

Hello. My name is Helen. Thank you for having me.

I am here to tell you about my son, his diagnosis, the problems we face in getting the correct services for him, and our experiences with local authorities, CCGs and NHS trusts.

In order to do so I must start by telling you about my caravan, and my recent acquaintances Brendan, Caira and Dennis.

Until September last year I had never set foot inside a caravan, let alone towed one. But at the start of the autumn school term, three days after passing my trailer test, I took to the road with a 22ft caravan and drove 120 miles to a campsite in a county I don't know.

My caravan has an awning on the side – a tent-like structure that gives me a glorified porch. Somewhere to hang wet coats and put welly boots. However, in bad weather it is the bane of my life. Much like the SEN team at our local authority it irritates me, frustrates me, and takes up a lot of my time.

January 14th this year was a night I will not forget due to my encounter with Brendan. Storm Brendan had me up at 3am in my pyjamas and welly boots, in the cold, holding down my awning while being drenched by the rainwater coming through the fabric roof, as 80mph winds did their best to blow the awning into the skies and take me with it.

My son does not sleep very well, as is the case for many cerebral palsy children. To add insult to injury, while I fought with Brendan, for the first time in a while he slept peacefully all through the night. I was not in a position to reap the benefit of this rare event. At least come the morning my awning was still standing, even if it did have a rather large tear in it.

Storm Ciara followed hot on Brendan's heels, but I was a little more prepared this time. I got storm straps for the awning, and called for reinforcements so I would not be alone during what was described as “the storm of the century”.

Life in a caravan is challenging enough, even without storms. I have to top up my water supply each day, dispose of my waste water and empty my toilet. Showering in a caravan is a bit of a squeeze, and washing a cerebral palsy child is even more awkward.

Toilet training a severely disabled nearly six-year-old presents many problems. I deal with (what we now call in our family) “poonamis” in a caravan with a child who is no longer a baby or a toddler, without washing facilities to hand. Dealing with a child's stomach bug in a caravan, having run out of your water supply in the middle of the night because you've already had to hose down your child once due to a toileting accident, is far from fun.

Not to mention doing this all by yourself, often in the dead of night. Not in a house, not with people around you to lend a hand, without access to a washing machine where you can quickly put a load on, but in a caravan, on a campsite, away from home, and all the while trying to keep your very loud and vocal child as quiet as possible in order not to wake fellow campers and caravanners and risk being chucked off the campsite.

And what about Dennis? Well, by the time Dennis came along I'd had my fill of storms, so we packed up, dismantled the awning, and headed back to a home made of bricks and mortar, with a proper roof.

Why am I telling you about my caravan? Because I live this way as my local authority cannot adequately meet my son's educational needs in the county we live in. I now have a school run of 120 miles, which requires a home away from home. Living in a caravan is the only way I can afford to do this, having looked into Airbnb and renting.

My son now attends Ingfield Manor School in West Sussex. We leave for school in the car at 5:30am on a Monday, and Wilf eats his breakfast in the school car park before he starts at 8:45am. We live in the caravan during the week and return home for the weekend on Friday after school to be reunited with his sisters and his dad.

My son is five years old and called Wilfred. Known as Wilf, Wilfie, Wilfo, Monster, Sleep Thief, and other names depending on what sort of chaos he has created at the time and what sort of mood we are in.

While it's easy to go straight into telling you about his diagnosis, I would like you to know that he can crawl around the house, he loves Hey Duggee, he has the best giggle you could ever hear, he enjoys whooping and clapping his hands in the middle of the night – as loud as he can – he can give the best 'dirty' look, and he can be both stubborn and lazy.

You see, it's so easy to go straight into telling you about Wilf's disability. And if I had done so, you would likely have conjured up a whole different image to the one you now have in your mind, hopefully of a cheeky five-year-old boy who wreaks havoc with my life and is not only brilliant but also annoying.

Wilf has four-limb cerebral palsy, he is globally developmentally delayed, has learning difficulties and is unable to talk. He is this way because he was born at 28 weeks' gestation, 12 weeks early, with meningitis, after my waters broke at 25 weeks.

Wilf was diagnosed with cerebral palsy at 16 months. It is only with hindsight that I am able to look back on that day and articulate what felt so wrong with the delivery of his diagnosis. I have sat in many paediatric clinics throughout my training to become a doctor, and for diagnoses of cancer, diabetes, epilepsy, asthma – conditions that impact hugely on your life – there is so often a specialist nurse who will spend additional time talking with you, going through things, giving you leaflets and information to take away.

For us, with this devastating news there was nothing. Cerebral palsy is a lifelong condition, there is no cure, and despite it being the most common physical disability in childhood there was little support in helping us as parents adjust to the new reality of our lives; a lifelong commitment as carers.

To make it worse, I was then told both his physiotherapist and paediatrician had suspected Wilf had cerebral palsy for some time. Why on Earth did they not tell me sooner? I'm a proactive parent, and had I known that the "golden years" for making the greatest

difference to my child's outcomes were the first two years, I would have got researching as fast as I possibly could to find more effective services.

The hardest things about being a mum to my little boy are the lack of sleep, the fact he cannot tell me about his day or tell me what's wrong when he's upset, and the obvious nightmares I have about his future and what happens to him when I'm not here anymore.

This is hard, but what makes it a lot harder is the constant battling with health professionals and health and education authorities, the chasing up of phone calls and emails and the feeling I'm constantly needing to prepare for a fight, that I'm an unnecessarily difficult parent with nothing better to do than kick up a fuss.

When you feel there is much more that your child could achieve, but at the same time you are told by your NHS physiotherapist that your then four-year-old son has already reached his potential, you feel angry and resentful that it seems they have given up on him before really starting to try.

This leads many parents of cerebral palsy children into a maze of research in an attempt to understand specialist areas of health and education as much as the professionals in order to argue their child's case.

Is it right that parents of cerebral palsy children have to make the SEND code of practice their bedtime reading in order to be able to fight for what is adequate for their children?

If there is anything worse than the sleepless nights and uncertainty of his future, it is being a parent to a child who is not progressing and learning, not curious about his world around him, and not exploring. Worse than that is not knowing how to support him, how to reach him in his world and see beyond your own physical, mental and emotional exhaustion to be able to relax and enjoy the journey you are on with him.

Life as a SEND parent can feel desperately lonely, particularly when you do not know and are not shown how best to support your child and provide for his needs. You cling on to the tiniest achievements as proof you are not failing in your job as a parent. Hospital appointments are dreaded, as the professionals you feel have already failed you proceed to tell you to stop aiming for anything bigger.

You may be wondering if this is the case for every SEND child and their family, but things are very different for children with cerebral palsy. The interplay between their physical and learning disabilities presents with a unique set of problems that places them in an unusual position, which does not seem to be appreciated by many education and health professionals.

The Conductive Education Professionals Education Group and the Professional Conductors Association describe the plight of a cerebral palsy child really well when they state: "Disturbed mobility is accompanied by a challenge in the ability to perceive. The impeded movement can restrict or prevent interactions with people and objects which assist with development. Therefore the ability to adapt formatively to the demands of the environment and to engage in constructive interplay can be affected. This can result in negative

experiences and frustrations which in turn affect personality. The dysfunction of the personality in turn restricts physical development and so the circle begins."

Notice, I have not once said that the hardest thing about having Wilf as my son is his lack of mobility. People assume the biggest thing that impacts upon the lives of cerebral palsy children and their families is their physical disability. Many professionals in fact, both in education and health, although mainly in health, also see cerebral palsy in this way.

They do not understand the hardest challenge is not the physical disability but the mental one, the inability of your child to learn. And the learning disability makes the physical disability all the more difficult to work with.

Physiotherapy is only a part of the solution, and it needs to be regular and intensive in order that constant repetition is learned. It is useless when it is sporadic in its provision and generic in its approach, as if it can help all cerebral palsy children in the same way as other children who do not have a learning disability.

When physiotherapy is delivered by therapists who are not specialised in cerebral palsy, and in brief episodic spurts, it does not work well. In Wilf's case, he disengaged – not only from physiotherapy but also from other therapies – and as a result he was referred for an assessment for autism. As we later discovered with him attending a specialist school for children with cerebral palsy, Wilf is very likely not autistic. He was probably just bored, possibly frightened, and I imagine he had given up on believing people would understand him. He also lacked a peer group he could relate to and learn from and with.

Cerebral palsy children are uniquely complex, and there are great educational approaches available for them, but not in every local authority. This is where the current system lets down those children. And this is why each week we have to travel to a different county that caters for cerebral palsy children better than the one we live in.

Before I tell you about where Wilf is today and how magnificently well he's doing now, I'm going to rewind and take you back to the spring of last year. After almost a year at our local special needs school, it became apparent Wilf was not making progress and lacked sufficient engagement that would enable him to learn.

As a doctor, my medical training has taught me about the importance of neuroplasticity. I knew the ability of Wilf's brain to lay down new connections was lessening over time, and that something needed to change quickly.

We are talking about a then four-year-old boy who did not have a reliable system for communicating his choices, ate with his hands as could not use a spoon, could not tell me when he had done a poo, could not stand independently or step, who outright refused to try different foods and who was not able to engage in order to learn. His world was becoming smaller and smaller. It was getting harder and harder to reach him.

Wilf was at a brilliant special needs school, one that is able to take children with the most complex medical problems, severe special needs and profound and multiple learning difficulties. The staff are dedicated and immensely caring. Wilf was in a class of up to ten

children, all of a similar age. However, there was only one other child with similar mental and physical challenges to himself.

At first we thought Wilf was happy at the school because he did not complain or play up. With hindsight, I now believe he had given up, switched off and disengaged in a class which, despite the efforts of the staff, was probably quite intimidating.

Imagine being strapped into your wheelchair, unable to move. With you is someone who keeps running around you, flapping their hands, screeching, and is unpredictable. Physically they are very able. Not only are you unable to move – even if you had the ability to do so – but you can't even tell someone how you feel about this. You are unable to defend yourself and you don't know how to make sense of the world around you.

Without the correct, sensitive, intensive and specialised input required for their education, for their life, and without a peer group of similarly challenged children and the possibility of friendships with people who they can relate to, what are cerebral palsy children to do and how are cerebral palsy children to progress?

Wilf's local special needs school was not in a position to adequately meet Wilf's needs. The staff – although able, enthusiastic and dedicated – were not adequately supported by physiotherapy, speech and language therapy and occupational therapy. Yes, those services/modalities all existed somewhere in Wilf's education, sporadically, but none of the dots were joined up, and Wilf lacked professionals that were working together, all singing from the same hymn sheet. More than that, he lacked the therapy professionals to work alongside his teachers who were ambitious and had high hopes and expectations for him. Tasks and activities were not meaningful to him because they were delivered in a way that did not make sense.

The local children's therapy team had apparently assessed Wilf, and had reassured us the provision offered was not resource-led but specific to his needs. Yet their assessment of his needs meant he was granted just one visit from physiotherapy every half term – for a four-year-old boy with four-limb cerebral palsy who was not progressing.

His school was not even given his physiotherapy care plan until a few weeks before the end of the school year, some eight or nine months after he started there, and that only happened as a result of me jumping up and down and making a noise about it. His physiotherapist had never even checked the skill set of Wilf's staff team in order to carry out his care plan.

Speech and language therapy provision was also very limited – his school has its own very capable speech and language therapist, but her job was only funded on a part-time basis and she had nearly ninety children to work with in a limited time. In addition, Wilf was not properly visited by occupational therapy during his first year in school. How can this be acceptable?

As Wilf turned five and the end of the school year drew close, I started to wonder how any child such as Wilf could have any hope or opportunity of progressing and understanding their world. I started to lose faith that Wilf would be given the tools to learn and to show he

could do things for himself. I started to despair that, as parents, we were not being shown how best to support our child as he retreated further and further into his own little world.

So we went on an adventure. Having heard of conductive education – an intensive and specialised educational approach devised by the Peto Institute in Hungry for children with cerebral palsy and other neurodevelopmental problems – we booked a visit with the Rainbow Centre in Fareham. In just one trial session, and after only a couple of hours, the Rainbow Centre's conductors seemed to know more about our son than all the health and education professionals we had dealt with put together over the previous five years. They observed him, interacted with him, challenged him, stretched him, talked with him, introduced methods for him to communicate back, and introduced him to other children who were similar to him. In many ways these people could speak his language.

Not only that, but for the first time ever we as parents were shown how to support our son, how to push him, where in our daily lives we could offer him new opportunities, and ways of incorporating language into his day that showed promising signs of him understanding and responding to. We finally had hope, and we were excited at the prospect of him being able to learn and communicate in a way that was meaningful to him.

There is a reason why a number of conductive education centres have very early intervention for cerebral palsy children, called "school for parents". Not only do they realise that early intervention is absolutely vital in giving a brain-injured child a fighting chance, but also that parents need a proper education specific to CP to help them feel empowered and able to support a child whose learning does not come automatically and naturally to them.

For example, I've never toilet trained a child that has a normal development, so where on earth was I going to start with a child that had profound and multiple learning difficulties and was severely disabled?

Unfortunately, the Rainbow Centre was not able to offer Wilf a full-time place, as it was not a full-time educational setting for children of Wilf's age. By this point, he was already too old for 'early intervention'. And yet nobody had said this service existed and was free as part of early years funding. Why was this? How is it that parents of cerebral palsy children can not be told of services that exist specifically for children with cerebral palsy?

Wilf's physiotherapists had neglected to inform us about the Bobath Centre for people with cerebral palsy, despite a number of them having trained in Bobath therapy. Wilf was not even assigned one of the Bobath-trained physiotherapists at his local children's therapy centre.

When I called the Bobath Centre in London to find out more about what they could do, by chance I was invited to apply for a free week of intensive treatment for Wilf as part of a study into early intervention. Yet when I asked for a report by way of a referral, to back up our application to the Bobath Centre, his physiotherapist said she felt it unnecessary for Wilf to attend and she would only write the report if she had time. Make of that what you will.

Having seen the level of expertise of the conductors delivering conductive education, and the effect of just one session, we were certain this was a teaching approach that would work much better for Wilf, and help him develop some life skills which had meaning to him.

We travelled far and wide around the country, from Ingfield Manor in West Sussex, to the National Institute for Conductive Education in Birmingham, PACE in Buckinghamshire and other schools for cerebral palsy pupils that were closer to us geographically but without conductive education at the heart of their curriculum; Treloars in Hampshire and Victoria in Dorset.

Wilf had visits, trial days and assessments. Every school we visited felt they would be able to meet Wilf's needs but all were concerned that his lack of engagement was too severe and that he was on the autistic spectrum.

And so our work began with building a case for Wilf to access conductive education. What we wanted was conductive education to be provided by our local authority, and we asked if this was an option – preferably at the school he already attended so that its other cerebral palsy pupils would benefit as well and we wouldn't have the upheaval of a move to another county. The alternative was for Wilf to be placed at a separate specialist school already offering conductive education.

We spent weeks researching, gathering evidence, getting advice. Many times we were told to enlist the help of a lawyer or advocate, but we could not afford to do that.

A team-around-the-child meeting was arranged where all of his professionals were invited to attend, including the SEN team, his head teacher, his paediatrician, physiotherapists, occupational therapist and the Designated Clinical Officer (DCO) from the CCG.

Despite showing video evidence of Wilf engaging at the conductive education centres we had visited, the children's therapy team refused to support our request for Wilf to receive conductive education, saying that they could not support it due to the lack of evidence.

Wilf's physiotherapy team, whose members are trained in Bobath therapy and embrace it despite the evidence to support it being mainly anecdotal, also refused to support our request for conductive education – on the grounds the evidence in support of conductive education was mainly anecdotal. Again, make of that what you will.

Wilf's paediatrician talked about the lack of good quality evidence, but acknowledged his lack of engagement and conceded that the current approach was not working. She remained open-minded and supportive while staying true to the evidence.

While Wilf's health and therapy professionals were recalling problems that were identified with conductive education back at the time of its inception in the 1980s – seemingly unaware of how it had moved on and developed since then – the representative from the SEN team had never even heard of conductive education in the first place.

And I kid you not, in that meeting when I said Wilf had not progressed and was not learning any life skills, such as learning to use a spoon, his occupational therapist turned to me and said: "You didn't tell me you wanted him to learn to use a spoon."

Why else was Wilf attending school? To learn history and chemistry? He was there to learn life skills that offered him the possibility of greater independence. Whilst professionals resist EHC Plans being too prescriptive, if the detail is not in them, it does not seem to happen. That was our experience.

What became strikingly obvious was the belief among professionals that once a child entered our local special needs school, their therapy needs would be met automatically. And so when we expressed our concerns, and argued our case that Wilf's education and therapeutic provision was inadequate, everyone looked stunned because his school was held in such high regard and had a waiting list for children to be enrolled. But with Wilf, according to the school's own reports, he was not progressing.

In a separate conversation with the DCO, who also had not heard of conductive education, I was told the local authority had a duty only to provide Wilf with a school place that was adequate. Thankfully we were able to prove that Wilf's provision was not adequately meeting his needs, and we had the evidence to prove it.

The result was that our local authority agreed the funding of Wilf's school place at Ingfield Manor for two years, at which point his progress will be reviewed.

My experience tells me that local authorities seem to be basing their decisions on whether or not to grant additional funding for school places, not necessarily on need but on the legal advice they receive as to their chances of winning or losing a case if it is to go to tribunal.

Not only have I swotted up on the therapeutic and educational approaches for cerebral palsy children, I have also had to familiarise myself with the related legislation, an area that until about a year ago was foreign to me. It is only when armed with those things, that you can argue and articulate your case about what local authorities need to do in order to adequately meet the needs of your child. But that takes time, it takes over your life, and there are many, many children who are missing out as a result.

The local authority only has a duty to place a child in adequate provision. What does that even mean?

For most parents, adequate educational provision may be the difference between their child getting greater depth or acceptable in their Year 6 SATS, achieving GCSEs or not. For Wilf, and for many other cerebral palsy children, it's the difference between learning to use a spoon or eating with hands, it's the difference between learning to support his own weight when transitioning from his wheelchair to a toilet rather than having the house kitted out with hoists, it's the difference between him being able to tell us when he needs to poo or him simply spending the rest of his life solely reliant on giant nappies. It is the difference between him learning life skills that parents of neurotypical children take for granted, or him retreating further and further into a world where I, his mum, cannot reach him.



So, what does adequate mean for cerebral palsy children in particular? It means specialised, intensive education and therapy, which for a child with cerebral palsy is one and the same, in a joined-up approach that offers meaning, with a peer group that cerebral palsy children can relate to and learn with. Wilf has benefited hugely from conductive education, and many of the specialist schools offer conductive education, or have themes of this approach running through their school day and curriculum.

My work as vice chair of governors for Wilf's previous special needs school, a role I continue in and commute from Sussex to fulfil, has shown me that special needs schools seem to be overwhelmed by pupils with severe autism and challenging behaviour. I totally agree with the report of the 2014 parliamentary enquiry on cerebral palsy, entitled 'Enabling potential – achieving a new deal for children with cerebral palsy', which stated "cerebral palsy is a non-subject" for the education sector. Where are all the cerebral palsy specialists? There are whole communication strategies for autism and subsequent specialist workshops for professionals. Where are they for cerebral palsy? Very little appears in the local offer for CP children.

Picking up more on what I've said about education and therapy being one and the same for cerebral palsy children, this is what causes massive fundamental problems in the joining up of services for these children and families. Both in education and health, as well as social care.

Health and education authorities alike get their knickers in a twist because they can't get their heads around the fact that Wilf's physiotherapy is his education, his speech and language therapy is his education, and his occupational therapy is his education.

This is where the uniqueness of cerebral palsy confuses education authorities and health trusts, and no one knows how to move forward.

So where is Wilf now? He is halfway through his first year at Ingfield Manor. He is in a small class of children, all of whom have cerebral palsy or similar.

Within two weeks he transitioned totally on to school dinners, and just half a year in he has been using a spoon for some time and he is now trying a fork. He is also sitting on the toilet – and delivering – and the communication around toileting is now slowly being introduced. He is making choices with the use of PECS and the PROX pad, and is given constant opportunities to show he knows what he wants and that he can make a choice.

He is not only standing, but he is side-stepping, and stepping forwards with a ladderback chair. The staff working with him have high expectations, and he now walks between classrooms with walking aids. He has progressed from needing very supportive specialised seating to small wooden healthfield chairs where he sits upright and sits beautifully. He is watching the other children, taking in what they are doing, and he is copying certain things, spurred on and motivated by watching them.

On one occasion he even said "awbry" when asked if he wanted a chocolate custard or a strawberry custard, and he is actively helping with getting himself dressed and undressed.

My son is now learning to enjoy being with his friends, and to care about them. Recently, when a little boy in his class got upset, Wilf held out his hand to comfort him and they sat there in their wheelchairs holding hands. He is finally with other children who are like him, with whom he has the ability to make friends.

As a parent, to finally see your child engaging and enjoying the world around them is the best feeling ever, and it makes all the current upheaval worth it. But it's a hard journey to go on, because in reality the professionals that now work with Wilf on some levels know him far better than I do. The staff at Wilf's school are in effect teaching me about my own son. It's very hard to describe how confusing this dynamic can be. This is both liberating and demoralising - but it's the way it needs to be and I'm incredibly grateful to the school.

Parents like me, who have a cerebral palsy child, are at the mercy of the professionals local to them, and the knowledge and skill sets they have. While there is no standardised pathways of care that everyone has a duty to follow, there is most definitely a postcode lottery. Wilf is lucky because he comes from a large family that is trying to support us on this journey. But unfortunately the current political and economic climate means that those who shout the loudest wins.

So where does that leave me now?

Honestly, I feel angry. This is not the life I imagined for myself. I have put my medical career on hold and therefore my ability to earn a reliable wage and to gain financial security. I have split our family up and live in a caravan in order for Wilf to get an adequate education.

I have no shame in telling you that the most useful thing about having my doctor title so far is that, as Wilf's parent, I have been listened to and people take more notice. The combined voice of a doctor who knows how to research a case, at least to some degree, and his father being a journalist who can articulate that case, is a strong voice that is likely to be heard. And while Wilf has benefited, it is simply not acceptable that those who shout the loudest are more likely to get their children's needs met.

Selfishly, I've done exactly that for my son. Wouldn't you? Yet while everyone in this room would be capable of fighting their child's case by themselves, most of those who need legal representation would simply be unable to afford it. This isn't just neglectful, this is disgusting.

I am angry that during a meeting with the DCO, he told me that parents should take more ownership of their children's education, health and care plan (EHCP). Yet when it comes to the challenges of cerebral palsy children, I don't even think the local authorities know what to do with the EHCPs of these children.

I am an educated woman and thought that Wilf's EHCP sounded OK when I first read it – that's if you apply a degree of common sense, and assuming the professionals do go on to provide services according to need rather than resources. However, in the end I was forced to take ownership of his EHCP. I rewrote it for his SEN team, quantifying every single input that was included. And nearly eight months after his last review, I have yet to receive his amended EHCP – perhaps at his next review we will get the paperwork from the last one. I

am also waiting to hear whether the £500 per month I pay in campsite fees will be reimbursed. I have reached the point where my next email to the SEND team will simply say: "Hello, is anybody there?"

I am angry that our local children's therapy team has more or less washed its hands of its obligation to provide hands-on, regular physiotherapy for Wilf because now he attends an out-of-area school. I never knew that where a child went to school would impact on their ability to access NHS services. The NHS/CCG don't even contribute financially towards the commissioning of Wilfred's school place, so how dare they?

I am angry that I have to spend time explaining to Wilf's local continence team that my now nearly six-year-old boy needs more than three nappies in a 24-hour period. And that, no, he does not need to see a doctor to see if anything is wrong from a health perspective – it's simply that he does not want to sit in his own excrement for several hours at a time.

What are we going to do about this? What are you going to do about this?

When are local education and health authorities going to put on their big girl/boy pants and start grown-up conversations about ways forward, together, in meeting the needs of cerebral palsy children?

To put it bluntly, I'm only five years into this game, and already I'm pretty fed up. It is clear to me, as I'm sure it is to many of you, that there are better ways of doing this. Better for my son and for children like him. Better for parents and carers like me. And better for taxpayers and society generally.

Ends