

Submission to the Fairness Commission from the Parent Carers' Council

About the PaCC

The Parent Carers' Council (PaCC) is a parent-led forum which represents parent carers with children and young people with any kind of physical disability, learning disability, complex or long-term medical/health condition, or special educational need, in Brighton and Hove. The group was formed to enable parent carers to work closely together to help improve services and support for their children.

The PaCC aims to help parents get more directly involved in the strategic delivery of services for disabled children and now has about 270 signed up members.

We are led by a Steering Group of 12 members where we also have representatives from the city's other key parent groups; mASCot, Kaleidoscope, Barnardos Link Plus, Extratime, Pebbles, Sweet Peas and T21. The PaCC is hosted and supported by Amaze.



Unfairness for families with children who have special educational needs or disabilities

Children and young people (CYP) with SEND experience significant social, financial and educational disadvantage and their families are more likely to experience poverty, relationship breakdown and poor health and wellbeing. These facts and figures have been collated by Amaze.

- On average it **costs 3x more** to bring up disabled child (Joseph Rowntree Foundation)
- Nationally **40%** CYP with SEND live in **poverty** (The Children's Society 2011)
- There is a local correlation between CYP registered on The Compass and the city's most deprived wards - 22% in East Brighton/Moulsecoomb and 15.3% from Hangleton & Knoll and North Portslade - parts of which are in the 10% most income deprived areas in England.
- There is a greater incidence of **family breakdown**, **44%** of parent carers are single parent households (Amaze Parent Carer Survey), which is higher than the latest national figures which say that 25% of families with dependent children are single parent families (from the Office for National Statistics Families and Household Report 2014)
- Children with SEN are **seven times more likely** to be **excluded** from school (Department for Education 2012) and **twice as likely** as other children to be **bullied** at school (Institute of Education 2014)
- More than **20%** of CYP on the Amaze Compass database have been **excluded** from school and **50% have been bullied**.
- **42%** of 20 year olds with SEND are **NEET** (BHCC SEND Review 2015)
- 48% of 19 year olds with a disability have been NEET, with 24% having been NEET for over a year at some stage (House of Commons Library Briefing Paper 2015)
- Disabled young people are **only half as likely** as non-disabled young people to move on to **further education or training**, half as likely to be qualified to degree level, and twice as likely to have no qualifications at all (New Philanthropy Capital 2009)
- By the time disabled people have reached the age of **26**, they are nearly **four times** as likely to be **unemployed** as non-disabled people (Joseph Rowntree Foundation 2005)
- Parents earning capacity can be limited by their caring role, with only **16%** of **mothers** with disabled children **working** compared to 61% of all mothers (EDCM 2006)

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- Amaze’s parent carer survey reveals **76%** have experienced **mental ill-health** such as anxiety and depression.
- Families with a disabled child are less likely to be living in a decent home compared to families with a non-disabled child. Those with a disabled child are **50 per cent more likely** than other families to live in **overcrowded accommodation**, to rate their home as being in a poor state of repair, and to report problems with wiring, draughts and damp in the child's bedroom (Joseph Rowntree Foundation 2008)

Feedback from PaCC Connect

About 20 parent carers attended a focus group on 25th February and met with Julia Reddaway. Sadly none of the Fairness Commissioners could attend but we hope they can now consider this written report.

Key Concern / Issue about unfairness	Suggested solution or next step
<p>Parent carers often can’t work because they cannot find appropriate childcare. Parents gave examples of having to give up work because they were unable to find suitable carers or personal assistants. Other parents said carers were not fully qualified to deal with the behavioural issues of their children, which would present very risky health and safety issues.</p> <p>Also children in mainstream schools are not usually eligible for respite – and a child’s behavioural issues can make respite and childcare provision very difficult. Children in mainstream have complex needs and behavioural needs too.</p>	<p>Provide childcare from more appropriately qualified care workers for parents who have children with SEND including those with behavioural difficulties. Raise the status of carers in the city with training and pay.</p> <p>Consider the relevant training needed for a specific child’s needs.</p> <p>Assess every family’s needs.</p>
<p>As children with SEND reach their teenage years they can still experience the same care needs, yet childcare is no longer available.</p> <p>Teenagers and young people need support to access the wider community, in an equitable way as their non-disabled peers. Social opportunities build confidence and would enhance young people’s chances of becoming employed.</p> <p>Being the family with complex needs makes you become isolated. This is a problem as you become so caught up</p>	<p>Care should be made available for teenagers and not just young children with SEND. To enable carers to work and young people to access the community.</p> <p>It would be better if there were after school solutions for teenagers. The Hub is good but does not address problems for children in mainstream.</p> <p>Build better communities in primary schools from reception onwards. We need “circles of friends” – to support/bolster us. Brighton and Hove must consider trialling a circle of friend’s</p>

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<p>with care, you lose confidence and get depressed.</p> <p>NEET figures in Brighton and Hove are very high.</p>	<p>pilot with the aim to roll this out to all schools. Circle of Friends is not an expensive exercise but is a very successful way to build inclusive communities within schools. The long term impact being very positive.</p> <p>PaCC are very keen for a stakeholder group to be set up to discuss and plan a pilot.</p>
<p>There are significant and worrying levels of unmet need in social care in Brighton and Hove. Partner groups such as Pebbles and T21 report looming crises. Without addressing these issues, Brighton and Hove, run a worrying risk of escalating costs in the Local Authority, if more families fall into crisis.</p> <p>The law states we are entitled to short breaks, but we're concerned that central government grants to local authorities don't match what is needed on the ground and we keep on being told there is no money." "We feel desperate and fear family break up."</p> <p>"Short breaks are not just crises management, as a family we are entitled to a life outside our house. We cannot lead a full life without support" " We hear we cannot get any help as other families are worse off, but our circumstances are very severe, much worse than our friends who don't have disabled children. We can't go to our local park or the shops "</p>	<p>The Law is explicit on the rights of families and young people who need short breaks for respite and to access the community. Social workers must apply the law when assessing families. Brighton and Hove must carry out an essential piece of research to quantify the exact level of unmet need in the city. Commissioners must act on the findings of the research.</p> <p>We need to revisit the city's short breaks statement and policy and revise it in line with the law.</p> <p>Provide social workers, LA officers and parent carer's joint training with specialist legal training from specialist lawyers such as Steve Broach. Contact a Family frequently publishes free materials and provides links to other good resources. It would be beneficial to all, to circulate these.</p>
<p>Families need more support – there are no advocates in the council, and there is little support for families who are struggling.</p> <p>One parent worried about cuts at Amaze.</p>	<p>Employ people at the council who have first-hand experience of living with or dealing with children with SEND.</p> <p>Unparalleled support has been given by Amaze to families with SEND children and this support needs to continue. Amaze in the city is so well known and its existence has made things better – we need to ensure that this stays. PaCC are a vital part of the city.</p>

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	Build capacity at Amaze and PaCC.
<p>There is a well-recognised (unfair) impact on the siblings of disabled children.</p> <p>Sibling carers status should be recognised early on – young carers are only recognised from age 8 – it should be younger.</p>	<p>Sibling carers should be recognised and registered as such and they should have more of a priority access to local schools for example</p> <p>Downs Primary school hold a sibling group once a week. Can all schools be asked to offer this facility?</p> <p>Clusters of schools must network to support each other with good practice. This is a very cost effective method.</p>
<p>Home to School Transport – parents would like to be treated with more dignity. We shouldn't be made to feel guilty or that we are somehow being greedy for needing extra help to get our children to school. This really adds a huge amount of pressure to the enormous worry and extra work having a disabled child entails.</p>	<p>Council needs to be more aware and respectful of parent carers' situations and not make comparisons to other families that are deemed to have greater need. Escorts and drivers must be properly trained.</p> <p>Other areas in the country have made small films of family's difficult experiences involved with disability and travel and shown the solutions. This could be an excellent and cost effective training tool.</p>
<p>Independent travel training – the inability to travel is a huge barrier to independence – the training is a great way to help children deal with this issue.</p> <p>The inability to travel independently isolates children and the family.</p>	<p>Extend training beyond home school route that would be a great thing and help to create a lifelong skill that will improve the person's quality of life.</p> <p>Training is very positive when done in the right way by people with expertise.</p> <p>Travel training must be available for all young people who can access this at the appropriate time. The city needs a sustainable independent travel training scheme. This will save money in the long run. Spend to save.</p>
<p>As SEND children get older they can become more isolated – problems are easier to disguise when they're younger. Problems get harder for children as they get older – if there was more support around these issues at a younger age then we would have fewer issues when they get older.</p>	<p>Provide more opportunities to develop friendships. More leisure/social activities.</p> <p>We need to support SEND children from a very young age so they can be independent and have jobs and this will be a long term saving.</p>
<p>Getting above the disability breadline – families a child gets help and then is</p>	<p>Invest in more support. Create more inclusive solutions in the community.</p>

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deemed to be doing ok in a mainstream school so school cuts their hours of speech and language therapy. Yet they grew older language and communication becomes more complex – they still need support.	
Children are in placements outside of the city because there's no provision in the city. A lot of money being spent on this. A parent carer who only gets to see her daughter once a week for a couple of hours – that's not a family.	Provision should be available in the city
Respite – there should be more transparency in the allocation of respite – sometimes it just seems to be luck, and not fairly done. It goes to panel and nobody knows who makes the decisions. Decisions are made that seem arbitrary.	More transparency over who makes the decisions. Someone who is part of the SEND community should be involved in the decision making. Parent Carer Reps should be sitting on the panels
Resource allocation system - The new allocation tool will potentially make things better but the algorithm is going to be set against a finite pot of money so we are worried this may mask the unmet need.	Brighton & Hove need to conduct a proper study on how to meet all the needs for short breaks (respite) in the city. Develop Personal Assistant registers for children. Skill up the work force. Provide seed funding for the community and voluntary sector to start respite and short breaks projects.
Continence dignity – not acceptable to have to change our children on a dirty floor in a public toilet– changing tables should be available for SEND adults and older children.	When new buildings are being built – the planners have the power to make conditions for planning – you can influence disabled access and facilities on new buildings. eg; Crawley have an action group that scrutinises every public building plan that comes up for disabled access. Begin local social media campaign highlighting the lack of safe/accessible changing places.
Insufficient funding ; Officers are getting paid to provide services and we need politicians or advocates to go back to central government and say we haven't got the money to meet our city's needs. What are you going to do about this? How are we supposed to make this work	Fairness commission, senior officers, councillors and MPs must address the significant issues of the funding drop from central government .The Council hasn't got enough money for services for CYP and this must be taken very seriously.

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without the money?	Equalities issues must be addressed. The council must adhere to the Equality Act.
Disability parking signs – one young person commented that her family are finding them unclear. Do you need to display badge? Do you need to pay?	More clarity on disability parking signs
Funding and fairness – the cumulative effects of cuts for families with SEND – a far greater impact for lower income families or families with SEND. Cutting services for disabled children and families implies they are getting their ‘fair share’ of cuts. That’s not a fair share – we’re part of the city as well – so we’re already experiencing cuts. SEND families are getting an extra cut on top of all the other cuts you are discriminating against them. Also you are cutting what has been clearly provided to give more equality to SEND people and their families. This is fundamentally unfair.	The local authority must carry out far better Equality Impact Assessments and act on their findings.
Parent carers often feel, as if we’re in opposition with the council . Never met anyone who is part of the council – always feel like an outsider. Not enough representation of parent carers within the council.	Employers should be encouraged to be more flexible to employ and support parent carers. All mainstream schools should have a named SEND governor. Schools must carry out their SEND duties according to the law.
Often letters from the council are confusing and don’t make sense. A parent comments that she had no choice but to go to tribunal to achieve the correct provision for her child. Many people don’t have the capability to do this. Parents from disadvantaged backgrounds don’t receive support to do things such as go to tribunal. The LA is known to back down just before tribunal and agree to meet the child’s needs	Brighton and Hove should publish figure of how many tribunal papers are submitted but do not reach tribunal because of an earlier agreement. Brighton and Hove should appoint a SEND Champion advocating for good consistent citywide provision for SEND families.

Conclusions

Locally there is a significant need:

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- To better understand and meet the needs of families to access **short breaks (respite)** well in advance of a family feeling they are heading into crisis. Conduct a full survey.
- To develop more 'changing places' – fully **accessible toilets**
- To develop more opportunities for inclusive **social/leisure activities**
- To support families to apply for **DLA** (an in-work benefit) to help support family meet additional costs of caring for a child with SEND
- To provide high quality **impartial information**, advice and support to families with a child with SEND and look at providing individual advocacy
- To identify and support **particularly isolated families** in more deprived neighbourhoods/community where the family is likely to be facing multiple disadvantage.
- To look in the '**circle of friends**' model of support and how communities can support each other
- To **build** the well-being and **resilience** of parent carers so they are more able to improve the resilience of their child(ren).
- Build on the strengths of Amaze and PaCC in the city to create more capacity for their workforce.
- Make Brighton and Hove proud to be a champion of Equality.

