Improving Support for Parents with Learning Disabilities in Brighton & Hove
Submission to Brighton & Hove Fairness Commission

Parents with learning disabilities are legally entitled to support to be able to fulfil their parenting role and meet the ‘good enough’ standard of parenting.

In Brighton & Hove the current system often does not provide or enable such support.

Parents with learning disabilities are put through an assessment system that is not adjusted to reflect their disability, which most are destined to fail.

As a result their children are removed and put into care at great personal cost to both parent and child, and at great financial cost to the Local Authority.

We propose Brighton & Hove City Council introduce ways of supporting parents with learning disabilities proven in other local authority areas.

The safety of the child is always paramount. Nothing that we are proposing would override that.

Interact is an Impetus service which provides specialist independent advocacy to parents with learning disabilities. Between 2013 and 2015, of the clients that we supported:

- 78% of cases went on to care proceedings
- 100% of these cases resulted in the removal of the child
- 26% of clients had previously had a child removed
- 56% report suicidal ideation or attempts related to the case following care proceedings

In this submission we summarise the issues discussed at our Fairness Commission event on 20th January 2016. The event brought together a leading lawyer and the leading academic in the field, practitioners from a comparable local authority area, and local professionals and colleagues working with parents with learning disabilities and their families. In this submission we provide:

- a short documentary film of one individual’s experience in Brighton & Hove (view at [youtu.be/eeX9VPUOibQ](youtu.be/eeX9VPUOibQ))
- an overview of the legal framework establishing rights of parents with learning disabilities (p.2-3)
- the economic case for alternative approaches, tested elsewhere and verified by academic research (p.3-7)
- our recommendations to the Fairness Commission (p.8-9)
- case studies of advocacy time spent and saved (p.10-11)
Summary of relevant Law, Policy & Good Practice


- Article 14 - Right to enjoy rights within the convention without discrimination of any kind.
- Article 8 - Right to respect for private and family life. The state can only interfere with family life if it is necessary for the safety of others
- Article 6 - Right to a fair hearing (includes court cases and the process leading to a court case meetings, case conferences etc)

Equality Act 2010

- S.29 Duty to provide a service without discrimination and to make reasonable adjustments
- S.149 Duty – elimination of discrimination and promoting equality of opportunity

DFES/DOH Good practice guidance on working with parents with a learning disability
(2007, update to be published in 2016)

Five key features of good practice in working with parents with learning difficulties;

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


Article 23 (2) “States Parties shall ensure the rights and responsibilities of persons with disabilities...in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities”

Article 23(4) protects the right of the child not to be removed on the basis of the disability of either the child or the parents.

Care Act 2014 (Summarised from Care Act training with solicitor Cate Searle)
Entitlement to support if:
Long term disability and support need relating to two Outcomes or more, without which there would be a negative impacts on individual’s well-being.

The Outcomes include:
- Maintaining family relationships
- Carrying out caring responsibilities for a child

**Economic Case for change**

**Today**
We calculate that the cost in Brighton & Hove of the current assessment and legal process - with advocacy support, if the parent fails to prove they can meet the needs of the child without parenting support - is as much as £74,371 per parent with a learning disability, per removal of a child. The figure of £74,371 is based on:

<table>
<thead>
<tr>
<th>Description</th>
<th>Cost Range</th>
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<tbody>
<tr>
<td>The PSSRU cost analysis which sets out the costs of assessment and a care package that results in the parent being able to care for their child after 3 months (full details in the table on p.8)</td>
<td>£37,109</td>
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<tr>
<td>In the case of our clients, the mother and baby placement is extended from 3 months to 9-12 months</td>
<td>£16,800 - £25,200</td>
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<tr>
<td>Final court hearing 3-5 days</td>
<td>£7,237 - £12,062</td>
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<tr>
<td>Total</td>
<td>£61,146 - £74,371</td>
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These costs are often repeated as many parents go on to have another child. Recurrent care proceedings are common: 1 in 3 proceedings in UK courts in 2014 involved a mother that had previously had a child removed, with the average time before re-presenting in court being 17 months1. In Brighton & Hove, 26% of Impetus parenting advocacy clients alone have had a child removed in previous child proceedings.

This cost does not take into account the costs of adoption, fostering, or special guardianship for the child. The PSSRU (Personal Social Services Research Unit, made up of LSE, University

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of Manchester and University of Kent) reports these to be up to £85,045 p/a\(^2\), or the costs of the ongoing support that the parent will require to deal with the emotional, practical, and health impact of their child being removed.

Our clients often require an extended assessment process which represents further 6-9 months of support in a mother and baby placement. It is difficult (due to the structure of the PSSRU report) to estimate the additional costs to BHCC and local health agencies of support during this period, so it has not been included in these costs, although it would be incurred.

**The Alternatives**
Medway is a comparable area to Brighton & Hove, with a population of 271,105 (ONS, 2014). It is also a unitary authority in the South East. Medway Council’s Valuing Parents Support Service (VPSS) has been used as a basis for costing this alternative approach. This provides specialised support to parents with learning disabilities to meet the legal standard of ‘good enough’ parenting, allowing the family to remain living together.

The Medway VPSS has been independently evaluated by researchers at University of Bristol. The PSSRU report assessed the service’s costs at £8,450 per family per year\(^3\).

Parents with learning disabilities, once identified by the ACAS (Advice, Contact and Assessment) team are assessed using PAMS (Parenting Assessment Manual Software, a specialist parenting assessment tool designed for parents with learning disabilities) to highlight their strengths and weaknesses in parenting.

The information then informs a **personalised parenting support plan**, put in place to ‘fill the gaps’ to enable parents with learning disabilities to meet the ‘good enough’ standard of parenting. Parents with learning disabilities are then tested to see if they can meet the needs of their child with this long-term support package.

If successful this intervention would ensure the local authority is meeting its legal obligations and would remove significant costs from the £74,371 package which ends in removal of the child.

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\(^2\)Unit Cost of Health and Social Care, Curtis L, PSSRU (2014) p.95

\(^3\) The total budget for VPSS was £253,440, for 30 families that had been supported as at the date of the study; the budgeted cost of providing the VPSS per family was £8,450. Costs of the full care package could not be derived from the research but a range of information was available for the group as a whole that indicated substantial care package costs. For example, 91% of children were subject to a legal intervention; 22% had a Public Law Outline, 19% were on a child protection plan, 19% had a care order, 13% had an interim care order; for 7% care proceedings were ongoing; one was under special guardianship and one a supervision order. The VPSS had referred families to parenting groups and programmes, drug and alcohol treatment, social work family finding team, speech therapist, debt and benefits advice, advocacy for the child, Shared Lives, tenancy support, domestic violence services, mental health and contraception services.
<table>
<thead>
<tr>
<th>Costs eliminated</th>
<th>£7,237 - £12,062</th>
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<tr>
<td>Final Court Hearing 3-5 days</td>
<td></td>
</tr>
<tr>
<td>Mother and baby placement 9-12 months</td>
<td>£25,200 - £33,600</td>
</tr>
<tr>
<td>Care proceedings (4 x 1-hour hearings)</td>
<td>£4,825</td>
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<tr>
<td>Social Services legal activity for Children in Need</td>
<td>£2,358</td>
</tr>
<tr>
<td>Total Savings per case</td>
<td>£39,620-£53,025</td>
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PAMS assessments have been used for some time in Brighton & Hove, but have often only been used to demonstrate shortcomings, instead of identifying support needs. We are pleased to hear that BHCC are reviewing the way they use these assessments. We have also offered to help adapt paperwork to be suitable for our clients, and look forward to working with the council on this.

**Shared Lives**

For some parents the Medway Valuing Parents approach will still not offer sufficient support, so a Shared Lives placement should be considered, especially in cases where sexual or domestic violence prevents the mother’s existing home and family network from being a suitable environment. Shared Lives already exists in Brighton & Hove for adults with learning disabilities, but is not currently considered an option for parents with a learning disability.

Shared Lives placements are an ongoing cost, but offer a cost-effective alternative to situations where long-term fostering has been the outcome of removal. Brighton & Hove budget papers 2016-17 state that Shared Lives is ‘good value for money’⁴.

In a Shared Lives placement, an adult who needs support and accommodation becomes a regular visitor to, or moves in with, a registered Shared Lives carer. Shared Lives provide long-term support to parents and their children, who become a part of the carer’s supportive family. It can also be used as an interim solution before the parent and child move to a permanent placement or home of their own.

The PSSRU report estimated costs of a Shared Lives package including specialist parenting support is £47,738 per year⁵, though it should be remembered that a fostering or special guardianship package can be up to £85,045 per year.

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The Wider Picture
Currently figures for the total number of parents with learning disabilities in the city are not available, but extrapolating from national figures we would expect there to be approximately 430 such parents in the city. Nationally over 40% of those parents have their children removed.\(^6\)

Brighton & Hove has an above average number of children in care. Numbers from the BHCC City Snapshot show that in 2012/13 there were 445 looked after children in the city, a figure 87% higher than the South East region average.\(^7\) 445 cases of removal represents a cost of £20 million to the city.\(^8\) The same report shows that the Brighton & Hove figure for Child In Need cases is also 37% above the South East average, and 74% above the South East average for child protection plan cases.\(^9\) Figures also indicate that this cohort is constantly changing. Nationally there were 99,230 looked-after children in 2014/15; 76,030 of these were new placements.\(^10\)

Support for parents with learning disabilities does come at a cost, but this submission demonstrates that there is significant scope for making financial savings through adopting approaches that support parents rather than remove children. In cases supported by Medway’s VPSS 87% of parenting needs were shown to be fully or partially met, at a cost of just £8,450 per family per year.\(^11\) Furthermore, the analysis by the Norah Fry Institute shows that just 37% of parents need to be successfully supported in this way to show a return on the investment in the service.

Risk of Litigation
A further cost is also emerging in the form of compensation claims, which legal professionals tell us are becoming increasingly common. In October 2015 in the case of Williams & Anon v London Borough of Hackney, a husband and wife successfully sued the local authority for unlawfully removing their children, violating their right to family life under the Human

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\(^6\) “Around 40% of parents in the English National Survey of Adults with Learning Disabilities were not living with their children.” Secondary analysis of data from Emerson, E et al, 2005, Adults with learning difficulties in England. 
\(^7\) p.6 Brighton & Hove City Snapshot, 2014
\(^8\) p.44, Unit Costs of Health and Social Care 2010, PSSRU,2010
\(^9\) p.6, Brighton & Hove City Snapshot, 2014
\(^10\) p.4, Children looked after in England (including adoption and care leavers), year ending 31 March 2013: additional tables (Department of Education, ONS), 2015
\(^11\) The most common outcomes were: improvement in parents’ relationships including domestic violence and substance misuse (40%); improvement in parent-child relationship (30%); improvement in confidence of parents in their ability to parent (17%); improvement in home environment and care provided (7%); reduced impact of loss and trauma (33%); reduced impact of parent’s childhood history on parenting (33%)
\(^12\) ‘The economic case for early and personalised support for parents with learning difficulties’ Personal Social Services Research Unit (PSSRU) Discussion Paper (2015) (Bauer) p.13

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Rights Act. Compensation of **£20,000** was awarded after the children were placed in foster care for less than 2 months.

Estimated costs of care package including advocacy per parent, in 2013/14 prices.
Whole table from PSSRU report.\(^{13}\)

<table>
<thead>
<tr>
<th>Costs per year (2013/14 prices)</th>
<th>Source and details</th>
</tr>
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<tbody>
<tr>
<td>Parenting capacity assessments</td>
<td>£1,273 Includes initial contact, referral to children’s social services, initial and core assessments</td>
</tr>
<tr>
<td>Social services legal activity for children in need</td>
<td>£2,358 Refers to Child in Need social care process costs per annum (PSSRU 2014, p171); here it included 5 meetings, 1 hour each per 6 months; meetings were attended by child’s social worker, social work manager, local authority lawyer</td>
</tr>
<tr>
<td>Care proceedings</td>
<td>£4,825 Refers to per case full cost fee for care proceedings (Plowden 2009, Review of court fees in child care proceedings); here this included 4 hearings, 4 hours each over 6 months period; 16hrs</td>
</tr>
<tr>
<td>Tenancy and financial support including housing benefit support</td>
<td>£4,003 PSSRU (2014), for health and social care, (1) debt advice £259 per case (p58); (2) housing benefit £72 per week (p132)</td>
</tr>
<tr>
<td>Health visitor</td>
<td>£520 £65 per hour of visit (including travelling and preparation time); number of visits were not provided; we assumed weekly visits for 8 weeks, 1hrs each; assumption about duration and frequency of visits based on health visiting intervention study for women with postnatal depression by Morrell et al 2009</td>
</tr>
<tr>
<td>Social worker</td>
<td>£923 PSSRU (2014), p99; £55 per hour of client-related work; 22.5hrs</td>
</tr>
<tr>
<td>Mother/ baby foster placement</td>
<td>£8,400 PSSRU (2014), p88; local authority provided foster care for 3 months with weekly costs of foster care of £700</td>
</tr>
<tr>
<td>Family support worker</td>
<td>£1,125 PSSRU (2014), p99; Family support worker £50 per hour of client-related work; 22.5hrs</td>
</tr>
<tr>
<td>Women’s aid</td>
<td>£698 PSSRU (2014), p152; weekly for 3 months</td>
</tr>
<tr>
<td>Advocacy</td>
<td>£12,500 From budget information provided by the project; referred to 22.5hrs</td>
</tr>
<tr>
<td>Total</td>
<td>£37,109</td>
</tr>
</tbody>
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\(^{13}\) *The Economic Case for Early & Personalised Support for Parents with a Learning Disability, A Bauer, PSSRU, 2015.*
Recommendations on improving support to parents with a learning disability

These recommendations are intended to replace the current situation. Savings will be made by adjusting current ways of working. Research suggests that these proposed solutions are likely to be significantly cheaper overall.

1. Establish a joint protocol between Adult Services and Children’s Services for referrals and support service for parents with learning disabilities (as set out in DH Good Practice Guidance on working with parents with a learning disability, 2007)
   
   - If there are any concerns that a parent may have a learning disability a cognitive assessment should be undertaken straight away. Ensure they have access to independent advocacy.
   
   - Establish a new pathway for assessing and supporting parents with learning disabilities which is followed prior to going down the current pathway (if there are concerns a child may be a child in need or at risk of significant harm).
   
   - Pooled funds from Adult Services and Children’s Services to provide specialist support for parents with a learning disability to meet the ‘good enough standard of parenting’ as set out in the Children’s Act 1989.
   
   - Joint team to use PAMS assessment as it was designed to be used: at initial referral to assess the abilities and support needs of the parent, focusing on what the parent can do and what support they need to meet the ‘good enough’ standard of parenting. (Since our event this work has been begun by Children’s Services)

2. Establish a Specialist Support Service for parents with learning disabilities

   - The service should be informed by the Department of Health Good Practice Guidance on working with parents with learning disabilities from 2007 (update to be published in 2016).
   
   - Support Services to parents with learning disabilities should be long term (ideally time unlimited), delivered on a one-to-one basis and done at home.
   
   - Consider examples from Medway Valuing Parents Support Service, Cornwall Special Parenting Support Service and Norfolk County Council.
3. **Extend Shared Lives to parents with learning disabilities (currently available in B&H to adults with disabilities including learning disabilities)**

- If pooled budgets exist this change could be jointly funded by Adult Services and Children’s Services as savings will accrue to both, and improved outcomes will benefit clients of both.

- This option should especially be considered where domestic violence or sexual violence are a factor in the case (89% of Interact caseload disclosed either one or the other between 2013 and 2015.)

- Shared Lives South West has offered support to Brighton & Hove based on its extensive and successful work on Shared Lives for parents with learning disabilities in the South West.

4. **Ensure all staff are fully aware of how the Care Act 2014 applies to parents with learning disabilities, at all relevant stages**

- At the earliest point of identification that a parent has a learning disability, a referral should be made for specialist independent advocacy. This is in line with Care Act duties and as per SCIE Guidance on Care Act 2014.

- All staff who may be the first point of contact for people who have a care and support need should be trained in Care Act duties regarding the right to advocacy for people with a learning disability, how/where to make a referral.

- Specifically, this should include staff at children’s Assessment, Contact and Advice Service (ACAS) and Child In Need (CIN) team. A Care Plan for a ‘child at risk’ or a ‘child in need’ requires the parent to have full understanding of that Plan, which may require advocacy support.

- If required, the local authority has a duty to provide statutory Care Act advocacy to parents with learning disabilities. A Care Plan is part of a statutory (child protection) process.

5. **Increase advocacy capacity for parents with learning disabilities in Brighton & Hove**

- This could be achieved at no additional cost by implementing recommendations 1-3. Services such as those provided by Interact at Impetus and Speak Out’s advocacy service would have a dramatic reduction in the number of hours required to spend on each case. Examples below.
Impetus Advocacy Case Studies

Interact cases can be broadly divided into 3 phases: pre-proceedings, proceedings, and post-proceedings. Analysis of recent Interact cases in each of these phases shows hundreds of hours of advocacy time could be saved:

**Case 1**: A is a mother who has had 3 children previously removed, and was referred to us because her 4th child was considered at risk and the council wished to pursue removal of the child. A maintained that she was unable to participate in the assessment processes because of anxiety, and a lack of reasonable adjustment to the process left her failing and being considered a risk to her child. Over the course of 6 months Interact provided 104 hours of advocacy to A (including support in meetings, travel time, and office time dedicated to the case) to achieve the reasonable adjustments and a package of support. This has resulted in the council withdrawing from legal proceedings.

Had adjustments been made as standard, and support offered from the first meeting, Interact’s involvement could have begun and ended with advocating for A during her Care Act Assessment and Care and Support Planning meetings, saving 90 hours of advocacy. The provision of advocacy and support prevented A from requiring ongoing advocacy during care proceedings.

**Case 2**: Interact was referred B when legal proceedings were initiated to remove the child of B in Jan 2014. Between January and June, when the case concluded, Interact provided over 150 hours of advocacy support, including 5 days support at B’s final hearing. The submission by B’s Barrister at this hearing included the following:

> “The Local Authority has very efficiently identified what B can’t do and the scope of work needed - but we don’t know what B could do if she was taught enhanced parenting skills and had ongoing support.”

Had support been explored before the initiation of care proceedings Interact believes, in this case, proceedings could have been avoided in their entirety. As support was not in place the client was unable to meet the ‘good enough’ standard of parenting, and the child was removed.

**Case 3**: Interact is currently advocating for a parent, C, whose child has been removed to foster care. Unlike in cases of adoption, in fostering cases, there is a need for ongoing advocacy as C has 6 annual visitations with the child and must attend both Looked After Child reviews and Personal Educational Plan reviews, as well as regular meetings with their social worker.
The impact of removing the child also brings up further advocacy issues, and C has required advocacy to access services supporting her mental and physical health, has had 2 suicide interventions, and has required further advocacy around housing and benefits issues due to the change in her circumstances following the removal. Interact has, so far, provided over 75 hours of advocacy to this client since the removal of her child.

Whilst there are many cases where removal of the child is both the correct and unavoidable course of action, in cases where support in the first instance could be provided there is the potential to save over 200 hours of advocacy work, spanning 6 to 24 months. As Case 1 shows, a streamlined route into the support clients are entitled to could allow Interact’s support to be limited to weeks, not years, vastly increasing the capacity of the service to work with many more individuals.

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