

SCOPE

= Equality for
disabled people



Now is the time

Supporting disabled
children and their families

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Introduction

All parents have hopes, dreams, aspirations and want the best for their children. With ‘overwhelming evidence that children’s life chances are most heavily predicated on their development in the first five years of life’. ^[1] It’s crucial that children and their families receive the right support from the start.

Our campaign report highlights the experiences of families raising a disabled child today. It focuses on how we can remove the barriers in early years which can prevent children from fulfilling their potential. We’ve specifically looked at families’ experiences of the information and support available during the diagnosis journey.

This point in time matters, because for many parents, seeking a diagnosis will be their first interaction with the services that are supposed to help them and their child.

Too many parents say they feel judged by others, and many aren’t even offered emotional support. Too often they are told what their child can’t do, and how difficult life will be. Childhood is a special time in the lives of all families. For many parents of disabled children, this precious time is taken away, as they spend time fighting a support system that isn’t working properly.

We’ve set out the immediate steps the Government must take, not only to overcome these barriers but also to demonstrate their commitment to supporting parents and disabled children. Families need to know they are not alone. Disabled children must get the same opportunities to thrive as every other child. As a society we need to do more to support disabled children and their families.

Now is the time to make a difference.

1. Department for Education (2011) Early years evidence pack.
<https://www.gov.uk/government/publications/early-years-evidence-pack>

About our research

This report is underpinned by research aiming to understand parents' experiences of the early years of their child's life.

Scope undertook an extensive literature review of available evidence, as well as conducting exploratory workshops with families of disabled children [2], and conducting surveys with parents of disabled children and public. We did this because we want to fully understand the breadth of issues that can impact on disabled children and their families. We have also drawn on expertise from our helpline professionals and our online community.

This campaign report also gathers evidence from primary research conducted by Scope and partners.

Our Lives, Our Journey, sponsored by the Esmée Fairbairn Foundation, is a pioneering longitudinal qualitative research study, following the lives of disabled people over five years. [3]

The research aims to provide a rich qualitative evidence base on the life-journeys of disabled people. This report utilises findings from our interviews with parents of disabled children.

Research data was gathered through a series of in-depth semi-structured interviews. The interviews were thematically analysed and the key themes across all participants were explored in detail. Common issues and barriers, as well as the solutions or enablers, have been identified. The quotes from parents which feature in this report illustrate these key themes.



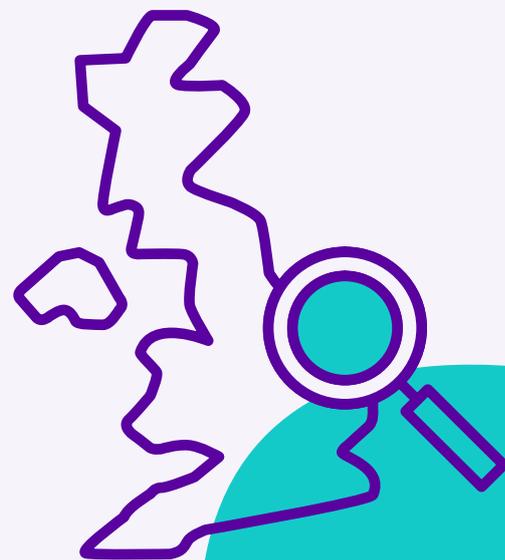
2. Workshops were conducted with 12 parents in Runcorn and Leeds.

3. Our Lives, Our Journey longitudinal study year one interviews were conducted by Scope between November 2017 and March 2018 with 81 research participants from across England and Wales. The full report 'Our Lives, Our Journey: Year One' will be available in January 2019.



Survey data was also analysed from a set of questions funded by Scope. [4] NatCen use a ‘gold standard’ sampling method, sample size and long history allow us to make robust population-level estimates of current and historical attitudes towards disability.

Finally, we commissioned a poll of parents of disabled children from across the UK to find out what their views were on a range of the issues identified, and to test the findings from the qualitative research at scale. [5]



4. The NatCen public survey was conducted by NatCen between 19 April – 20 May 2018 with 2315 adults aged over 18 across Britain. The survey was conducted by telephone and online, with the sampling based on a random probability design.

5. Polling was conducted by Opinium between 18 – 25 May 2018 with representative sample of 200 parents of disabled children aged zero to five.

Key findings and recommendations

Access to timely and appropriate information and support

93% of parents of disabled children aged zero to five believe they can have the same aspirations for their child as parents of non-disabled children. [6]

43% of parents of disabled children aged zero to five described the experience of getting a diagnosis for their child as ‘anxiety inducing’. **55%** of parents described it as ‘stressful’. [6]

46% of parents of disabled children aged zero to five think that getting a diagnosis is important because it would help them understand their child’s needs. [6]

Attitudes

87% of parents of disabled children aged zero to five have felt judged by members of the public when they go out with their disabled child.

74% of parents of disabled children aged zero to five have experienced negative comments by the public when they go out with their disabled child. [6]

Three in 10 adults believe that they would feel uncomfortable or awkward around a disabled child. [7]

79% of people who know a disabled child think that there is a lot of prejudice against disabled children. [7]

42% of parents of disabled children aged zero to five have not been believed by teachers or assistants about their child’s disability. [6]

Emotional stress

34% of parents of disabled children aged zero to five would like counselling during the diagnosis process. [6]

41% of parents of disabled children aged zero to five were not offered any emotional support during the diagnosis journey for their child. [6]

25% of parents of disabled children aged zero to five became more isolated as a result of the diagnosis journey for their child. [6]

6. Polling was conducted by Opinium between 18 – 25 May 2018 with representative sample of 200 parents of disabled children aged zero to five.

7. The NatCen public survey was conducted by NatCen between 19 April – 20 May 2018 with 2315 adults aged over 18 across Britain. The survey was conducted by telephone and online, with the sampling based on a random probability design.

Now is the time for the Government to take action

To ensure disabled children can fulfil their potential in early years, we are calling on the Government to:

Appoint the first ever Minister for Disabled Children and Families

This new ministerial appointment would provide an accountable focal point within Government, championing the issues facing disabled children and their families, and bringing together relevant departments and bodies.

Establish an early intervention and family resilience fund

This fund would include investment in emotional support for the whole family during the diagnosis journey, such as counselling, advocacy and relationship advice.

These recommendations are supported by the Disabled Children's Partnership (DCP). The DCP is a coalition of 60 organisations, of which Scope is a member, campaigning for improved health and social care for disabled children, young people and their families.



Supporting disabled children to fulfil their potential

There are over one million disabled children living in the UK today. That's eight per cent of the country's childhood population. **[8]** With the right support, all these children can fulfil their potential and meet the aspirations their parents have for them.

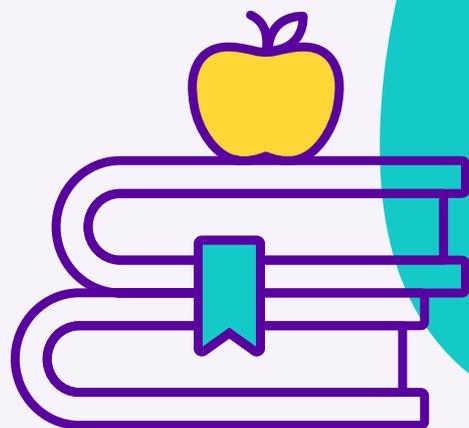
“Elise has defied what everyone said she was going to be like”, says mum, Christie. “I walked into nursery one day and she was sat on the mat playing with her toys without help. That was a huge achievement for her, and **I won't ever forget the feeling of pride I had for her.** I remember I came home and I put her in front of the Christmas tree, because all I wanted was a picture of her sat up in front of the Christmas tree, because everybody had pictures on Facebook of their children in front of the Christmas tree. I remember my friend whose little boy's got autism, he just said, ‘You'll look for the little things she does.’ He said, **‘You just change the goalposts.’** So, every time something little happened, I knew what he meant”.

As part of the Our Lives, Our Journey research parents spoke to us of the positive impact they've seen when professionals and early years settings are supportive of their child's needs. **“I would say, for me, it's probably nursery where Alexander has equality”**, says Cheryl, mum to Alexander, aged three. “How responsive they've been, how amazing they've been in helping us get the education, health and care plan, and the support that he's entitled to. He's making a lot more progress than I'd anticipated.

These stories not only illustrate how parents adapt their aspirations over time, but the crucial role society has in supporting children to fulfil their potential.

“They've [the nursery] taught him little things that I suppose I didn't have the time with, or the knowledge to do it. I don't know but there's so many things where you think ‘God, he's only been there since September and he's doing that””.

Vicki, mum to Daniel, aged four



8. Department for Work and Pensions (2018), Family Resources Survey 2016/17. <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-201617>

Sadly, parents don't always have positive experiences, and professionals aren't always able to see beyond the disability.

Helen, mum to Jack, aged five, says "I want to know whether he's doing numeracy. I want to know where he is in his literacy. Those are words I would expect to be coming from a school, and he's in Year one now. **I don't expect to hear the highlight of his day was playing in a sandpit**, but that is the feedback I am getting. I'd love to see him being pushed, and I don't think he is, and that's a shame to see".

Vicki, mum to Daniel, told us about a time at a particular nursery when "they kept him in the baby class. He was three. I was so cross. It didn't matter how many times I said 'but he's not a baby' and they said 'yeah but he's at their level'. But so what? **He's never going to get up to his own level if you're keeping him with the babies**".

Helen and Jack's story

“ I would love him to talk. My God, I would love him so much to talk. I want to see him make decisions for himself, I want to see him make choices. I want to see him learn to tie up his own shoelaces. I want to see him potty trained. I want to see him use a knife and fork at the table. I want to see him dress himself. I want to see him reach the potential I think he's capable of.

If you sit down and watch him, for a long enough period of time, you can see the cogs whirring in his brain. You can see him taking stuff in and processing it. I will be happy knowing that I've done everything I can to get him to the point he's at, and that he's not lacking for the input that he got. If that's as far as he gets, throughout his life, and he can't go any further because of mental blocks, or lack of understanding, or there's just something there that's stopping him, and he can't get any further, that's grand, because he got as far as he could. I don't want it to be because he was lazy. I don't want it to be because I didn't throw enough money at it. I don't want it to be because I didn't have the time to throw at it.

”

All too often parents are told of the limitations, the struggles and the barriers they will face raising a disabled child, rather than the opportunities. **It's time to change this.**

The barriers which stand in the way

Access to timely and appropriate information and support

A barrier parents often tell us they face is the inability to access timely and appropriate support. When parents turn towards education, health and care services, they encounter a fragmented and confusing system. Parents have described 'going round and round for years', negotiating services that are hard to understand and interact with: **'you're in a process, that's what I hear a lot. You're in a process, you're in the system'**.

One of the earliest interactions parents will have with services designed to help them is if they seek a diagnosis for their child. For some parents and their children, the process can be relatively straightforward. For others it is very complicated, and some may never receive a formal diagnosis for their child.

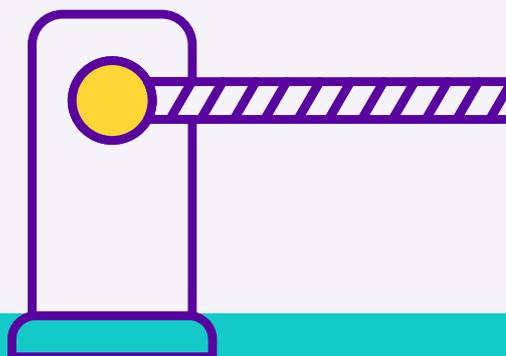
The Opinium research found that 94% of parents of disabled children aged zero to five said it was important to get a diagnosis. Half (51%) of parents did so because they believed it would help them access services and support as early as possible. For 46% of parents, they felt it would help them understand their child's needs.

Whatever their reasons, parents expressed confusion over the information and support available to navigate the diagnosis journey.

43% of parents of disabled children aged zero to five we asked described the experience of getting a diagnosis for their child as "anxiety inducing", with 55% of parents describing it as "stressful".

"We were given a book to take away, but, to be honest, I didn't find it particularly helpful. I think especially once you first get the diagnosis the local authority need to be better prepared and more geared up to make support available at point of diagnosis."

Shell, mum to Oliver, aged four



Attitudes

We found that parents continue to face negative attitudes which can make them feel judged and isolated. The NatCen Public survey found that 79% of people who know a disabled child think that there is a lot of prejudice against disabled children. Alarming, 74% of parents of disabled children aged zero to five we asked have experienced negative comments from the public when they go out with their disabled child. One mum told us “**there is a lot of sneering and frowning and a lot of judgement...** that’s enough to upset your whole day if you’re not strong enough”.

Another parent told us “my [autistic] son was having a meltdown in the middle of, I think it was the tinned goods aisle. I’d told him he wasn’t allowed to pull them off the shelves, so he had a meltdown, and **I overheard a member of staff call my kid a spastic!** I went, ‘Did I just hear you correctly? Did I just hear you call my kid a spastic?’ He just goes, ‘Well, if the boot fits’”.

The Opinium research found that 42% of parents of disabled children aged zero to five have not been believed by teachers or assistants about their child’s disability. Of these parents, 43% felt as if they were a bad parent.

For many parents the impression they are given, including from health professionals, about having a disabled child is very negative and too focused on the medical model of disability. Parents spoke to us about the emotional strain of being repeatedly asked if they wanted a termination when scans showed their child would be disabled. Vicki, who took part in the Our Lives, Our Journey research project, told us that “**the paediatric doctor... said to us about thinking about having a termination** because we’d had egg donation IVF to have Daniel and ’cos we had paid such a lot of money to have a baby surely we wanted a perfect one. That was her exact words and it was just heart breaking”.

Richard and Cheryl are parents to Alexander. They describe the moment they were told their child would be disabled. “It’s the assumption that this is bad news, and that it’s all wrong. **Being told ‘you should probably not go full-term with kids with Down syndrome.’** You know, you can speak to almost anybody. The whole system is just so negative about the diagnosis”.



Emotional impacts

Fragmented systems and narrow-minded attitudes act as triggers for the emotional stress many parents experience. One parent told us “you’re accused of being paranoid, you’ve got a sibling who’s showing similar signs and you’ve got similar concerns, and they’re like, ‘well, are you sure it’s not learnt behaviour? Are you not just over-analysing everything because of his brother?...’ **And then you’re questioning yourself and then you become paranoid**”. Similarly, one parent remarked “you become the angry parent... I’d ring up every day, hello it’s your daily phone call”.

If parents don’t receive the right emotional support, then supporting their child becomes that much harder. We know that getting a diagnosis revolves around medical decisions, but we believe that a more holistic, whole-family approach that considers attitudes, information and emotional support would improve the experiences of disabled children and their families. Parents should be able to access counselling, advocacy and relationship advice services to help them at challenging times. However, the Opinium research revealed that 41% of parents of disabled children aged zero to five were not offered any emotional support during the diagnosis journey for their child. A quarter of parents of a disabled child aged zero to five we asked said they became more isolated because of the diagnosis journey.

Almost a third (32%) of parents on this journey told us that they argued or argued more with their partner. As Richard observed “I can’t be the sole emotional support for Cheryl, and she can’t be the sole emotional support for me because we’re too involved in the situation”.

“Basically unless you’re suicidal or self-harming, you don’t meet their criteria. So it has been quite difficult for us to find a place as a family where we’re going to fit. We haven’t had any kind of informal or formal support, but I see a (private) counsellor”.

Jools, mum to Hugo, aged four



Toni, mum to Daisy, aged three, told us “some sort of counselling right at the beginning, to help deal with that initial diagnosis, you know, I think would be a massive, massive thing. **When you receive a diagnosis, or when you’re first told, or confirmed what you believed, there’s almost a grieving process.** I read a lot of blogs on it, which has helped me, you know, to not feel guilty for feeling grief, because it’s almost like that future that you had imagined has died...”

To cope in the absence of NHS counselling services, parents turn towards networks of parents of disabled children. Through these networks, parents can share experiences, learn coping and parenting strategies and not feel so alone.

“They have a dads’ group that try and meet monthly, they go out for a curry and a few beers”, says Rebecca, husband to Mike and mother of four-year-old Sebby. “Mike said that when he went the first time, that it was the first time since Sebby was born that he’d actually spoken to anybody, or another dad, about having a child with Down syndrome, and he finds it really reassuring to go and really supportive”.

Some parents proactively seek private counselling, which piles an extra cost on top of an already challenging budget. Helen said “**at least in a counselling session, I can say exactly what I think, exactly what I feel. I can get it off my chest and then it allows me to be emotionally level enough to then fight those battles out with the services.** It helps me moderate myself because I’ve already done my angry thing in counselling. So, I’ve found it a really good coping strategy, but I have to pay for it.”

“We finally got offered the counselling support about two months after Felicity was born, at which point it was a bit late really. Ironically, we’d have had counselling if we’d decided to go ahead and have an abortion, but I did feel quite abandoned by that side of things. In terms of actual counselling or any support with the emotional side, there wasn’t anything. Or at least there was but it was too late”.

Charlotte, mum to Felicity, aged one



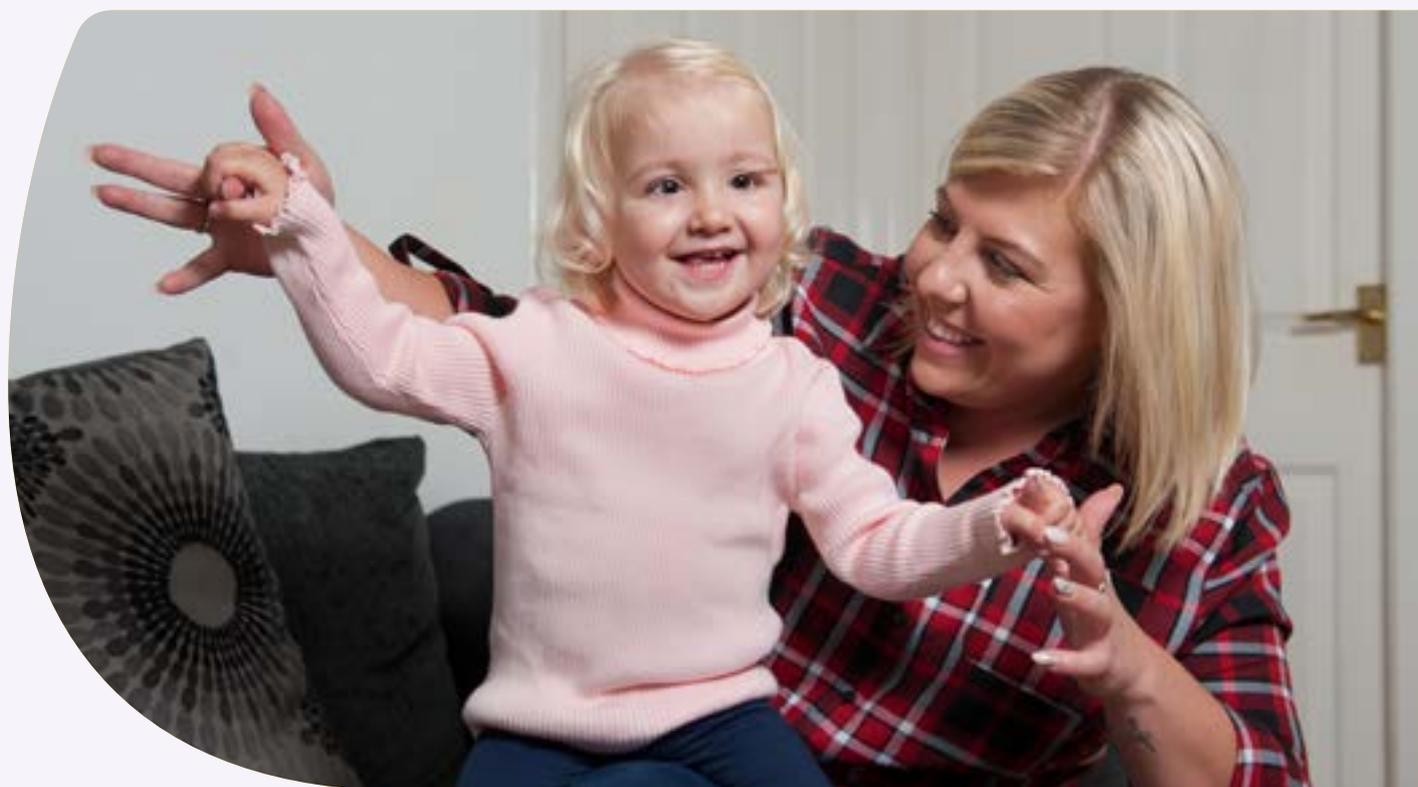
Christie and Elise's story



I think you're supposed to be over it by then. I was left to struggle alone. As a parent of a disabled child you struggle with all the emotions that comes with it, such as anger and guilt. It's a battle every day. I was really anxious wondering if I could have done something differently while I was pregnant or what I did wrong in those last few weeks. I was angry with my friends, because their kids were fine.

I think it's a difficult thing for a mother to admit that she's struggling as well, because I think there's always this stigma around mental health anyway and to admit that you're struggling with a baby you're thinking, 'What might they think? Someone's going to take my baby away'.

He [another parent] chatted with me and he told me his story and he made me, kind of, understand that it wasn't my fault that happened, because it wasn't his mum's fault what had happened to him. He said to me, like, 'nobody else can do it for her, but you.' That made me think I need to try and pull myself together a little bit. I didn't for a long time, but it always stuck with me what he said, that I was the only person that could get her where she needed to be.





A way forward

The issues we've highlighted are by no means revelations. Organisations and professionals working in this area for decades have repeatedly stressed the need for action.

Based on a detailed new body of primary evidence, what our report demonstrates, once again, is that the package currently on offer to young disabled children and their families simply doesn't meet their needs.

The Government acknowledges that for the system to be responsive, there needs to be a joined-up approach across departments and statutory bodies. Reforms to the Special Educational Needs and Disabilities system in 2014 and initiatives like the Interdepartmental Ministerial Group on Disability and Society (established in 2018) are a step in the right direction.

Despite this, the voices of families of disabled children continue to be lost or drowned out. This is because current ministerial positions do not adequately oversee the cross-cutting issues which need tackling. Disability touches every aspect of a family's life, from accessing health and care services during the diagnosis journey to educational support in early-years settings. We believe that key to addressing the barriers we've highlighted is a holistic approach driven through national leadership.

To move the agenda forward, the Prime Minister should appoint the first ever Minister for Disabled Children and Families. This ministerial role would provide leadership to strengthen existing reforms and initiatives. It would offer a targeted and much-needed strategic focus on the needs of families with disabled children. A new Minister would play a strategic role in bringing together national and local decision makers to address challenges in the diagnosis journey.

The Government need to show families of disabled children they are not alone. One of their immediate tasks should be to lead Government thinking on how to challenge the negative attitudes which hold disabled children back.



The funding gap in services for disabled children is well documented. Research from the Disabled Children's Partnership demonstrates a £1.1 billion shortfall in funding for health services for disabled children and £433 million extra needed for social care. [9] The funding needed would plug the gap in services such as specialist equipment, speech therapy and short breaks.

As our own research shows, there is also an urgent need to strengthen emotional support services for families. Parents should not feel abandoned because they have a disabled child. The government must recognise that the diagnosis journey is an emotionally testing time, and that parents need to be supported through this journey.

We believe the Government should establish an early intervention and family resilience fund to ensure families have good resilience. This fund would include investment in emotional support for the whole family during the diagnosis journey, such as counselling, advocacy and relationship advice. Developing this fund would require the political commitment which can only be driven by a high-level ministerial appointment.

This is only the start of what a new Minister could achieve for disabled children and their families. We would seek to work closely with the Minister, through coalitions like the Disabled Children's Partnership and existing Government groups like the Interdepartmental Ministerial Group on Disability and Society, to set out the roadmap for positive systemic change.

9. Disabled Children's Partnership (2018), The case for a Disabled Children's Fund. <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2018/07/Case-for-a-Disabled-Childrens-Fund.pdf>

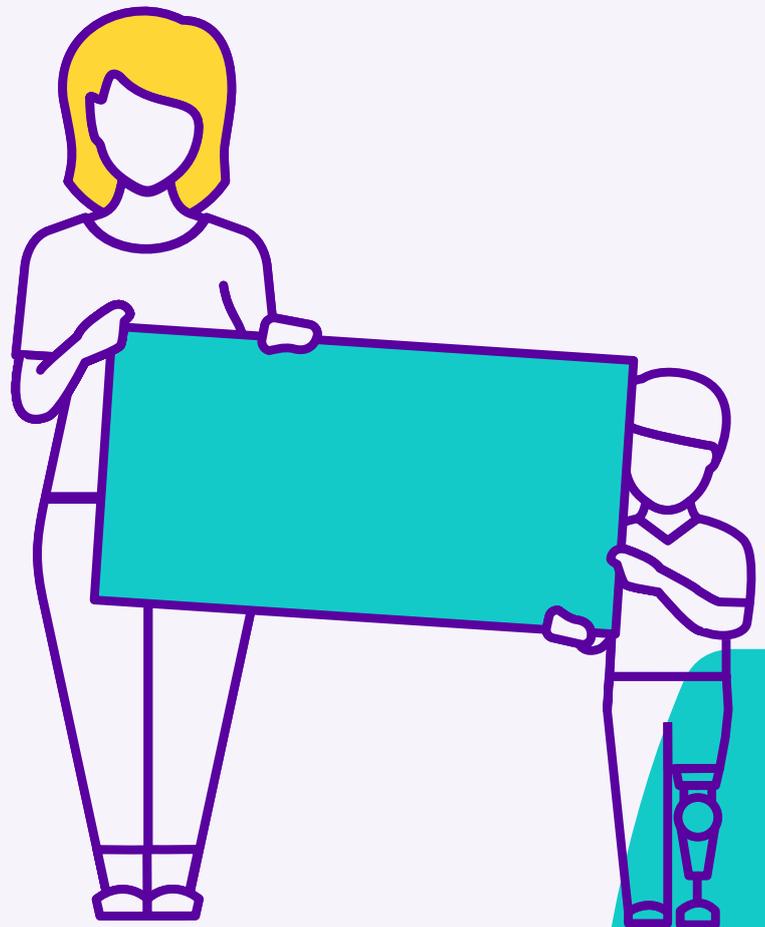
Recommendations to Government

Appoint the first ever Minister for Disabled Children and Families.

This new ministerial role would provide an accountable focal point within Government who can champion issues facing disabled children and their families, bringing together relevant departments and bodies.

Establish an early intervention and family resilience fund to ensure families have good resilience.

This fund would include investment in emotional support for the whole family during the diagnosis journey such as counselling, advocacy and relationship advice.



Next steps

Our campaigning

This campaign is part of our commitment to ensuring that disabled children can fulfil their potential during the early years. The recommendations outlined are only the beginning.

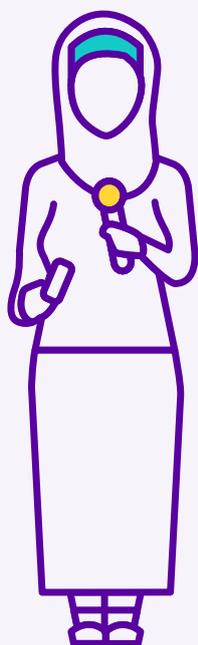
The first step is structural change at the heart of Government to address the support system which currently isn't working properly. This needs to be complemented by investment in the services which will increase the resilience of families.

Beyond this, we urge an ongoing dialogue with families, national and local Government and organisations working in this area. Through collaboration we can identify new solutions for the challenges this report has touched upon.

In the coming months, we will set out further thinking on how to challenge negative attitudes towards disability, which present a barrier for families at that early stage in their children's life.

We are also committed to finding solutions for the extra costs families face. As this report shows, parents incur costs if they need counselling which they can't access through the NHS. When speaking to parents, we also heard of the additional financial burden they face, whether that's from having to provide specialist equipment, or the extra cost of childcare. We will build upon this evidence, present new data on the value of the cuts families of disabled children face, and identify solutions to drive down these costs.

For more information on our campaign, visit scope.org.uk/nowisthetime



Our services

Scope's services for parents of disabled children directly support thousands of disabled people and their families each year.

Sleep Right helps parents improve sleep for disabled children aged two to 18. It offers families a bespoke sleep plan from a sleep practitioner and support over a six-week period.

Parents Connect is a course for parents of disabled children, that enables them to learn, share and meet in their local area.

Navigate is a one to one advice service from parents who have been there, to support others at the start of their journey as the parent of a disabled child.

We also provide information and advice on our website for families with disabled children, from diagnosis, through education, to adulthood. Families and young disabled people can also find peer support and discussion on topics that affect their lives, on our free online community.

For more information about the services Scope offers families, visit scope.org.uk/support



About Scope

We're Scope and we want equality for disabled people. We're a strong community of disabled and non-disabled people. We provide practical and emotional information and support when it is most needed.

We use our collective power to change attitudes and end injustice. We campaign relentlessly to create a fairer society. We won't stop until we achieve a society where all disabled people enjoy equality and fairness.

scope.org.uk

Contact us

campaigns@scope.org.uk

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