Changing Realities participant speeches on SEN (special educational needs) at the DfE, Westminster: 13 March 2025

Changing Realities parents and team members outside the DfE building in Westminster, 13 March 2025. Photographer: Paul Shields.

On the 13th March 2025, eight parents from Changing Realities (CR) attended a roundtable meeting with the Secretary of State for Education, Bridget Phillipson MP, and senior civil servants. Two further parents wrote speeches but were sadly unable to attend the event in person – their speeches were read out by CR team members. This document contains all eight participant speeches delivered on the day, which spoke to four identified challenges for parents/carers of children with SEN, while also living on low incomes. It is framed by opening and closing statements by two additional parents. We are grateful for the time, effort and determination of Changing Realities participants, both in sharing their own experiences and through seeking better changes for all.

Opening

Yvonne

I live in the north of England. I am a disabled single mother of two children, and a participant of Changing Realities. Both of my children have special educational needs.

The Government's plans to cut £6 Billion in disability benefits in the near future is being flagged extensively in the media at the moment, and is causing me great concern because I am currently using my PIP money to pay for my youngest child’s support. I am having to do this mainly because even though I have applied for Disability Living Allowance (DLA) for him, there is a 25 week wait for a decision. Moreover, I am also on a waiting list for him to be officially diagnosed with other conditions that he is suspected to also have, such as Autism and Dyspraxia, however, the wait for this is three years. Hence, I often worry about the impact that losing my PIP money could have on me and my family, because if I lose it, I won’t be able to support my son's additional needs anymore, especially in the interim of awaiting a decision from the DLA team and also official diagnoses from the Children and Young Peoples Service (CYPS) who do the assessments for children with suspected conditions like Autism and Dyspraxia.

I understand that it is also part of the Government's plans to make a large amount of people who are on disability benefits, get off these benefits and back into work, but finding and maintaining a job could be very challenging for some of us parents with SEN children because we have to attend lots of different appointments during the day, not only for ourselves and our adult issues, but for our children too.

I am pleased to be part of Changing Realities, and to have been given the opportunity to highlight some of the many challenges that parents like us with SEN children face on a daily basis. Some of these challenges include: not having enough money to live on in order to support all of the needs of our SEN children, not getting enough support from education and services, dealing with the often complex conditionality around SEN, and also often not getting the appropriate support as and when we need it.

I/we hope that sharing our thoughts and experiences on this subject will influence and be taken into account when you are writing the Child Poverty Strategy and other similar or related policies and procedures.

Challenge 1: Living on not enough - parenting children on low incomes

Rachel

I am a single mum to one child with potential undiagnosed SEN requirements. Undiagnosed because waiting lists are years long, and we've been refused CAMHS because the referral came from our GP, rather than the school.

My child has Adverse Childhood Experiences due to me being in an emotionally abusive home in her early years. She is in secondary school now and is what is 'labelled' as a school refuser. She doesn't refuse to go to school - she quite simply is unable to go. We could be going out the door and it just hits her, she freezes and cries and I'm left with no alternative but to leave my 14-year-old at home upset and annoyed with herself, whilst I continue on my journey to work. Can anyone even begin to try and understand how that feels? Just this week, I had a text from her because she was in distress at school, whilst I was at work supporting SEN kids myself. I wish I had the funds to get her an official diagnosis, but I can't afford it and I don't even know if school will accept it. School funding has been cut and they are "rationed" to the amount of statements they can introduce each year.

I am a public sector worker in education. I hear comments frequently about these "school refuser" children, how their parents are lazy and have no control or discipline over these kids! I challenge these discussions in my own workplace because no-one knows the circumstances of any child. To be judged or feel judged is unfair whilst managing our children and trying to teach them to be more resilient. Resilient to what exactly? Unfair treatment, cutbacks and poor support? That's not their job, it's politicians' jobs to ensure all children are safe, heard and valued.

My child is struggling because she is unable to access adequate appropriate support before school. I drop my child at the school gates at 8.30a.m., the earliest I can to be at work on time. Because she is over the age of childcare there is very little support for these teens that don't feel safe on their own or struggle to get out to school whilst us parents try to get to work.

Society has changed. These children are our future taxpayers and we are failing them now, leading them into a path of low wages and a life no different to how they have grown up. Struggling and barely getting by. Since when has that been a successful target to achieve … Just to survive?

I would like to see the services there in place for our children. Within school, or at home where the child is comfortable. Because some children are homeschooled, and this seems to be forgotten at times when we discuss SEN children. School is *not inclusive and certainly for a lot of children it's not accessible. Are you prepared to listen to parents, to support the discussions between schools and parents, perhaps in Focus Groups, to address the issues? And provide the funding to make it happen?*

Jolene

I am an autistic and ADHD mother of three wonderfully neurodivergent children. I now work from home part time for a children's charity. A few years ago, I was plunged into poverty when I was forced to give up my job of 20 years due to my children being denied the healthcare and education that would have enabled them to meet their full potential.

The increased stress of navigating systems that are supposed to support while managing tight budgets makes it extremely difficult to meet the needs of my children and at one point drove me to the point of considering suicide.

You don't have the same options of support when your child is different. My autistic child has ARFID, an eating disorder which means she is restricted in the food she can eat. Food banks don't cater for this, so I was forced into debt to feed her. If a child isn't given a school placement that meets their needs, they are also denied access to free school meals as well as increased costs in cooking and heating the home.

Another aspect of my life I would like you to understand is that my children can never experience a family holiday. As education secretary I'm sure my mentioning this might raise eyebrows but hear me out! Holidays out of term time are impossible for my family - they are too crowded, busy and overwhelming. That's how it makes me feel as a neurodivergent person without then having to try and regulate my children in order to have any enjoyment. Blanket bans are discriminatory as the only time my family would cope is in the quieter times when most children are in school. We also cannot afford a fine so therefore families like mine will never have the opportunity to have quality time together. Can you Imagine never having a family holiday with your children? For us it would be a chance to be away from the relentless stress and trauma that SEN families face. Some of my fondest memories as an undiagnosed autistic child with a special interest in history and cultures was visiting historical sites while on holiday it really lit the passion in me to want to learn more.

While I'm here I would like to take the time to share my horror at the recent announcements that the government is targeting PIP - a payment that is designed to offset the increased costs that come from being disabled. Targeting this benefit increases the stigma that already exists in society. I now work part time, but it costs me more to be able to work. My older children also receive PIP, had they not been traumatised by the education system they would be in a different situation and wouldn't have the additional costs that relate to their disabilities. If you really want to reduce the cost of disability related benefits you should maybe look at how the education system is breaking neurodivergent children and causing PTSD. Often leaving them reliant on state benefits for the rest of their lives.

Adding further stress through proposed disability cuts does nothing to help families who are already experiencing additional emotional and financial strain due to coping with systems around children with additional needs. Parents and carers of SEN children need to be involved in co-producing policies that protect children and support, rather than hinder, their education journeys - I'm really interested to hear your thoughts on this.

Challenge 2: Getting support from education and services

Jade

I have multiple sclerosis, and I am unable to work because of my poor health. I am a single mum to 2 children, a daughter who is 18 and has autism, and a son who is 14 and has ADHD, dyslexia, dyspraxia and mild autism.

I would like to tell you my experience in navigating the school SEN system and trying to get official diagnosis for the children. My daughter has been waiting four years for an official diagnosis. Her high school said she was on a waiting list. All forms were correctly filled. Each time I called, I was fobbed off and told she was on a waiting list. On the day after her GCSE exams, I received an email from the school saying the SEN coordinator had spoken to her teachers and there's nothing wrong with her. So, the forms were discarded. This is after two years of me asking for updates. Girls are very good at masking autism and good grades do not mean she wasn't struggling incredibly with socialising, emotions and being in a loud, busy environment. So, the process has started again in college where forms were filled as she's waiting to be assessed.

A similar situation has happened with my son. The school has lost his forms twice. And apparently he is now on a waiting list to be assessed. This has taken a year and a half. So far, without assessment, the school is not providing adequate care, like timeout areas, extra time in exams and a computer for his dyslexia. I have not been able to claim PIP to help with the extra costs that are incurred with a SEN child. For example, a computer for homework, extracurricular activities for socialising and to help with pent up energy from ADHD. And costs with food as both children have a very restricted diet as a result of ARFID which is like a food avoidance.

Parents get desperate at this point and many feel the only way is to get a private diagnosis. My friend paid £1500 five years ago for this. No doubt that figure has risen by now. So children from poorer households, as my own, are definitely being left behind. I feel helpless. Unable to correctly support my children and constantly battling with the schools for updates. This is impacting both my children and my mental and physical health.

It has been so stressful not knowing the process and who to contact. I feel I am constantly trying to get the school to respond to me. To take me seriously. After all, I know my children best. And I can see the impact trying to behave, fit in and socialising at school has had on them.

I belong to a support group of mums with SEN children. Most of the children are in my son's year but have had to be home schooled as they could not cope. If the schools were more accommodating, or able to make minor adjustments for children and support parents, I think many could attend school again. For example, my friend's daughter has autism with severe sensory issues. She couldn't cope with the feeling of the school uniform. Her mom even sewed silk inside her school shirt but it still didn't help the child who was very distressed. If the school had let her wear the clothes she can cope with, she could have attended at least part-time.

There is an attendance crisis at the moment. With many parents home schooling, as they feel they have no other choice. With some minor adjustments, many SEN children could attend.

Going forward, we should mirror Denmark or Finland’s attitude to SEN children. That they have the right to be in mainstream schools. They are included with support in classes and not ostracised. The school's SEN program is run by the headteacher, who works closely with the parents to ensure an inclusive, supportive, positive environment is nurtured for the children. That should be a right for every child in this country, too. So all can enjoy the experience of school and achieve their potential.

Also, in light of the government's recent proposed cut to PIP rates. There will be even more of an impact on me and my family when I add this to an increase in energy prices yet again, and a massive percentage increase in my water rates. I feel hopeless. I already put every penny I have into the children and their needs. And I can't tighten my belt any further. There will be so many families that will be pushed further into poverty because of this decision by the government. I would urge you to reconsider.

Ella

I am a parent of two children currently in primary school, who struggle with dyspraxia, GDD (global developmental delay) and complex needs. It is a real pleasure to be here today, to be given the platform to draw collectively on our lived experiences and to hopefully help shape future policy for those who so often aren't able to speak for themselves.

I would start by saying, SEN Parents and their families have been living at crisis point for far too long. Every meeting I have had, and every SEN parent I have ever met is in agreement that nine times out of ten, there is no guidance on which 'pathway' your child is on, or what support is or isn't available to them. A lack of clear information leaves parents feeling lost in the system. The support available is inconsistent which means we are living in a postcode lottery which is failing monumentally. The unfortunate truth is that without a diagnosis, children and families are left in a grey area – somewhere between being noticed and ignored. A two-year waiting list on the NHS is not something that necessarily can be helped, but in the interim those families and children need support, rather than being left in limbo.

There is a lack of government support, for example, with school uniform costs. SEN children often have complex needs; as an example, my daughter's developmental disorder and dyspraxia grossly impacts her coordination, so we are on our 4th pair of school shoes since the start of the year. The financial support is lacking as is the emotional; SEN parents face an ongoing battle just to get their child an assessment of a condition, which involves 'proving' that what they are witnessing at home is true. This can be highly distressing whilst simultaneously navigating battles such as school refusal, depression, anxiety and extreme emotional dysregulation.

The crossover of systems between GPs, schools and hospitals is badly broken, and leaves children at the crux of a terrifying black hole. It took eight months before our school heard our pleas for help, and it was only when an occupational therapist supported us that our voice was finally heard. We owe it to our children, who will one day prosper into young adults, to not allow them to be the casualties of this nonsensical system. After all, it isn't their fault that they are born differently to their peers.

Parents need support to navigate this treacherous journey. They need helpful, and accessible information condensed into one place (for example, a website) explaining the process of what happens when your child is placed on a SEN register, for example. We need more SEN assistants in classrooms, because teachers are overwhelmed and unable to cope with students requiring extra *support. Families like mine and many others are left in the dark with no point of contact. We need family liaison staff who can guide parents through the SEN minefield, and an understanding that not every family can afford to 'go private' to achieve a diagnosis of their child. We need to collectively stand together and unite in finding a solution which helps, not hinders, the most vulnerable members of society. Our children.*

Challenge 3: Conditionality and SEN

Helen

Advocate, PDA (pathological demand avoidance) Expert, Administrator, Carer, Lawyer, Therapist, Mediator, Educator, Campaigner and Lobbyist …

All these roles go hand in hand with being the parent of a child with additional needs – I just want to be his Mummy!

Other than "Mummy" I go by the name Helen, I'm a single solo mum from Newcastle upon Tyne and I have an eight-year-old autistic son who is demand avoidant.

I'm currently training as a child psychotherapist; I work as a counsellor for neurodiverse young people. The majority of our caseload are not currently able to access education. I also work part-time as a special needs teaching assistant in a private girls' school.

As a SEN parent, life can be lonely, isolating, abusive, exhausting and relentless. I wouldn't swap places with anyone, though, but we need workplaces to be mindful of this.

Leaving the house is like planning a military operation: carefully chosen words, impeccable timing, bribes and rewards. Sometimes it ends up just being easier to stay at home.

I work very hard to make our life work. My money goes on supporting his special interests and buying the specific foods he will eat. I prioritise the needs of my child above everything! I know, metaphorically speaking, I should secure my own oxygen mask before seeing to his. I work very hard at maintaining my own mental health.

Other than 'home' my son's other happy place is school! I have an amazing relationship with the staff and we all work collaboratively to meet my son's needs. They have absolutely gone above and beyond to make sure he thrives. His attendance to date is 97% and above average for the school.

He currently has a 1:1 TA throughout the whole school day. This comes at a cost of £20K to the school. The school is expected to fund the first £6 thousand and the Pupil Premium allowance and Individual Pupil Support Fund contribute an additional £5.5 thousand. This leaves a shortfall of £8.5 thousand.

The school is carrying this deficit which is unsustainable. We are currently mid-way through the ECHP (education, health and care plan) process. IF we are successful, it is likely the maximum award would be Band D, which is the equivalent of £5.5 thousand, so there is still a shortfall. With only 7% PP population there is very little surplus funds available from the school.

So at present - Everything is going great! My worry is the future!

My son's school can't operate with a financial deficit.

If I have a traumatised, dysregulated child that can't (not won't) attend school then I am no longer able to work. Not only does this have a huge financial impact on our family but the wider picture of me not being able to support other vulnerable children in my professional role.

So my request, obviously, is that there needs to be more money within the system to meet the individual needs of the children with SEN.

Mainstream education is the best place for my child: he is very academically capable with the fully funded support that he needs.

We need more SEN hubs within schools that adopt a trauma informed approach to supporting children with SEN and those with mental health issues to allow them time away from the formal rigid classroom environment to recover from burnout and re-engage with education in a safe place which is supportive and nurturing.

Tayyaba

Let me tell you about my world, my universe, my son.

I am a single parent of a teenager. When he was in primary school, he had 100 percent attendance and was well mannered. The primary school teachers still praise him. Year 7 was a big transition to a new phase of life.

My son witnessed domestic violence against me by his father at a young age. He was beaten and bullied in school twice. Nothing was done by the school. It took three months to change my son's school. I have to fight with the system to get a new school. My son is now in year 9. He is struggling with physical and mental health.

Last week, one teacher called my son “dumb” even though they have been well informed for 2 years that he needs support. CAMHS, emergency services – we are still waiting for support today, and my mental and physical health are hanging on.

Throughout this time, I have been a key worker for the NHS. Sometimes because of the nature of contracts I have been in receipt of benefits while looking for a new job.

Employers and the Jobcentre need to understand the challenges that parents of children with SEN face. Recognising the work that goes into raising children with SEN, acknowledging that it may require more time, effort, and specialised care compared to parenting children without additional needs.

Parenting a child with SEN requires constant attention, adaptability, and emotional resilience. The work involves not only day-to-day care but also actively navigating complex systems of support (e.g., educational and healthcare systems). Parents are often advocates for their children, pushing for the necessary accommodations, therapies, and specialised resources to aid in their child's development.

Today I would ask for a broader recognition from Government of the "work" involved caring for children with SEN. Clear steps could be taken to make life easier for parents, including:

1. *Extend Paid Family Leave – Give parents of SEN children more paid leave to attend medical appointments, therapies, and school meetings.*
2. *Flexible Working Rights – Require employers to consider flexible working for parents to balance work and caregiving.*
3. *Specialised Childcare – Develop childcare options for older SEN children and teenagers, filling the current gap.*
4. *End Conditionality – Ensure benefit rules don’t unfairly penalise parents of SEN children.*
5. *No Sanctions – Remove the threat of sanctions, recognising the emotional and mental toll on families.*

I’d like to share a quote with you from Dr Haim Ginott: “Children are like wet cement. Whatever falls on them makes an impression."

Challenge 4: Childcare and Work

Sam

Covering childcare costs: The current childcare cap is £1014.63 for one child, of which 85% is paid for by Universal Credit, subject to income eligibility.

The current childcare cap needs to be raised to truly reflect the cost of childcare during the school holidays, as it stands presently, it is woefully inadequate. The childcare element of Universal Credit is predominately used by single parent households. In November 2024, 177,000 households received the childcare element of Universal Credit, of which 143,000 were single parent households. The households who predominately make use of the childcare element of universal credit are the most financially vulnerable, as there is only one working adult in the household.

There are 13 weeks of school holiday per year and 6 inset days. Parents on the childcare element of Universal Credit are self-funding large sums to cover school holidays. For example: My childcare fees from August 2024:

Summer club 7.30 a.m. to 6 p.m. from 1st August to 31st August = £1360.00

Childminder half fees (all childminders have this written into their contracts) for 1st August to 31st August = £397.00

£1360 + £397= £1757

Universal Credit childcare payment I received for August 2024 was around £850

Self-funded £907 pounds myself.

The childcare cap is capping parent’s ability to work and is a barrier to single parents entering employment. This is impacting child poverty as either parents are not able to enter the workforce or they have to limit their hours, or self-fund childcare during school holidays. The childcare cap is penalising the most financially vulnerable households in low-income jobs that do not offer flexible working arrangements or work from home options. The government childcare cap fails to take into account the burden of additional childcare payments for school holidays and inset days.

The universal credit childcare cap needs to be increased immediately. A rise in childcare allowance would have a huge impact on my son and I, instead of having to save money to pay for the additional childcare which isn’t funded during school holidays, we might be able to use the money for a holiday or other meaningful activities.

Additional challenges facing children with SEN:

This can be especially challenging as most childcare options are private, and the childcare provider is under no obligation to offer a child with SEN needs a place. They are able to do this by asking if your child has SEN, if you say yes, they ask for further details and then if they believe that they cannot meet your child's needs they can refuse a place. Any childcare places such as summer camps run by the council or local education authority tend to have limited hours. My son's school runs one for three weeks from 9.30 a.m. till 2.30 p.m. during the summer holidays; we are unable to take advantage of this because of my working hours. I think the summer camps run by the school are good, but they are not aimed at helping parents who work full time. Parents of children with SEN face many challenges, and the near impossible task of finding appropriate childcare is a barrier to employment. *The government needs to explore options to making childcare for children with SEN more accessible.*

Jo

Changing Realities is a group of people sharing experiences of surviving in the current economy on a low income. My hopes from a new child poverty strategy would be to involve more people with lived experiences to help advise of situations and where the current downfalls are.

When returning to work after my maternity leave, I had numerous difficulties in finding childcare, not only due to my hours of work as I needed a 6 a.m. start, which meant paying double time up until 8:30 a.m., but also in holding a childcare place, early on my son had speech problems so couldn't communicate as effectively as other children; although it was never directly said I know this was the reason for being sent home sick when he wasn't, resulting in me losing pay at work, still having to pay for the Childminder, and having numerous disciplinaries at work due to childcare issues.

I solely relied on a childminder as a single parent, but then it would be that the childminders didn't want to start work as early. I went through four Childminders in one year! At this point, I had had enough and thought, I'm going to train to be a childminder, so I contacted my local council and started an evening course. It became apparent through the training that there was no additional information provided on children with special educational needs. There was no extra support. There was no training or legislation on how to care for children with additional needs and no incentive around keeping children on even though they may be a little more work.

There is also a lack of support around what SEN means. It would be good if they could provide some sort of information pack with websites and further help socially or financially. The school wasn't very good at explaining what it all meant, and I think sometimes they can just assume that people know.

I believe a good policy to change around childcare could be to include extra training for childcare providers around children with special educational needs, and also to provide an incentive for childminders, some extra government funding such as schools receive for extra equipment and support, and also to include an incentive for retaining children.

I would like to keep working together through these sorts of meetings. I believe it is very beneficial to share experiences and advise from a point of view of people actually living on a low income, in the situations the government wants to discuss.

Closing

Sahar

In summary:

There is not enough support for teaching staff, according to the ratio of SEN children in class. We want to see more support – and more training – for all teaching staff.

Parents need to be educated as well, through school, with more information and support for parents and carers of children with SEN via school-led training programmes.

The education system needs to take responsibility and provide robust support for SEN children through to their career progression, including if or when they drop out of education.

More needs to be done to tackle poverty so that parents can support their children with SEN no matter what their personal circumstances are, including whether or not parents are able to work, or whose immigration status doesn't allow them to work. Because children have needs, and they deserve better.