Disabled Children's Partnership

#SENDABetterMessage

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Campaign and SEND Green Paper briefing

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About the Disabled Children's Partnership

The DCP is a coalition of over 100 organisations, and a network of 10,000 parent carers, disabled young people and supporters, that campaigns for a fairer system of support for every family with a disabled child. If you have any questions about the contents of this briefing, you can email us at **disabledchildrens.partnership@mencap.org.uk**

What is the #SENDABetterMessage campaign?

What are the DCP's other campaigns?

The DCP also campaigns on funding for disabled children's services, raising awareness of the impact of the pandemic on families, and increasing understanding across society about the secret lives of families with disabled children. Find out more at **disabledchildrenspartnership.org.uk/our-campaigns/**

The campaign in a nutshell

- The **#SENDABetterMessage** campaign calls for the government to reform how disabled children's services work, to create a fairer system that gets families the support they deserve without having to fight tooth and nail to get it.

- Currently, too many **disabled children and families have to battle through a confrontational, bureaucratic process** to get the services they're entitled to in order to live a good quality of life - with different services providers not working well together with unclear accountability. This campaign aims to challenge this broken system.

- The campaign was launched shortly after the government released its SEND Green Paper in March 2022, and was designed with parent carers and supporter organisations from the DCP.

How you can get involved

- Keep an eye on the campaign webpage for the latest way to take action and get involved: **disabledchildrenspartnership.org.uk/sendabettermessage**

- At the time of writing, you can email your MP, record a video or write a blog sharing your experiences, or take part in the government's consultation. As the campaign develops, there will be other ways to get involved.

What is the campaign calling for?

- **#SENDABetterMessage** calls on the government to use its SEND reform programme to create a more just, fairer system of support for disabled children and families – one that is easier to navigate and gets them the services they're entitled without having to fight for them.

- Different services, local government departments and agencies should priortise the needs of families with disabled children, and work together to **present a joined up and effective landscape of support - and they should be properly accountable** for doing so.

- The government should **seize the SEND Review to implement these wholesale reforms**, but also look at implementing quick wins with small changes that could make a huge different to families in the short-term.

Background on the government's green paper

The SEND review

- The SEND Review is a **government investigation aiming to understand how to improve support services for disabled children and families**, end the postcode lottery many families face, and create value for money in services. It was first announced in September 2019.

- However, since then the government repeatedly delayed the release of a green paper on the review – citing interruption from the pandemic.

- The recommendations of the SEND Review were published in a Green Paper on 29th March 2022.

What is a 'green paper'?

- A green paper is a large-scale government consultation, giving **wide sections of society the opportunity to feed into what the government plans to do**. Members of the public, businesses, charities, councils and more can call get involved.

- The SEND Green Paper contains the recommendations to improve services from the SEND Review, alongside a series of questions the government is asking about these recommendations and how better to improve services for disabled children.

What are the key points in the SEND green paper at the moment?

At 104 pages long, the Green Paper is a lengthy document that goes into a lot of detail.[1]

It summarises the main challenges in the SEND system as:

1. Outcomes for children and young people with SEND are poor.

2. Navigating the SEND system is not a positive experience for children, young people and their families, with services not joining up.

3. The system is not delivering value for money for children, young people and families.

4. Intervention is not happening early enough, creating long-term impacts on young people and families.

The Green Paper suggests a number of different policies to tackle these problems, including:

- A new national SEND system, including changes to how getting support works.

- Improving provision of services from early years to adulthood, such as making a more inclusive education system.

- Reforming and better integrating alternative provision.

- Clarifying roles and responsilbities in the system.

Many of the aims of the Green Paper are welcome, however we are concerned about whether it will actually deliver them.

The DCP's view on the green paper

We recognise and agree with a lot of the description of the problems in disabled children's services in the Green Paper. However, we are very concerned that some of the proposals will **restrict families with disabled children from getting services and create extra barriers** in an already burdensome system.

In particular, we are concerned by the proposals to:

- Only let families pick a school from a pre-defined list – this could limit choice and prevent a young person from accessing the school that is best for them.

- Decide the levels of support disabled children get from a national banding system, possibly restricting access to support – it should be based on individual need, as was laid out in the Children and Families Act 2014.

- Make mediation mandatory before allowing families to go to Tribunal – this adds an extra step and could make it harder for families to access tribunals.

Finally, the Green Paper does not answer the biggest issue for many families – **how are councils, schools, the health service and others going to be held to account** if they don't meet their legal duties?

The problems in disabled children's services

There is an emergency in disabled children's services. Disabled children and families have a right to respite care, therapies, specialist education and other services to live a good quality of life, manage conditions and go on to achieve great things for themselves and society. They have a right to these services without having to fight tooth and nail through layers of bureaucracy to get them. **But this is simply not happening.**

Needs are not being met

Our October 2021 report, *The Gap Widens*, showed that there was huge funding gap in disabled children's health and care services – including £573 million in social care, creating a huge amount of unmet need.

There is a

£2.1billion

billion funding shortfall in disabled children's health and care.[2]

This was only made worse in the pandemic as services like therapies, respite care, and equipment were further delayed and diverted.

Nearly

3 in 4

disabled children have seen their progress managing their conditions regress in the pandemic.[3]

Nearly

1/2

of disabled children are waiting over a year to see an educational psychologist.[4]

The specialist education system is under resourced, with schools lacking places and staff, and the training needs of staff constantly missed.

Fighting for support

Parent carers often find themselves at the centre of an extremely bureaucratic system, having to fight constant battles to access support they are entitled to.

These **lengthy battles take a huge toll on the mental health of the entire family**, and result in lengthy delays to families receiving the services they are entitled to live a good quality of life - especially when parents end up having to traverse through legal and administrative battles at tribunals and hearings. This also prevents parents from contributing to society, and results in many parents having to spend a huge amount of their own money.

3 in 4

parent carers have seen their emotional or mental health deteriorate because of not getting the right support.[5]

Local authorities only won

3%

of hearings when families with disabled children took them to tribunal over not getting the right services.[6]

40%

of families with disabled children have seen their savings wiped out fighting and paying for support.[7]

Services are not joined up

At both national and local level, responsibility for the support that disabled children and their families need sits with a range of organisations.

All too often, **the needs of disabled children and their families are not the priority within those services**; and no-one sees it as their responsibility to ensure that services join-up and meet the needs of families. Services seek to shift responsibility onto other services, and families constantly have to retell their stories.

The law must be simplified

The existing law related to disabled children and their families stems from **over 10 different acts of parliament, regulations and guidance** which have developed over the past 50 years.

It is difficult for parents to navigate and it leads to families falling between the gaps.

References

Reference	Link
1	gov.uk/government/consultations/send-review-right-support-right-place-right-time
2	disabledchildrenspartnership.org.uk/families-of-disabled-children-call-on-government-to-giveitback/
3	disabledchildrenspartnership.org.uk/leftinlockdown/
4	disabledchildrenspartnership.org.uk/sendabettermessage
5	disabledchildrenspartnership.org.uk/sendabettermessage
6	gov.uk/government/statistics/tribunal-statistics-quarterly-july-to-september-2021
7	letuslearntoo.com/the-send-money-survey/

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Children's
Partnership

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The Disabled Children's Partnership (DCP) is a growing coalition of over 100 organisations who have joined forces, working closely in partnership with parents, to campaign for improved health and social care for disabled children, young people and their families. We are administered by Royal Mencap Society (registered company in England and Wales no. 00550457; registered charity numbers are 222377 in England and Wales, and SC041079 in Scotland).