

20.06.25

Dear Councillor,

Concerns about changes to disability benefits and SEND support

Ahead of the Special Council meeting on Monday 23rd June. We are writing to you as parent carers who are part of PaCC (Parent Carers' Council), a group that represents families of children and young people with special educational needs and disabilities (SEND) in Brighton & Hove.

There are ongoing reports in the media, and now more detailed information from the Government as set out this week, about changes to disability benefits and welfare. Additionally, there are government proposals to change the way SEND is supported in schools. These changes will have a huge impact on the lives of our families – and not in a good way. This news is deeply concerning to families with children and young people with SEND.

We want to add PaCCs weight of concern to that of national charities and disability organisations who are clearly highlighting the significant impact of both benefit changes and SEND support on families, children and young people. We ask all Brighton and Hove City Council Councillors to consider why these issues are so concerning to PaCC and to the hundreds of families we represent, and we seek your support to challenge these proposals.

Disability benefits

The detail released this week relating to changes in the benefit system sets out.

- **Cuts to PIP:** Up to **800,000** could lose the daily living component, with as many as **250,000 more people (incl. 50,000 children)** expected to fall into poverty by 2029–30
- **Disproportionate impact:** More severe effects projected on women—44% of those losing out are single mothers.
- **Concerns of national disability charities** (eg. Scope, Mencap, Contact a Family etc) have raised alarm, warning of deepening poverty and serious harm.

This is extremely worrying. Many of us already struggle to afford the extra costs that come with caring for a disabled child. These might include higher energy bills, more expensive food, specialist equipment, care costs, and travel to appointments. National charity Scope says disabled people face, on average, £1,010 a month in extra costs.

In a recent survey of local parent carers:

- 27% of families rely only on benefits to get by

- 71% of parent carers have had to cut their working hours, take lower-paid jobs, or leave work completely because of their caring responsibilities
- 18% said they have skipped meals or reduced their food portions to save money
- 46% said they haven't had a break from caring in over a year
- Over half said their mental health has got worse because of the stress they're under

It's not an exaggeration to say that disability benefits are a lifeline. They help cover basic needs, reduce stress, and allow us to care for our children safely. These benefits are not a luxury – they are essential.

We are especially worried about how changes could affect families with older children. When a disabled child turns 16, their Disability Living Allowance (DLA) ends, and they must apply for Personal Independence Payment (PIP) instead. Many young people with invisible disabilities – like autism, ADHD, or mental health conditions – will find it difficult to meet the proposed stricter PIP criteria. It is of huge concern that outcomes for young people will worsen.

If the young person is refused PIP, not only do they lose their benefit, but their parent carer also loses important support like Carer's Allowance and access to other linked benefits. This can be a huge financial shock to families who are already struggling. We ask you to help protect these families from being pushed into crisis.

EHCPs for children in mainstream schools

At a recent education event, Dame Christine Lenehan said that Education, Health and Care Plans (EHCPs) might in future be given only to children in special schools.

EHCPs are legal documents that set out the extra support a child needs. Many children with SEND are in mainstream schools – because that's where they want to be, or because it's the only option available. Removing EHCPs from these children would mean they no longer have a legal right to the support they need to learn and thrive. It would be devastating.

Our children already face challenges in getting their needs recognised and supported. They often wait years for assessments, and we regularly have to fight to get help. Taking away EHCPs would make things even worse.

Every child should be able to access the support they need, no matter what type of school they go to. That's what inclusion means. We ask you to help protect this principle.

Changing the term 'SEND'

Tom Rees, who chairs the Government's expert advisory group on inclusion, recently said he would like to stop using the term "SEND" altogether.



While we understand the desire to improve the system, we are very worried about this suggestion. Our concern is that removing the word without fixing the problems first will mean children with additional needs are overlooked or left behind.

SEND is not just a label – it's a way of recognising that some children need extra help to access their education. If the system no longer recognises these needs clearly, children and families will find it even harder to get support.

Mental health support in schools

We support the idea of more mental health support in schools – it's desperately needed. But we are worried that the new Children's Wellbeing and Schools Bill does not fully take into account the needs of disabled and neurodivergent children.

Families tell us that mental health practitioners don't always understand autism, ADHD or learning difficulties. This can mean their children are refused help, or that the support offered doesn't work for them.

Mental health services must be designed to include children with SEND. If they're not, inequality will grow.

Protecting the rights of home-educated children and families

We are also concerned about the impact the Children's Wellbeing and Schools Bill could have on families who home educate their children – including many who do so because their child's needs were not met in school. These families often make great personal sacrifices to give their children a safe, supportive and suitable education.

The Bill proposes a national register for children not in school and gives local authorities more powers to monitor them. While we understand the aim is to safeguard children, it's vital that this doesn't lead to families being unfairly pressured to return children to unsuitable school environments. For some children with SEND, school has caused trauma, distress, or a complete breakdown in wellbeing.

We believe the Bill must protect the rights of families to make informed choices about their child's education and ensure that any new powers are used with care, understanding and in partnership with parents – not against them. Home-educating families should not be treated with suspicion just because they have chosen a different path.

What we're asking you to do

We know you care about our community. We're asking you to help protect children with SEND and their families by raising these concerns with others in the Council, with local MPs, and with Government if you can. In particular, please highlight:

Parent Carers' Council (PaCC), Community Base, 113 Queens Road, Brighton BN1 3XG
• Tel: 01273 234 862 • email: admin@paccbrighton.org.uk • www.paccbrighton.org.uk



- Disability benefits to stay accessible and fair, so families can afford the basics and children can be properly cared for
- EHCPs to remain available to all children who need them, whether they are in a special school or a mainstream school
- Any changes to SEND policy or language to be made carefully, with families and professionals involved every step of the way
- Mental health support in schools to be inclusive, so SEND children don't miss out
- Parent carers to be involved in shaping policies, because we know what our families need
- The rights of home-educating families to be respected and protected in any new legislation
- Retain and improve the focus of support for Children and Young People with SEND in line with the framework of The Children and Families Act ,2014 that has at the heart of act, good outcomes for Children and Young People with SEND.

If you would like to hear more from us, or if you need local examples to help raise these issues, we would be very happy to talk with you.

Thank you so much for your time and support.

Yours sincerely,

Becky Robinson Co Chair PaCC

Fiona England Co Chair PaCC