

Rt Hon Nadhim Zahawi MP, Rt Hon Sajid Javid MP
20 Great Smith Street
Westminster
London
SW1P 3BT



09 May 2022

Dear Secretaries of State,

Concerns over how proposals in the SEND Review could restrict support for disabled children and families

We're writing to you as a broad coalition of organisations who are passionate about creating a fairer system of support for every family with a disabled child, to raise our concerns over several worrying policy proposals in the recently published SEND Review. We acknowledge and welcome the stated intentions of the government to create a less adversarial system of support in disabled children's services, so we hope to engage with you constructively around some of our concerns.

Firstly, we recognise the huge level of work and consultation that has gone into the SEND Green Paper. As a result, we recognise and agree with the vast majority of the problem analysis in the paper, including that: navigating the SEND system is not a positive experience for many young people and parent carers; services are not joining up; and intervention is not happening early enough – creating long-term impacts on young people and families. We welcome many of the proposals in the Green Paper, including to make mainstream schools more inclusive and to clarify responsibilities between different agencies, although we need to see more detail of how these will be achieved.

However, we are very concerned that some of the proposals in the paper will have the opposite effect to your stated intentions and 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. We have spoken to many families where they had to fight, sometimes through tribunal, to get a place at a school that their local authority would not accept – such as it being out of borough. The needs and development of young people should be the priority when deciding a school placement.
- 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. Through a national system like this, we are concerned that young people may be grouped together generically by condition – rather than by being assessed as individuals.
- Make mediation mandatory before allowing families to go to Tribunal. We recognise the important role mediation can play, but we are concerned that making it mandatory, rather than the current requirement to consider mediation, simply adds an extra step in an already arduous process. The way to reduce the number of Tribunals is to ensure that local authorities are meeting their statutory duties, not to put additional barriers in way of parents.

Finally, the SEND 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? In the current system, local authorities and other services providers are often unable to meet their duties, resulting in thousands of families going to tribunal every year – with the overwhelming majority winning.¹ We would urge you to again look at additional measures that could be put in place to increase accountability, and to urgently relook at the proposals outlined above which could make an already confrontational system worse.

Reform is needed now more than ever. The latest report from the Disabled Children's Partnership – *Left Behind: 6 Months On* - based on surveying hundreds of parent carers of disabled children, has revealed that the pandemic has severely exacerbated challenges that families with disabled children already faced accessing support.² Shockingly, the research exposes that:

- A third of disabled children are experiencing more pain as their support is delayed or reduced.
- 2 in 3 disabled children have seen their emotional or mental health deteriorate due to not getting the right support.
- Nearly 70% of parent carers of disabled children have seen their physical health deteriorate because the right support wasn't there.

As the DCP's recently launched SEND A Better Message campaign calls for, we believe you must implement reforms that creates 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; rather than implementing proposals, however well intentioned, that could further restrict support and create additional barriers in an already burdensome system.

We must work together and seize the important opportunity that the SEND Green Paper has created to produce a fairer system that gets families the support they deserve without having to fight tooth and nail to get it.

We would appreciate your thoughts on our challenges to the proposals outlined above, and we look forward to continuing to engage with your departments on these issues.

CC: Will Quince MP, Minister for Children and Families, Gillian Keegan MP, Minister for Care, and Chloe Smith MP, Minister for Disabled People

Yours sincerely,

Linda Lascelles, Chief Executive, Afasic

David Coe, CEO, AFK

Rachel Travers, CEO, Amaze

Jolanta Lasota, Chief Executive, Ambitious about Autism

Sue Millman, Chief Executive, Ataxia UK

¹ <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-july-to-september-2021>

² <https://disabledchildrenspartnership.org.uk/left-behind-six-months-on/>

Amanda Mortensen, Chief Executive, Batten Disease Family Association
Madeleine Cassidy, CEO, Bobath Centre
Keith Sinclair, Chief Executive, Brainwave
Helen Hewitt, Chief Executive, Chailey Heritage Foundation
Toni Wolff, Chair, British Academy of Childhood Disability
Gen Dearman, CEO, Challengers
Vivien Cooper OBE, CEO, The Challenging Behaviour Foundation
Sarah Dearman, Chair and Trustee, The Children's Hyperinsulinism Charity
Dalton Leong, Chief Executive, The Children's Trust
Amanda Batten, CEO of Contact and Chair of the Disabled Children's Partnership
Damian Haywood, Treasurer, Cri du chat Support Group
Catherine McLeod MBE, Chief Executive, Dingley's Promise
Carol Boys, CEO, Down's Syndrome Association
Cheryl Ward, Chief Executive, Family Fund
Pete Richardson, Managing Director, Fragile X Society
Samantha Barber, CEO, Gene People
Emma Fouls, Executive Director, Guide Dogs
Debbie Holden, Head of Services, KEEN London
Katie Ghose, Chief Executive, KIDS
Hayley Harding, Founder, Let Us Learn Too
Nikki Taylor-Price, Head of Development, The Maypole Project
Julie Calveley, Director, NAC
Caroline Stevens, Chief Executive, National Autistic Society
Clare Dangerfield, Campaigning and Public Affairs Manager, Newlife the Charity for Disabled Children
Parmi Dheensa, Executive Director, Include Me TOO
Zillah Bingley, CEO, Rainbow Trust Children's Charity
Brian O'Hagan, Director, Reaching Families
Robert Adamek, CEO, Rett UK
Louise Griew, CEO, Roald Dahl's Marvellous Children's Charity
Edel Harris, OBE, Chief Executive, Royal Mencap Society
Matt Stringer, Chief Executive Officer, Royal National Institute of Blind People (RNIB)
James Taylor, Executive Director Strategy, Impact and Social Change, Scope

Richard Kramer, CEO, Sense

Lisa Hopkins, Chief Executive, SeeAbility

Sherann Hillman MBE, Head of Family Services, Seashell Trust

Kate Steele, CEO, Shine

Angela Smith-Morgan, CEO, SMA UK

Tania Tirraoro & Renata Blower, Co-Directors, Special Needs Jungle

Laura Lewis, Chief Executive, Swings and Smiles

Andy Fletcher, Chief Executive, Together for Short Lives

Mark Lee, Chief Executive, Together Trust

Gill Gibb, CEO, Tree of Hope

Louise Fish, Chief Executive, Tuberous Sclerosis Association

Matt James, Interim CEO, WellChild

Sarah Pugh, CEO Whizz-Kidz

Mark Devlin, Chief Executive, Young Epilepsy