Stronger together across Sussex

Sussex Parent Carer Forum Collaborative

A changing landscape
Key issues for SEND families, spring 2026
Report of survey results

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Summary

SEND families across Sussex are worried about the impact of forthcoming changes to legislation around education, health, and local government. A survey carried out by the Sussex Parent Carer Forum Collaborative (SPCFC) shows that families with children with special educational needs and disabilities (SEND) are unsure what the changes mean for them and are concerned that their access to support and services will suffer as a result.

Between January and March 2026, the SPCFC asked parent carers for their views on a range of forthcoming changes:

- Schools White Paper (SEND reforms consultation)
- Children's Wellbeing and Schools Bill
- Proposed changes to NHS integrated care boards (ICBs)
- Devolution and proposed changes to local government

The overwhelming message from the survey responses is that parent carers are anxious and unsure about what the changes will mean for their families. SEND families regularly report feeling overwhelmed with the stress and struggle of securing appropriate services and support. Now, proposed changes to the provision of health and education, and the organisation of local government, are causing uncertainty and worry that already stretched services and specialist education placements will be even further reduced.

In addition, the vast majority of parent carers are not sufficiently informed about the changes, if they are aware of them at all. There is not enough information available, and not enough use made of existing channels of communication with parent carers such as schools and voluntary organisations. This means that parent carers are without the information and support they need to meaningfully engage with national and local consultations on changes that potentially have a hugely significant impact on the lives of their families.

Parent carers are overwhelmed by the sheer quantity of proposed changes across so many different areas of their lives. Change is happening across SEND provision in education, in home education, health services, and local government. Families are worried about how changes in one area will affect the provision of services and support in another and are concerned that different agencies and organisations will not talk to each other to ensure joined-up provision. It is vital that decision-makers listen to the voices of parent carers and try to minimise disruption for vulnerable families.

Recommendations for policymakers

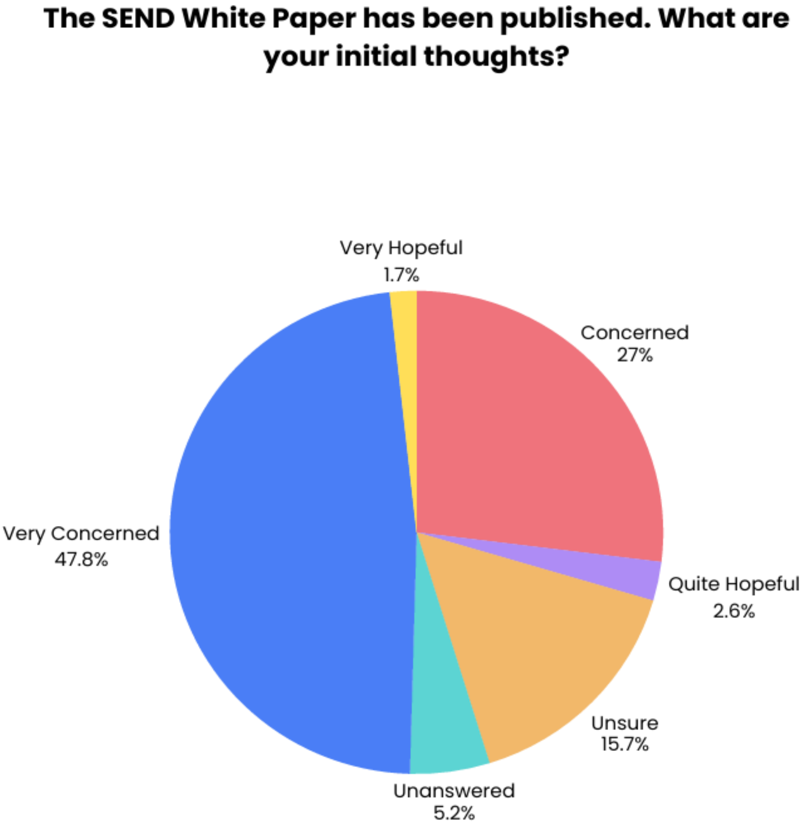
SEND families already deal with high levels of stress and anxiety caused by the constant battle to secure appropriate services and support. Parent carers have limited capacity to get involved with wider political issues, and many report feeling burnout. Families have become disengaged with the wider context. In order to improve consultation with parent carers, the SPCFC recommends that policymakers consider doing the following:

1. Make more and better use of existing communication channels, i.e. schools, services, the local offer, voluntary and community sector organisations.
2. Develop more accessible information designed for parent carers, e.g. accessible briefings outlining proposed changes.
3. Develop sufficient engagement activities in co-production with representative organisations such as parent carer forums.
4. Acknowledge the impact that uncertainty has on SEND families, taking steps to plan consultation in advance and ensure information is clear and appropriate.

This document now outlines the key findings from the survey on parent carer views on: Schools White Paper/SEND reforms consultation; Children's Wellbeing and Schools Bill; proposed changes to NHS integrated care boards; devolution and proposed changes to local government.

Schools White Paper & SEND reforms consultation

Only 4% of survey respondents report feeling "very hopeful" or "quite hopeful" about the Schools White Paper (sometimes referred to as the SEND White Paper or SEND reforms). Three quarters (74.8%) report being ''very concerned" or "concerned", and 16% are "unsure".



In particular, families are worried about the proposed changes to education, health, and care plans (EHCPs), and that their rights under the new system will not be legally binding. Parent carers describe the White Paper as "*not solving core issues*"; schools and teachers are already overwhelmed, and the proposals do nothing to ensure that children's needs will be met. There are also concerns that children with "complex needs" will not be adequately supported.

There are mixed feelings about whether the White Paper will improve families' access to support and services. Roughly 43% are unsure, 27% feel that it wouldn't, and 24% think that it might.

Similarly, when asked if the White Paper would help their child access education in their local area, 67% are unsure or do not answer, 28% think that it won't, and only 5% feel that it would.

When asked if the White Paper would improve accountability in educational settings regarding SEND provision, only 6% answer positively, 29% feel that it won't, and the remainder are unsure or do not answer.

Overall, SEND families do not feel that the White Paper responds to the concerns that they, and PCFs across the country, have been raising for years. A quarter of respondents say that it does not, while only 14% answer that it does. Families worry that the proposals do not address the real issues of delays, shortages, and quality in provision. Also, that the proposals do not recognise that some children cannot cope in school despite proposed adaptations. There is a strong belief that the reforms are financially motivated rather than child-centred, and concern that savings will be prioritised over children's needs.

> "*I believe that, ultimately, the government is trying to remove legal protection for families.*" *Parent carer response*

A key area of concern are the proposals to limit EHCPs to cases of "complex need", transitioning instead to Individual Support Plans (ISPs). Parent carers are worried that this signals the end of legally enforceable support packages, and that families will lose the right to tribunal and school choice, thereby creating an increased postcode lottery.

> "*Individual schools are already so hit and miss with children's experience. I believe this will make things worse.*" *Parent carer response*

There is particular concern for children with "invisible disabilities", children who mask, and cognitively able children with high support needs - all of whom are feared to be at risk of falling through the support net, possibly causing long-term mental health damage. There is a worry that support will only be offered once a crisis point is reached.

Another main concern is that the White Paper risks shifting focus to mainstream education provision, which is not suitable for all children. Parent carers stress that some children simply cannot cope in mainstream settings despite proposed adaptations, leading to the danger of trauma and burnout. Sensory needs and anxiety can make attendance impossible for some, and, for others, travel to and from school is itself a major barrier.

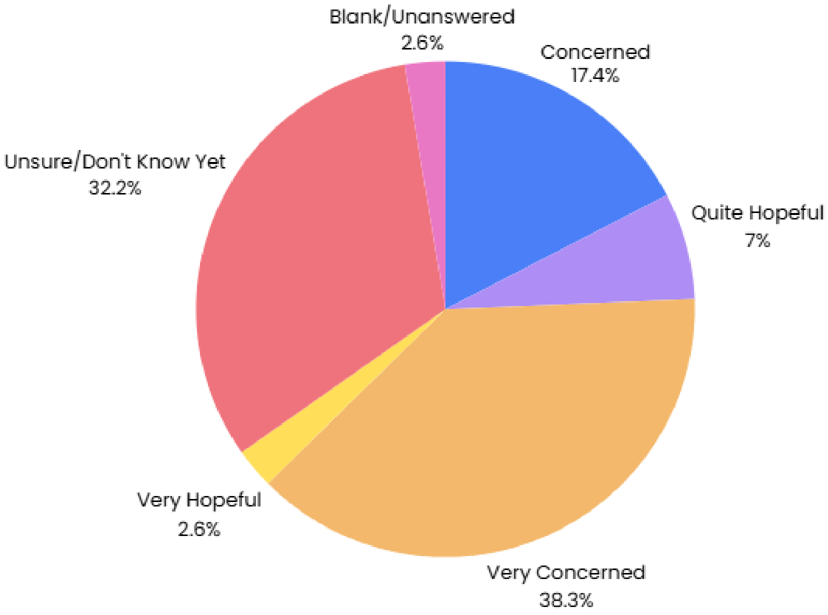
Many parent carers also voice concern that the White Paper demonstrates a lack of realism about current capacity and workforce in schools. Parent carers are sceptical that schools will really be able to deliver specialist interventions such as physio, occupational therapy, and speech and language therapy. This situation could be made worse by further cuts to support staff and teaching assistants.

Parent carers are worried about the impact on their mental health, and the long-term impact on family wellbeing. Survey respondents report exhaustion, stress, and the fear of constant battles for support, during which they feel they are "*ignored or not being listened to*". Many parent carers feel the proposals ignore the daily reality for children and families and are written by people without any lived experience of SEND.

Children's Wellbeing and Schools Act

SEND families are confused by the possible impact of the Children's Wellbeing and Schools Act, and many are concerned that it will negatively affect their access to services and support. This survey was undertaken when the legislation was still a Bill; it became an Act on 29th April 2026. Roughly 55% of respondents say that they are "very concerned" or "concerned" about the Act, whereas under 10% say that they feel "quite hopeful" or "very hopeful".

How do you feel about the Children's Wellbeing and Schools Bill?



The majority of parent carers, 57%, are unsure whether the Act will improve their ability to access support and services, 22% are hopeful that it will, and 13% feel that it will not.

> "*Many parents are concerned about trauma and mandatory registration: language around 'elective home education' may not reflect realities for SEND children."* Parent carer response

Overall, the reforms are viewed as punitive rather than supportive, with a focus on control rather than care, and, ultimately, likely to worsen educational experiences for SEND families. There is strong concern that many families home educate due to school failure, not choice, and that the reforms will end up punishing families for the systematic failures in education and SEND provision.

> *"Whilst I understand the need to safeguard children, I am concerned that with such a lack of support in mainstream education, more and more parents will be fined and prosecuted due to poor attendance."* Parent carer response

While some respondents welcome better safeguarding and a register to ensure vulnerable children are not missed, many feel that safeguarding systems risk targeting SEND families rather than those genuinely at risk. There is a widespread concern that families' right to choose home education will be restricted or removed, and that decision-making will move from the family to the state. Moreover, parent carers point out that many families choose to home educate not out of personal choice but because their children do not receive enough support to stay in school. There is a fear that children will be pushed into inappropriate, unsupportive environments, and will suffer long-term mental distress as a result.

> *"The system is very adversarial at the moment which is why we elected to home educate. I did not have the strength to fight on top of everything else."* Parent carer response

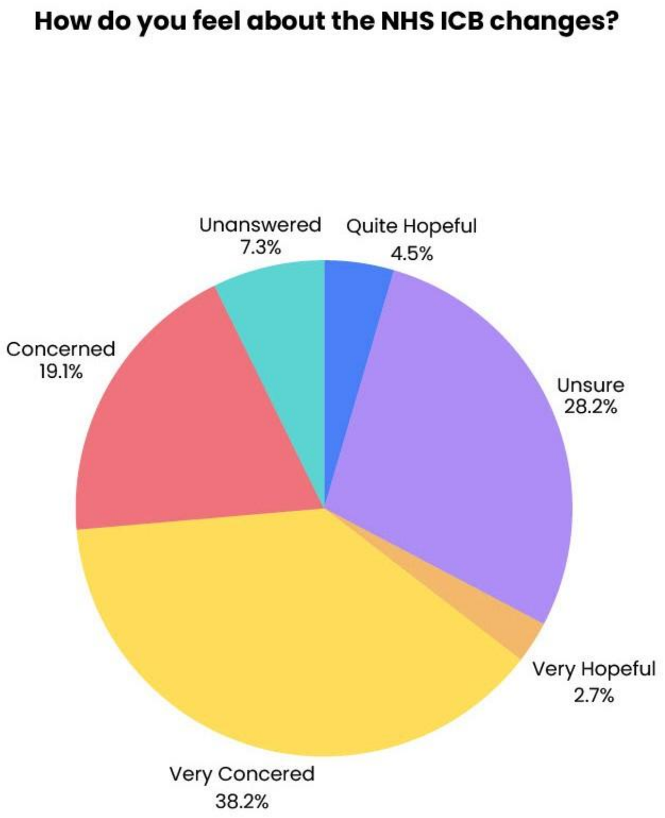
Furthermore, there is a lack of trust in schools and in local authorities, and a concern that past failures will undermine confidence in new powers. Many respondents cite previous illegal, coercive, or discriminatory behaviour by schools. The proposed reforms are seen as "*adding more hoops*" for already struggling families by increasing paperwork without increasing support.

> *"Decisions should be based on individual child needs, not blanket policy."* Parent carer response

The overarching sentiment from families is that the Act will make it harder to respond to the needs of individual children. Respondents feel the policy paints inclusion as a "*one size fits all*" fix and does not take neurodivergence sufficiently into account. Parent carers feel strongly that they know their children best and should be able to make decisions to protect their wellbeing.

Proposed changes to NHS ICBs

Most families are worried about the proposed changes to the NHS ICBs. Roughly 57% report being “very concerned” or “concerned”, whilst only 7% feel “quite hopeful” or “very hopeful”.



56% are unsure whether the changes will affect their family’s ability to access support and services, and a further 35% feel that it will.

> “*How can this possibly transition and ultimately work with less funding and less staffing?*” *Parent carer response*

Overall, parent carers worry that the changes will bring fewer services, reduced availability, and watered-down provision. In particular, families are concerned about shortages of specialist staff (e.g. CAHMS), longer waiting lists, and slower treatments. There is a worry that fewer staff covering larger areas will lead to missed needs. In addition, there is a strong perception that the changes are driven by cost-cutting rather than care.

The survey responses highlight particular concerns around proposed changes to ND (neurodevelopmental) assessments. Parent carers are worried about the quality of ND assessments if these are to be carried out by non-specialist staff. This could put too great a reliance on teacher profiling instead of clinical diagnosis, and this means that children who mask, and those with “complex needs”, could be missed.

Families also point out that larger organisations tend to be less agile, and less able to respond to local and individual needs. There are already concerns around poorly joined-up working between different organisations, and that further mergers will make this worse. Survey responses highlight existing problems, such as the lack of communication between health, education, and local authority services. Parent carers point out that, in many cases, families already have to coordinate care themselves. There is significant anxiety that mergers will worsen fragmentation rather than fix it.

In addition, parent carers are worried about reduced accountability as a result of the proposed merger. There is a fear that families will struggle to know who to contact in larger systems, and that failures will be harder to challenge. There is a concern that individual needs will disappear, and that children and data will be lost in the system, causing a negative impact on monitoring and continuity of care. Moreover, some respondents believe that mergers signal further moves towards privatisation and a loss of public accountability.

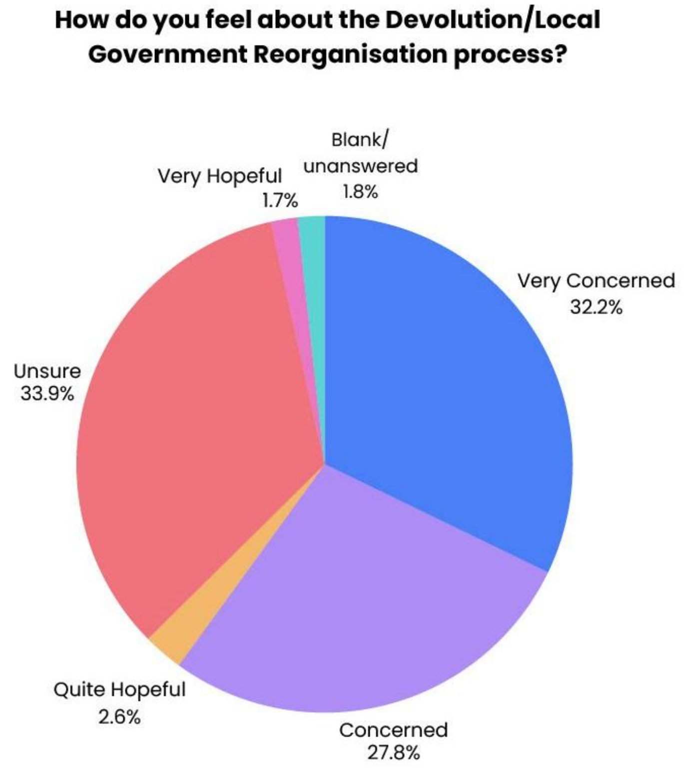
> *"As a parent carer, waiting lists and delays for diagnosis, assessment, and specialist services create significant anxiety for me."* *Parent carer response*

Families are worried that the transition period to the merger will be disruptive and unsafe, leading to delays and confusion. There is particular concern about CAMHS, which already has waits of several years in some cases. There is a fear that mental health services will further deteriorate, causing a serious emotional toll on children and families. In addition, families flag that if services are being centralised further away, this leads to increased travel times and may mean families are unable to access support consistently.

Most survey responses communicate fear, distress and anger, and a loss of trust in system leadership. However, a small minority express limited cautious optimism, and a hope that joined-up services could improve efficiency. However, this optimism is conditional on investment in frontline staff, and no cuts to existing budgets.

Devolution and proposed changes to local government

Most survey respondents - 60% - are worried about devolution and proposed changes to local government. *See chart on the next page.*



Nearly 62% are unsure of the potential impact on their ability to access support and services, and 37% feel the proposals will have a negative effect.

> *"Larger combined areas may create longer waits and differing priorities."* Parent carer response

In particular, families are concerned about a future postcode lottery, and that SEND services won't run smoothly after the changes. They are worried that services will get worse rather than improve, becoming more stretched or even being cancelled. They are worried about local school SEND provision changing if local authority boundaries change. This is a particular concern in East and West Sussex, where boundaries are likely to change more significantly. Respondents highlight that rural, coastal, and urban areas have very different SEND needs, and doubt whether a single system can ever fully understand the local context.

Moreover, parent carers are worried about accountability. There is anxiety about not knowing who is responsible for education and SEND decisions. There is fear of less accountability across a larger authority and a low level of trust based on past failures of local authorities to meet legal duties, as well as previous experience of delays, missed support, and poor communication. In particular, parent carers are worried that EHCPs may become harder to access. In addition, there is widespread worry about disruption during future transition periods. There is fear that children will be "*lost in the system*" or moved further down waiting lists, and concern around missed referrals, delays, and gaps in provision.

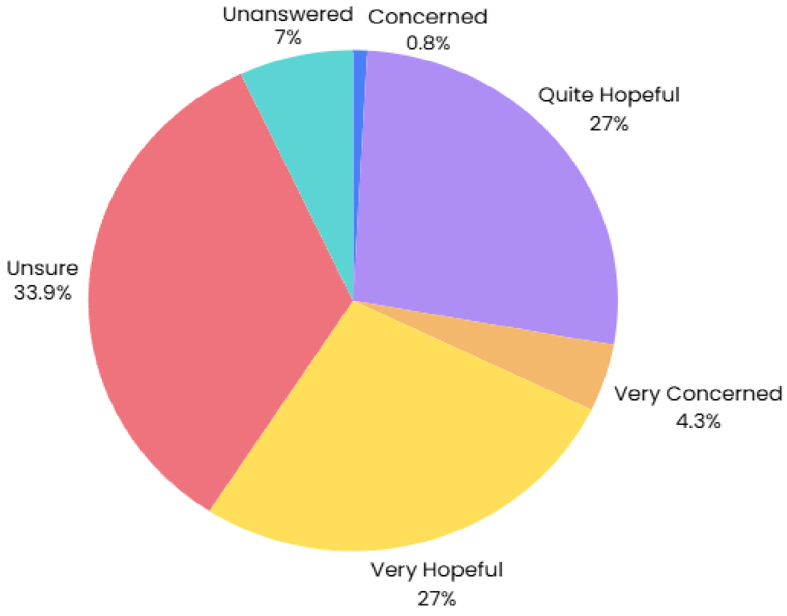
> *"Living on the East/West Sussex border poses challenges for our family. So a unified system could resolve some of those issues."* Parent carer response

Some respondents feel there are grounds for optimism as families might move to one point of access instead of multiple services, but this optimism is greatly outweighed by uncertainty and concern. Overall, survey responses show a lack of clarity and understanding around the proposals. Many parent carers feel the proposals are vague and that it is unclear what the impact “*on the ground*” will be. There is also confusion caused by political messaging and media coverage.

What do you feel about the formation of the SPCFC

The survey also asked what parent carers felt about the formation of the SPCFC. A total of 54% of survey respondents feel “very hopeful” or “quite hopeful”, 34% are “unsure”, and only 5% are “concerned” or “very concerned”.

How do you feel about the formation of SPCFC?



Several areas are identified as priorities for the SPCFC to work on:

- SEND support
- Mental health services
- Local-level support
- Working with the NHS
- Working with schools
- Advocacy for parents and children

> *"I think it will be a great resource for families all over Sussex, especially those who cross lines with services and locations, i.e. living in the West but using services in Brighton and East Sussex."* Parent carer response
>
> *"I think it will ensure that there is a strong voice no matter what happens with local government and it makes sense to get ahead of potential changes. It wouldn't be the first time parent carers have been more organised and proactive than the local authorities!"* Parent carer response

About the survey

The survey captured the views of 97 families across Sussex between January and March 2026. Nearly 75% of respondents come from West Sussex, with 20% from East Sussex and 5% from Brighton & Hove. In addition, in-person and virtual engagement events were held across Sussex by the three PCFs. 30 people attended an event hosted by PaCC in Brighton & Hove. In East Sussex, 20 people attended an in-person event, with a further 15 people attending online. In West Sussex, 48 people attended an online event, and 14 attended in-person events.

Of families surveyed, over half care for two or more children with SEND. Most children are of school age and half have an education, health, and care plan (EHCP) in place. The most common needs or disabilities cited are: neurodevelopmental differences; social, emotional, and mental health; speech, language, and communication; learning disability/difficulty; hypermobility. A wide range of other needs appeared in smaller numbers, including multi-sensory impairment, obsessive compulsive disorder, epilepsy, acquired brain injury, Tourette syndrome, and cerebral palsy.

About the SPCFC

The Sussex Parent Carer Forum Collaborative (SPCFC) is an initiative of the three Sussex-based parent carer forums: East Sussex PCF, Parent and Carers Council (Brighton & Hove), and West Sussex PCF. The SPCFC has been developed in response to the changing political landscape which has led to an increasing pan-Sussex nature of the issues affecting parent carers.

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