and (b) interviews (anonymised) the Alliance had transcribed with young disabled adults concerning their experiences of inadequate paediatric continence containment products.



The research report, to be entitled ‘Inaccessible, unacceptable and unaccountable: the provision of paediatric continence supplies in England, Wales and Scotland’ will be published in 2025 by Cerebra.

## 2. Systems generated trauma.

A common theme that runs through all the reports that have emerged from the Cerebra LEaP research programme has been the harm experienced by disabled children and their families when dealing with statutory social welfare ‘systems’: systems that ostensibly exists to ensure that families can access their legal entitlements. We use the phrase ‘Systems Generated Traumas’ to describe this phenomenon – and sadly it is a daily experience for many disabled children and their families. Our research has identified a myriad of intersecting examples, including:

- the barriers erected by local authorities to frustrate applications being made for disabled facilities grants;
- the unlawful reasons given by local authorities to refuse home to school transport requests;
- local authorities threatening parents with prosecution when their disabled child is ‘school refusing’ for impairment related reasons;
- parents in desperate need, being refused essential social care support by local authorities, but then having their home inspected and their children interviewed for child protection purposes;
- parents being accused of fabricating or inducing their child’s illness (FI) because they have (for example) requested a second opinion from a health professional;
- parents being unable ‘to access justice’ to gain redress for the damage done by harmful behaviour of the kind described above.

It was decided in 2024 that a research programme should be undertaken to better understand the nature, the prevalence and the impact of Systems Generated Traumas on disabled children and their families. The research plan involved a number of ‘data gathering’ strands (briefly outlined below) as well as a desktop analysis of a number of English local authority ‘Trauma Informed’ policy documents and the convening of a national conference on this issue.

The ‘data gathering’ strand of the research programme included a Cerebra survey of parent carers’ concerning their adverse experiences when dealing with social welfare systems. The survey attracted over a thousand responses and this data (anonymised) was then analysed by the Leeds research team with the assistance of 50 *pro bono* student advisers. This phase of the research is on-going and will be subject of next year’s annual report. We hope to be in a position to publish the research findings during the summer of 2025.

### Conference

As we note above, one element of the Systems Generated Trauma research programme involved the convening of a national conference on this issue. This was held at Leeds on the 9<sup>th</sup> July 2024 and was made

possible as a result of generous sponsorship from Cerebra, Fletcher's solicitors and the School of Law, the University of Leeds.



### 3. The problem solving and ‘resilience building’ research strand

As noted in previous annual reports, a key objective of the LEaP research project is to critically analyse the knowledge gained from the individual advice and the generic research strands in order to achieve a practical understanding of why commonly occurring legal problems arise and to devise practical mechanisms to overcome these difficulties.

In 2015, with the administrative and organisational support from Cerebra and an ESRC Impact Acceleration Award, a ‘Toolkit’ was prepared that summarised the main problem-solving approaches that had emerged from the LEaP programme. The project included the recruitment and training of eight parents of disabled children (as ‘experts by experience’) to critique drafts of the Toolkit and then to disseminate the research to their wider communities.

In 2017 a new edition of the Toolkit was published (re-titled the Cerebra ‘Accessing Public Services Toolkit’) and in the same year a Scottish Law version of the Toolkit was also published. The Toolkits have been well received by families with disabled children and the Cerebra LEaP programme now runs a rolling programme of seminars / workshops demonstrating how the Toolkit can be used in practice. Details of the dissemination programme are provided as Appendix 2 at the end of this report.

In 2021 the Toolkit designed to support English and Welsh disabled children and their families was further updated.

#### Implementation and impact of earlier research

The LEaP programme has produced a significant number of research reports since its inception. These are listed in Appendix 1. We are conscious that such reports are not ‘self-executing’ and that in order for them to effect real change in practice – ie change that materially improves the experiences of families with disabled children – there is a need for concerted action to ensure that the findings are implemented by the relevant public bodies.

This means that, in so far as our resources allow, we continue to monitor the impact of all our research reports and not simply the most recent. During 2024 we have been involved in a large number of meetings and events with the aim of bringing



about the practical changes that these reports have identified as essential. Examples of implementation work of this kind, include:

#### Home Adaptations & Disabled Facilities Grants (DFGs)<sup>1</sup>

Luke Clements spoke at a national Conference 'Disabled Facilities Children Summit' convened by Foundations (the National Body for DFGs and Home Improvement Agencies) on the 27 July 2024 and since that time has been involved in discussions with English Government departments, NHS England and others with the aim of improving mechanisms for budget sharing between various statutory sector parties.

#### Challenging parent blame practices<sup>2</sup>

The Law Commission's Consultation Paper *Disabled Children's Social Care* (October 2024) makes extensive reference to publications by Luke Clements and Dr Ana Laura Aiello (including 11 references to their 2021 *Institutionalising parent carer blame* report). Key proposals emerging from the 2021 research included the need for there to be a distinct assessment route for disabled children (distinct from the route for children for whom there is credible evidence of neglect or abuse) and that those assessing disabled children should have disability related expertise. Both these proposals have been adopted as law reform recommendations in the Law Commissions Consultation Paper (at Consultation Question 82 p.306 and at Consultation Question 9, p.60 respectively).

During 2024 Luke Clements and Dr Ana Laura Aiello finalised the editing of a publication '[Understanding Parent Blame: Institutional Failure and Complex Trauma](#)' (eds) Luke Clements and Ana Laura Aiello to be published in 2025 by Policy Press. The book contains chapters written by academics, social care activists, lawyers, parents and siblings, on topics such as the prevalence and impact of FII allegations, the challenges posed by the current Data Protection regime to families who seek to have erroneous personal details expunged from their health and social services records, and the blame families experience when in conflict with health, education and social care agencies

#### Challenging current FII guidance<sup>3</sup>

The 2023 research [The prevalence and impact of allegations of Fabricated or Induced Illness \(FII\)](#) suggested: (1) that there was *prima facie* evidence that Royal College of Paediatrics and Child Health '*Perplexing Presentations (PP) / Fabricated or induced illness by carers: A practical guide for paediatricians*' guidance indirectly discriminated against disabled parents; and (2) that there was a compelling need for the guidance to alert practitioners to the traumatising and long lasting impact on parents and other family members, against whom of FII allegations were made. During 2024 Luke Clements and Dr Ana Laura Aiello have worked with a number of organisations and individuals who are seeking revisions to the guidance to address these concerns. This has included preparing

---

<sup>1</sup> L Clements and S McCormack [Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants](#) (Cerebra 2017) and L Clements and S McCormack [The accessibility of Disabled Facilities Grant application forms in England](#) (Cerebra 2018)

<sup>2</sup> L Clements and A L Aiello [Institutionalising parent carer blame](#) (Cerebra 2021).

<sup>3</sup> L Clements and A L Aiello [The prevalence and impact of allegations of Fabricated or Induced Illness \(FII\)](#) (Cerebra 2023).

and submitting an Open Letter to the Royal College asking that it withdraw (and then revise) its 2021 Guidance. The Royal College declined the request, and the Leeds LEaP team is in discussion with interested NGOs and individuals as to how this impasse can be resolved

---

It has been another successful research year and for all of us involved in the *Cerebra* LEaP Project an enjoyable one. I end this report by making very special thanks to everyone at *Cerebra* for the wonderful support we have received.

A handwritten signature in brown ink, appearing to read 'Luke Clements', written in a cursive style.

Professor Luke Clements

## Appendix 1

### LEaP research publications as December 2024

#### Research reports / publications

- 2013 A [Digest of Opinions](#) concerning commonly occurring legal problems that disabled children and their families encounter;
- 2014 A further [Digest of Opinions](#) concerning commonly occurring legal problems that disabled children and their families encounter;
- 2015 A generic research report on the accessibility and accuracy of '[Short Breaks Statements](#)' involving over 40% of English social services authorities;
- 2016 A '[Problem-Solving Toolkit](#)' to support disabled children and their families who experience difficulties in relation to health, social care or other support services;
- 2017 [Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants](#);
- 2017 [Local Authority Home to School On-line Transport Policies: Accessibility and Accuracy](#);
- 2017 A new edition of the '[Problem-Solving Toolkit](#)', renamed as the [Accessing Public Services Toolkit](#);
- 2017 [Accessing Public Services in Scotland: A problem-solving toolkit](#);
- 2018 [Disability related expenditure and pets care costs](#);
- 2018 [The accessibility of Disabled Facilities Grant application forms in England](#);
- 2019 [Unacceptable delay: Complaints procedures for disabled children and their families](#);
- 2019 [Direct Payments for Disabled Children and Young People and their Families](#);
- 2020 [Unlawful restrictions on the rights of disabled children with autism to social care needs assessments](#).
- 2021 [Institutionalising parent carer blame](#).
- 2022 [An impact snapshot on the unlawful restrictions on the rights of disabled children with autism to social care needs assessments 2022](#) .
- 2022 [Challenging Parent Carer Blame: Interim research report 1: Disability and human rights training and guidance for disabled children's assessors](#) .
- 2023 [The prevalence and impact of allegations of Fabricated or Induced Illness \(FII\)](#).

## Appendix 2

### Toolkit data – December 2024

#### Printed copies

Since the launch of the first Toolkit in February 2016 Cerebra has had 4,940 copies printed.

#### Website downloads

- English Toolkit: 44,016 downloads;
- Scottish Toolkit: 733 downloads.

#### Workshops

From June 2016 to date, there have been a total of 115 workshops with a total of 1,156 attendees (an average of 10 per workshop).

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!!*
- *'It was very informative, with lots of information provided both prior to and in the session. It was pitched well for the audience and the presenter was very engaging.'*
- *'I felt very empowered and ready to fight for my children's needs. I am honestly shocked how far I have got since January this year and all of our success stories.'*

Not included in these workshop figures are the presentations that Cerebra has delivered on the Toolkit at Conferences and other themed events / exhibitions.

#### Comments on the casework have included:

- *'We wanted to express our gratitude for your help and effort to sort out our Travel Assistance application process. Your support means the world to us as parents, thank you!'*
- *'I would just like to say thank you for all your help and support during DFG process I could not have managed it without you.'*

## Appendix 3

### Student feedback responses – December 2024

The feedback provided by the students participating in the 2024 Cerebra *pro bono* Research Programme has been (once again) extremely positive and rewarding. Below are a few extracts from their feedback:

- *'I enjoyed the experience of analysing the survey responses and the confidence given by Ana and Luke on our analysing report.'*
- *'Every session I learn something new after hearing from different people and it leads me to think about the reliability of laws in the area and broader issues.'*
- *'The stories and valued experience shared by Ana and Luke, it helped me understand deeply about the challenges in this legal field and the meaning of our work.'*
- *'The work was very interesting and rewarding. I enjoyed reading the survey answers and gaining insight into the issues people face. It felt worthwhile and like I was making a positive contribution. I would definitely join Cerebra again.'*
- *'I enjoyed being immersed into a different type of law that I have not learned in my actual modules, now recognising the impact of families with disabled children. In a way it felt personal and touching to hear all of the stories, seeing the struggles of people in real time. It's often easy to forget when reading behind the textbooks and cases, that there's a story behind each individual.'*
- *'The feeling of accomplishment at the end of the experience was extremely rewarding.'*
- *'It has been such a great experience. It helped me step out of my comfort zone, work with strangers who became teammates and collaborate on meaningful projects aimed at contributing to society, especially supporting families facing systemic challenges.'*
- *'This experience has left a lasting impact on me, strengthening my belief that compassionate academics and activists like your team will never give up on creating change.'*