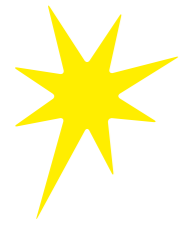




# Impact Report 2024

**CEREBRA** 

Working wonders for children  
with brain conditions



# Together we are working wonders for children with brain conditions

At Cerebra, we are driven by a simple yet powerful belief: every child with a brain condition deserves to thrive. Everything we do is focused on supporting children, families, and carers to achieve this goal.

Over the past year, thanks to the generosity of our supporters, we have continued to transform lives. This impact report highlights just some of the initiatives we have delivered and the children and families we have supported.

Impact takes many forms. It can mean influencing government policy to ensure that children are included and their rights protected, producing groundbreaking research that deepens our understanding of complex conditions, or it can be something as simple as the joy of reading a good book. Whatever the change, if it matters to the children and families we support, it matters to us.

The achievements shared in this report are only possible because of our dedicated supporters. There are so many incredible people who help us to do what we do. Whether you are a regular giver, a lottery player, a fundraiser, a Foundation or one of our incredible corporate partners, your commitment helps us provide vital support so that children with brain conditions and their families do not face their challenges alone.

Looking ahead, we are ambitious about the change we can create. We recognise the growing demand for our services and are determined to be there for every child that needs us. We will continue to drive pioneering research, expand our life-changing support services, and develop innovative solutions tailored to families' needs.



Jess Camburn-Rahmani  
Chief Executive Officer

With your support, we will make an even greater impact.

## Thank you for being part of this journey. Together, we are changing lives.

## 2024 at a glance:



We spent **£481,458** on life changing research.



Our Sleep Service helped **861** families get a good night's sleep.



Our Legal Rights Service helped **104** families access public services.



We lent **1,266** books and toys to help families learn and play.



Our information resources were downloaded **43,053** times.



Our Innovation Centre helped **123** children discover life and have fun with their friends.

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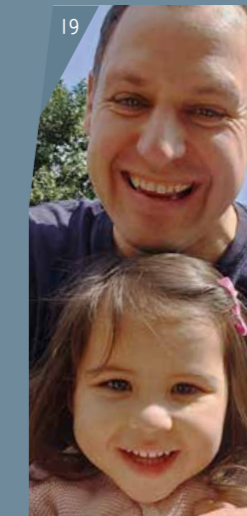
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By 'brain condition', we mean any neurodevelopmental condition that affects the developing brain, including those caused by illness, genetics or traumatic injury. Brain conditions include (but are not limited to) autism, ADHD, Down's syndrome, learning disabilities, cerebral palsy, epilepsy and developmental delay.





# I. We use what families tell us to inspire the best research and innovation

In the UK today there are around half a million children and young people with brain conditions that result in complex medical, educational and social support needs. Our research work across neurodevelopmental conditions gives us a unique perspective within the charity research sector that allows us to provide research-driven solutions and advice to those who need it most.

We want to see a world where neurodiversity is respected and celebrated and where children with brain conditions get to fulfil their greatest potential without barriers to their participation in society.

Read our Research Strategy in full on our website.



## Summary of completed research in 2024

In 2024 funding of four of our research projects came to an end:



Professor Eduard Gratacos discussing ultrasound scan as part of BCNatal research project.

### Preventing Prenatal Brain Damage with New Tools for Improved Risk Identification and Therapy

Barcelona's Clinical and Research Centre of Maternal/Foetal and Neonatal Medicine (BCNatal)

Neurodevelopmental disorders affect approximately one in ten children, with many cases originating before birth. Even subtle disruptions in the womb environment can hinder brain development, leading to long-term effects on learning, memory, and social skills.

The team's research helped to identify at-risk pregnancies and develop early interventions to minimise impacts, providing children with the best possible start in life. They conducted ground-breaking work in identifying foetal conditions that can lead to neurological damage, developing diagnostic imaging tools, and exploring preventive therapies.

The project's success in developing tools and interventions to support healthy pregnancies potentially has long-term impact on public health policies and prenatal care standards worldwide.

Read more about the research project here:



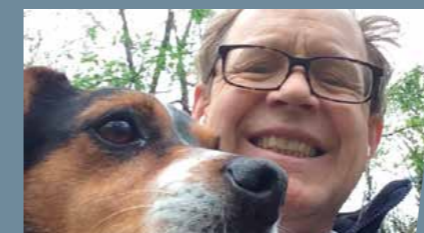
## Preventing Neonatal Brain Injury and Childhood Disability

University of Leeds

Neonatal brain injuries have significant and lasting impacts on children's cognitive, social, and academic potential. These injuries are often associated with pregnancy complications such as foetal growth restriction (FGR), pre-eclampsia (PET), and preterm birth (PTB), conditions that affect up to 20% of pregnancies and can lead to irreversible outcomes.

Research increasingly reveals the placenta's critical role in the health of both mother and child and the team conducted ground-breaking work to uncover key insights and develop innovative tools to reduce the risk of brain injury in newborns.

The establishment of a robust placental tissue bank, advancements in 3D imaging and analysis, and the development of new methods for identifying biomarkers have set the stage for lasting improvements in neonatal and maternal health.



Mr Nigel Simpson, University of Leeds

Read more about the research project here:



Dr Caroline Richards (University of Birmingham)



Dr Hayley Crawford (University of Warwick)



Dr Jone Waite (Aston University)



Dr Jo Moss (University of Surrey)

## Celebrating Progress in Neurodevelopmental Research

Cerebra Network for Neurodevelopmental Disorders (CNND)

Children with rare genetic syndromes often experience co-occurring challenges, such as anxiety, sleep difficulties, and behavioural issues, which can severely impact their development and quality of life. Traditional care approaches often fail to account for the complex interplay of these conditions or the unique needs of affected families.

By creating a unified, interdisciplinary Network, we aimed to address these gaps through holistic solutions, drive meaningful change, and develop interventions that empower families and improve outcomes.

The Network's achievements provide a blueprint for sustainable, impactful research that bridges the gap between science and real-world application.

Read more about the research project here:



## PosFam – A positively-oriented, family systems intervention for families of children with developmental disabilities

University of Warwick

Parents and caregivers of children with developmental disabilities often experience higher stress levels, reduced relationship satisfaction, and an increased prevalence of mental health challenges.

Despite the availability of support programmes, few emphasise positive outcomes like wellbeing and strong family relationships. This research aimed to co-create a positively oriented intervention and evaluate its feasibility.

The Positive Family Connections program exemplifies the potential of co-produced interventions to create meaningful, long-term change. We envision a future where co-produced, strengths-based family interventions are widely adopted, providing essential support and fostering resilience for families of children with developmental disabilities.



Dr Joanna Griffin (University of Warwick)



Daniel Sutherland (PhD Student)

Read more about the research project here:



## Additional research projects in 2024 included:

### Digital Wellbeing Interventions for Family Carers: A Systematic Review

University of Warwick

The research team carried out a systematic review of all the current academic research on digital interventions that are available to support family carers whose loved ones have a learning disability or are autistic.

Family carers were partners in this piece of work. Their role was to offer insights from their lived experience to the researchers with the aim of improving the quality of the research.



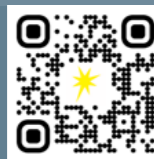
Ellie Finch (above), Debbie Thompson (right) – family carers involved in research at the University of Warwick

Debbie Austin took part in the research as a family carer:

*"When I was asked to be involved in a systematic review, I was not sure that I would have anything to offer. My involvement and that of my family carer colleague was to view the results from a family carer perspective and to offer comments to the researchers. At every meeting we found there were questions to ask, and we made contributions that were welcomed. If you are a family carer with no background in research and are asked to participate in a research study – please know that you do have something to offer. Your insights from your lived experience will bring a different perspective and your participation is genuinely valued".*



Read more about the research project here:



### Tailored Sleep Interventions in Neurodevelopmental Conditions

Researchers at Aston University have been working in partnership with Cerebra to understand how practical and effective behavioural sleep interventions are for children with neurodevelopmental conditions.



Georgie Agar

Led by Georgie Agar the project aimed to examine whether tailored sleep interventions improve children's sleep, daytime behaviour, and caregiver wellbeing.

This research directly informed a research project within Birmingham Community Health Care NHS Trust looking at clinicians' perspectives on sleep difficulties and interventions in children with NDCs. Taken together, these projects have identified areas where more sleep training and support are needed for both families and professionals.

The research assistant who worked on this project, Miriam Shabetai, has recently started her PhD looking at sleep in adolescents with mild-moderate intellectual disabilities.



Miriam Shabetai

Read more about the research project here:



## Our research events in 2024:



2024 Student team at the University of Leeds, School of Law

### Conference

#### Systems Generated Trauma

Professor Luke Clements, Cerebra Professor of Law at the University of Leeds

In 2024 we began a research programme to better understand the nature, prevalence and impact of Systems Generated Traumas on disabled children and their families.

The associated conference aimed to generate awareness and debate about practical solutions for families. By sharing solutions as widely as possible, we can ensure that many families can benefit.

*"We hope that this event and our research concerning 'Systems Generated Trauma' will bring about meaningful change in the way public services operate."*

*"Social welfare agencies must understand the harm that their systems and their practices are causing to those that approach them for support. This understanding should then result in fundamental revisions to their policies and their practices – so that those in need of assistance are not traumatised but supported."*

Professor Luke Clements, Legal Entitlements and Problem Solving Project (LEaP)

The full report into Systems Generated Trauma will be published in 2025.

### Cerebra Webinars

#### 'Sleep Problems for Children with a Genetic Syndrome'

Professor Caroline Richards, Cerebra Network

Delegates told us:

*"It was refreshing to hear some evidence that supports our experiences working with young people and reassuring to know that an evidence base is building up to inform support pathways and options in the future."*

*"The messages from the parent talks about allowing an alternative sleep pattern to exist in a young person and how to support this practically was also a refreshing approach and a helpful perspective based on real life experience."*

#### 'Diagnostic overshadowing for children with a genetic condition associated with an intellectual disability'

Dr Jo Moss, Cerebra Network

Delegates told us:

*"My main takeaway from this event was to always first consider that could there be something else going on rather than assuming it's the main diagnosis."*

*"I have never felt that my son was wanted by society, until I attended this event."*

The webinars are available to watch on our YouTube channel.





## 2. We provide families with the highest quality evidence-based information and support

From our Information Resources to our Sleep Advice and Legal Rights Services, Postal Lending Library and Innovation Centre, we give families the advice and support they need to overcome challenges and discover a better life together.



## Information Resources



We publish a series of guides and factsheets to help families of children with brain conditions with common problems they may be facing.

From physical and mental health, financial and legal affairs, to education and finding information, our resources are free to download from our website.

85% of users who gave feedback rated our guides as excellent.

Our top 5 downloaded guides and factsheets for 2024 were:

1. Disability Living Allowance Guide	13,721
2. Sleep Guide	3,885
3. Sleep Tips	3,096
4. Sleep Cards	1,206
5. Sensory Processing Guide	1,196

Parents told us:

*"Our son is autistic with high anxiety which can prevent him from leaving the house. The Cerebra guide was very detailed and comprehensive. I think without it my application for DLA may not have been successful or may have resulted in a lower rate being awarded. The money from the DLA helps to pay for taxis as we don't have a car, and I is anxious about using public transport. It means he can visit his dad and his grandparents and get out of the house".*

*"Our 2 year old daughter lives with epilepsy. I found your guide to completing the DLA application - what an amazing treasure trove! It's been incredibly useful. I felt confident in applying and two years in a row now I've been able to secure the highest rate for DLA for our daughter, allowing us to pay for physiotherapy and osteopathy for her".*

### Self-injury in children with intellectual disability

In 2024 we published new resources for parents and carers to help them understand self injury and challenging behaviour.

## Sleep Advice Service

Our Sleep Advice Service offers a range of information and support to help children – and everyone in the family – to get a good night's sleep. Alongside our Sleep Guide and resources, we offer one-to-one support for families.

Short and disrupted sleep is common in children with brain conditions and specialist advice is needed to overcome the complex challenges they face. Our Sleep Advice Service is unique in being able to provide the tailored support that children with a brain condition need.



### How Our Sleep Service Helped:

In 2024:

We received 2,750 self-referrals through our website and helpline

We helped 663 families on a one-to-one basis

198 people attended our seminars, workshops, webinars and courses

Our sleep resources were downloaded 8,187 times

Parents told us:

*"Without tempting fate, sleep is so much better. (Child) now goes in his cot awake at 7pm and gets himself to sleep. We haven't had him wake up at night now for around 4 months. He's still an early riser but he entertains himself in his cot when he wakes up until we go in and get him. On the whole things are so much better. Can't thank you enough for your advice".*

*"C struggles sleeping and can get tired and very overwhelmed very quickly. This means that sometimes the whole house is up from the early hours or one parent's up most of the time with him, so it becomes very tiring, and we don't feel like doing anything. We received a lot of information about anxiety, sleep and other struggles within the home, some very informative workbooks and suggestions for various aids of support that were cost effective for us to use to try help C sleep a little better. It has definitely made a difference. C may not still be sleeping as well as we would like but we have got lots of tips and tricks and aids that we can use. We have had occasions where he has slept really well too".*

*"I needed support and advice on how to support B with her sleeping pattern. I was able to get advice on the tools and strategies to help B's sleep. It's made so much difference because I have more knowledge on how to help improve how she sleeps".*

### Sleep Training for Professionals

We have developed high-quality training to equip professionals with the knowledge and skills to support children, particularly those with additional needs, with their sleep.

This training means that professionals, from health workers to educators, can access high-quality, research-backed training to make a tangible difference in the lives of children and families.

In 2024 we launched two key accredited training courses.

#### Delegate Feedback:

*"The use of the online videos in the initial stages was invaluable as gained so much knowledge just from these. The whole first day of face-to-face was also fantastic, just the concept of looking at sleep difficulty in a completely different way to consider the child's whole day with focus on sensory, pain, diet, anxiety, support networks etc. was invaluable and a completely new perspective. It was also clear that you were all so passionate and overall, the course content was brought alive because of your clear passion."*

## Legal Rights Service

Public bodies in the UK have certain duties to provide health, social care and other services for disabled children. But many families encounter difficulties. Our Legal Rights Service provides families of children with brain conditions with help when facing challenges accessing support services they are entitled to.

We provide help through our unique Legal Entitlements and Problem-Solving (LEaP) Project, our Accessing Public Services Toolkit and workshops along with a range of template letters to make it less daunting for families who need to write to their local council, social services or health body.

In 2024 we helped 104 families with specific information:

Social care	34
School transport	22
Disabled Facilities Grant	15
Education	13
Safeguarding/child protection	6
Health	5
Continence services	5
Transition	3
Clinical negligence	2
Family Law	2
Total	107



Our Legal Rights Service in 2024:

Our Accessing Public Services Toolkit was downloaded 1,177 times

Our legal rights template letters were viewed 945 times

We held 5 Problem-Solving Workshops

94% of attendees reported that the workshop had improved their knowledge on how to access public services and that they now had the confidence to try this at home

Parents told us:

*"I've just got off the phone from Social Services and they have awarded us 8 of the 12 hours we asked for. Thank you ever so much for all your help. Providing me with all the information and helping me to make it clear in my own mind. Honestly, I am so very appreciative".*  
(Social care and Parent Carer's Needs Assessment)

*"I can't thank Cerebra enough, not just my family but many other families in (the local authority) have benefited as a result of the advice that Cerebra gave which allowed us to challenge the LA's unlawful policies."*  
(Social care support)

*"I would like to express my gratitude for your support! R's transportation has been granted and he will be taken from Monday. It's a huge relief for me. Thank you for all your support."*

(School transport)

## Library Service



Our specialist Postal Lending Library helps families to play and learn. We have a wide range of books for both adults and children and a selection of toys specially chosen for children with brain conditions.

In 2024:

We helped 422 families

We loaned 1,266 items

100% rated our service as excellent



### Our book library

has titles on a variety of topics for both adults and children.

In 2024:

We loaned 652 books

88% said the book improved their understanding of a condition

90% said it helped them meet their child's needs

44% reported it improved their ability to access services for their child

44% said it improved their child's understanding (if a child's book)

Our most popular books for adults were:

1. 'A Different Way to Learn: neurodiversity and self-directed education' by Naomi Fisher
2. 'Raising an ADHD Child: a handbook for parents of distractible, dreamy and defiant children' by Fin O'Regan
3. 'Nurturing Your Autistic Young Person: a parent's handbook to supporting newly diagnosed teens and pre-teens' by Cathy Wassell

Our most popular books for children were:

1. 'ADHD is Our Superpower: the amazing talents and skills of children with ADHD' by Soli Lazarus
2. 'Superhero Brain – explaining autism to empower kids' by Christel Land
3. 'All Cats Are on the Autism Spectrum' by Kathy Hoopman



Our BorrowBox service allows families to borrow e-books and audiobooks using the Borrowbox app and website.

In 2024:

We loaned 351 BorrowBox books

Our most popular BorrowBox loans were:

Adults:

1. 'Your Child is Not Broken' by Heidi Mavir
2. 'Explosive Child' by Ross W Greene
3. 'ADHD Parenting a Complex Child' by Jennifer Mindlin

Children:

1. 'Matilda' by Roald Dahl
2. 'Hey Jack' by Sally Rippon
3. 'Feelings Are Just Feelings' by Andrea Kate McKenzie

Parents told us:

*"I will be forever grateful to the service for enabling me to be the better mum I am today through the advice and strategies learnt from the books I've borrowed".*

*"Using your library has helped an awful lot as Grace has found the information in the books particularly helpful and she has been able to relate to it, which has let her talk about herself and given her more confidence to be herself. She found it helpful to know others feel the same".*

*"It's such a wonderful service so efficient and easy to use and a huge help to families so they can borrow books without being financially impacted".*

### Our Sensory Toy Library

helps children to discover a favourite sight, sound or smell with one of our switch toys, fibre optics or sensory kits.

In 2024:

We loaned 263 toys

80% reported improvement of their child's skills

95% reported improved enjoyment of life

76% reported improved interaction

98% said the toy met their child's sensory needs

Our most popular toys were:

1. Sensory Suitcase
2. Hip Hop Mats
3. Fibre Optics Kits



Bright ideas for brilliant kids! The Cerebra Innovation Centre (CIC) designs and builds innovative, bespoke products to help disabled children discover and engage with the world around them.

In 2024: We helped 123 families with unique and wonderful new designs.

## Super cool walking sticks

Motability very kindly donated towards a variety of mobility products. We developed some beautiful, light-weight walking sticks to help increase children's independence.

The walking sticks needed to be light weight, strong and cool! We chose to use carbon fibre poles, 3D printed Titanium, 3D printed rubber grips and 3D printed Nylon handles. These really are space age walking sticks that have given children a functional product to be proud of.

In 2024 we helped Matilda with some custom walking sticks. Matilda lives close by, so she came to the CIC office and coloured in a picture of the walking sticks so we knew her favourite design. The team "wrapped" her walking sticks in these beautiful colours, and her smile made all the effort worthwhile.

We made another set for a young man called Darcy. Darcy's mum, also Matilda, told us :

*"How do I thank you for such invaluable and fantastic tri-walking stick crutches for my 5-year-old son. It was like Christmas when they arrived, and they are truly amazing! Not only are they super lightweight, which takes away a lot of the burden of lifting and shifting the sticks when already struggling to step and walk, but they are also aesthetic, smart, sturdy and will grow with him for many years to come thanks to their easily adjustable design.*

*The work you do is life-altering for children like mine and has a positive physical and emotional*

*impact. We now have a sense that we are supported and can make new and realistic goals in our son's physiotherapy programmes. We know our son's physical health is cared about by charities like yours.*

*Access to the right disability aids is not only exhausting but difficult and financially crushing at times. You have taken all of this away and we are so pleased with our new equipment. We will be caring for them and be sure to contact you when we are no longer suitable to use them in case they can be of use to another family".*

Matilda with her super cool walking sticks



## 'Hydro Beatz' are a hit!

Our floating music stations combine the benefits of music and hydrotherapy and are a hit with pupils and their teachers.

Dr Ross Head from CIC explains more:

"We were aware of the amazing therapy enabled by both music, and hydrotherapy, and had a beautiful idea to bridge both disciplines 'Hydro Beatz' were born."

The music station has a soothing Ibo drum, mystical chimes, musical bells, a magical tongue drum, and an atmospheric Ocean Drum. Children with complex conditions such as cerebral palsy might have hydrotherapy sessions to maximise the relaxing effect and support of warm water. The music station gives them something to play, something

to reach for, or to grip, a reason to try to stand or swim, or quite simply a relaxing sound experience to enhance their pool time.

The stations were made using brightly coloured closed cell foam and beautifully crafted instruments. The instruments were chosen for their simplicity and beautiful sounds that would enhance an aquatic environment.

We are grateful to Welsh Water and Anthem Wales for choosing to support this innovative project and have been able to supply special education schools across the country with a floating music station which will help many children each year and for years to come.

Schools told us:

*"It has been such a wonderful experience for them. Our non or pre-verbal pupils have responded particularly well to this addition, and we have noticed that they are vocalising as they hear the sounds that the float can make. Our non-ambulant pupils enjoyed the sensory experience of touching the chimes and ringing the bells. Often, they rely on adults to assist them with various aspects of their world, but they are able to float and independently make music with just their touch".*

*"Our physios have been getting some great arm stretches from the students ringing the bells and we have been working in the pool this morning with a student who is blind, and he had a ball".*

*"We have a lot of children working on standing and reaching in the water. We have a few children who have fluctuating tone and struggle to plan their movements and these give them a reason to slow down and take more control over their actions whilst being supported by staff in different positions. We also have a few children with visual impairments and having access to sound whilst in the water is amazing. The children with high tone who relax in the water also find it much easier to access these than they would with instruments on land".*



### 3. We help children to fulfil their greatest potential without barriers to their complete participation in family life and society

Over 500,000 children in the UK live with a brain condition.

This can make normal activities such as learning, playing or simply experiencing the world a huge challenge. We offer solutions, support and advice to help these children, and their families enjoy lives full of hope and discovery.

We'd like you to meet just a few of the families we helped to discover a better life together in 2024.



#### 'James' brings joy and laughter

'James' the Scoot Horse has become a much-loved member of one family:

"Our daughter is 6 years old. She has Cerebral Palsy and loves movement – swings, scooter boards, her specialist bike. She also loves music and books.

With her now being taller and older a lot of equipment is not available for her anymore. When she was tiny, we could get away with some high street options, but now she just misses out normally. It is heartbreaking to see when she can't join in with her friends because of her physical limitations.

We saw a post of the Scoot Horse and it was Eureka moment! We trialled so many options over the last year, but it never worked – either our daughter was too big or too disabled. She used to have a little car, similar principle for scooting around the house, but she outgrew it.

I got in touch with the Cerebra Innovation Centre (CIC) and we were placed on the waiting list. And then – after a little wait – the horse showed up. Communicating with CIC is always just joyous – it is so rare for families like ours to encounter people that really care and just want to help.

The horse got a name immediately – James. He is supplied with apples throughout the day and stands next to her during dinner. He's also in her room at night. We all had a go down the little wheelchair ramp and he brought so much joy and laughter.

We are beyond grateful".



#### Fish tank fun for Arthur

Arthur's grandad, Sean, noticed how fascinated Arthur was with watching his fish. He explained:

"My grandson is autistic and spends literally hours just staring into my aquarium and talking to the fish. This seems to soothe him and prevents meltdowns. Unfortunately, he does sometimes gently bang the glass which isn't fair on the fish and is a worry regarding breakage. When I saw your aquarium, it seemed perfect!".

Our Innovation Centre team set to work to build a fish tank for Arthur to enjoy – and one that would keep him, and the fish, safe. The Cerebra Fish Tank is designed to bring calming sensory stimulation into the home. Our aquarium features protective plywood casing and polycarbonate windows to keep fish safe from curious hands. The tank allows children to enjoy the therapeutic experience of watching fish swim, while preventing damage to the tank and equipment.

The fish tank has been a huge success. Arthur's mum, Jess, got in touch to say:

"I just wanted to say a massive thank you for the wonderful fish tank you've made for Arthur. Arthur has been absolutely obsessed with it since it arrived and it has really helped to calm him, and keep him still, which rarely happens! He has also been saying 'fish' and wanting me to watch them with him. He doesn't often communicate so this is very special. I can see this being a wonderful thing for him. I can't thank you enough for your generosity, it really does mean a lot".

It got the seal of approval from grandad Sean too: "It honestly couldn't have come at a better time. He just loves fish so this will be his pride and joy".



#### Discovering the happiness of reading and playing

Vicky is mum to eight-year-old twins Isaac and Enoch, who both have disabilities. The boys love football and vehicles, reading, watching videos and playing with friends. Life is very busy, and Vicky's daily routine revolves around taking care of the boys' needs.

Vicky explained that her elder son has very stiff hands and arms and isn't able to use his hands to play with traditional toys or even turn the pages of a book on his own. The family were struggling to find suitable things for their sons to play with. Their physiotherapist suggested our lending library as we have a range of adapted toys that are perfect for her children's needs.

Vicky told us: "I find it difficult to take the boys to a library as I don't drive and the library in our district is not wheelchair accessible. Cerebra's library service is very convenient for us as I can reach it online to search for books and toys and they are sent to us. We've borrowed books, audio books and adapted toys so my son can enjoy the happiness of reading and playing with toys. To provide this service with free delivery and collection as well is amazing".



#### Better sleep for Verity

"Our daughter Verity is 11 years old. Verity loves to read and to write her own stories too. She loves our two cats and she also enjoys baking (although not the clearing up part afterwards!). She has an autism spectrum diagnosis and has struggled with sleep since she was tiny.

Verity's struggles with sleep mean that she is often tired, which adds to her anxiety, and she struggles to regulate her mood. She is often worried about being able to concentrate at school. This can be very stressful for the whole family; she has often been distressed at bedtime and in the mornings. It felt like a vicious circle of tiredness, anxiety, poor sleep.

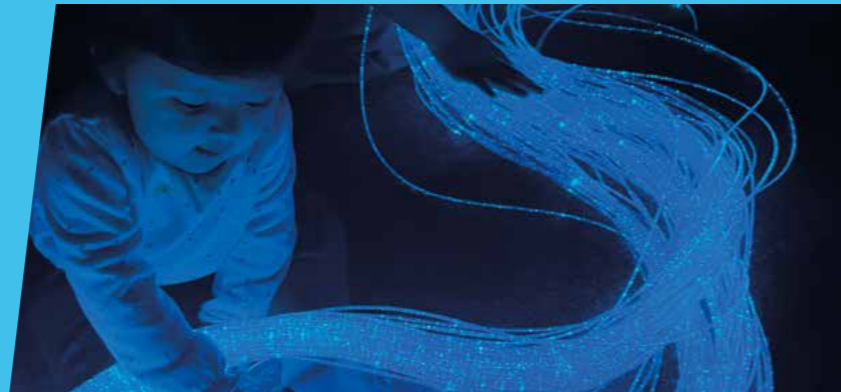
We worked with our Sleep Practitioner over several months, identifying specific problem areas, looking at options that we could try and then reviewing what was working and what wasn't. We adopted many of the suggestions that our Sleep Practitioner gave us.

Verity now settles more quickly and seems to have a better quality of sleep. The whole process has also helped me to feel less stressed about the situation. I view her sleep differently now and I feel much more empowered to try different things and identify problems. We are finding fewer nights where bedtime is stressful, and Verity settles herself better.

Our Sleep Practitioner made me feel like I am doing a good job as a parent, rather than failing my child. His suggestions were practical, helpful and effective and I felt that he was really focused on helping us. I felt very supported and he really helped me, my daughter and our family.

I know that there is no miracle cure for my daughter's sleep challenges, but I feel much calmer about the situation now, I realise that there are often small changes that we can make that will add up to a big difference. I really can't thank Cerebra enough".





## A sleep solution for the whole family

"Six year old Viktor is an autistic but very smart and energetic little lovely boy. He likes to play all day; he will not settle, not even for a second. Like any other child, he likes pizza, sweets, going to the park and spending time with his family. He seeks attention all the time and he does not like to do anything in any other way than his own agenda.

Parenting is hard, but parenting for a disabled child is astronomically harder. Viktor cannot, and perhaps he also does not want to, fit into the neurotypical society's rules. Therefore, we had to adapt to his needs and to change our life around him.

We got in touch with the Sleep Advice Service because Viktor went through a phase when he was only sleeping 4-5 hours a night and that was interrupted.

We received a lot of information and support. Our Sleep Practitioner worked with me very closely and he offered me lots of suggestions and advice. For example, our Sleep Practitioner suggested using a diffused red light and some very low background noise, such as sea waves or the sound of the rain, so that Viktor could associate these with going to sleep and remaining asleep.

To begin with we did not see significant improvement but after a while, we managed to adapt some of the suggestions and things started to get better.

Although the problems are not completely resolved I found our Sleep Practitioner's input very helpful. Viktor still wakes up some times through the night but it's a lot less frequent – and that makes all the difference".

## Toys to entertain Asiya

"Asiya enjoys watching things moving around her and doesn't like the quiet. She enjoys watching other people, especially children making lots of noise and running around and playing around her. As she has limited movement in her lower limbs she likes being entertained and can get bored of the same things quite easily.

Asiya has spina bifida which affects her movement and also has hydrocephalus which means we have to be careful how she moves and interacts with toys. Her older brother likes to play with her but sometimes doesn't fully understand that we have to be careful around Asiya.

I was looking into different ideas of how to play and interact with Asiya as she has limited movement. That's when I found Cerebra's Library Service.

We received a sensory suitcase packed full of amazing toys and equipment to borrow for one month. We also regularly borrow books from the children's book library. The sensory suitcase had lots of different toys and equipment so we could find out what Asiya liked to play with and what sounds and images she liked, that would also aid her development. With limited movement, we were not sure what she would enjoy but she really enjoyed the light projectors and was mesmerised.

It was refreshing for her to be able to use the toys how she wanted. Her older brother enjoyed using the toys to play with her too and they made up lots of games with the various noisy balls and shakers.

We enjoy reading the books together that we receive regularly. Some of the books are more specialist to her conditions that we can't find in our local library.

A lot of the books and equipment that Cerebra loans out is available to purchase online but are out of our budget, so we are really pleased that Cerebra is free and Asiya is able to enjoy and use them in this way".

## Our books make an impact

"I wanted to share my experience of using Cerebra Library and the awesome impact it has had on my family's life.

Firstly, I am Mum to 2, very different, autistic young people. When my children were diagnosed, I had no idea about how being autistic affected how they see the world and how they understand life. So I decided to build on the limited knowledge I had. I researched which books best suited the needs of my children and borrowed them.

As a result, I have been able to change how I parent them and how to create a healthier, neuro diverse environment for them. We now use lots of visuals at home and we have a low demand approach to life. This has meant that my children feel heard and understood more.

They have both developed a stronger positive identity and now embrace their differences. We can now enjoy family days out and even holidays without meltdowns and anxiety as I have learnt the best way to support them – through the wealth of information I've learnt from the books I've borrowed from Cerebra. These used to be stressful times for us all.

Also, I have purchased the odd book which I've borrowed that I felt was so valuable and haven't spent oodles of money on the 'wrong' book.

I will be forever grateful to the service for enabling me to be a better mum through the advice and strategies learnt from the books I've borrowed.

As my children grow and their needs change, I will continue to borrow the books which are relevant to them at that time. Thanks so much".

## Independence for Farrah

Farrah has autism and a rare and severe form of epilepsy called Dravet Syndrome. She had her first seizure when she was just 3 months old and has frequently been admitted to hospital for weeks at a time following prolonged seizures. Her parents often felt terrified and helpless not knowing what was happening and if Farrah was going to be okay.

Farrah is now 16 and loves going to school. Her seizures are managed with special medication that brings her out of a seizure, avoiding the need to call an ambulance or go to hospital. It has meant that her epilepsy can now be managed at home and in the community. It does mean that Farrah needs two people with her when she is out and about to keep her safe and administer medication when needed.

Her school advised that they were unable to provide this level of support, and it was very demanding for her parents. Unfortunately, the local authority considered Farrah to be ineligible for Direct Payments to pay for personal assistance to take her out into the community.

That's when the family got in touch with us for some help. Our Legal Rights team supported the family to challenge the local authority's decision by providing information, writing letters and guiding them through the appeals process and referral to the Ombudsmen. We were with them all the way through this complicated and challenging process.

Eventually Farrah was allocated a new social worker who conducted a new assessment of her needs. Farrah was awarded 4 hours of 2:1 care a week to support her independence. The family have been able to employ two personal assistants for Farrah who have been trained in the use of her emergency medication.

Mum Francesca told us "Farrah is loving spending time in the community developing her independence and confidence. For the first time we can feel at ease knowing that Farrah is safe, has the right level of support and is also having fun. Farrah's enjoying her time away from us and her sister is able to have one on one time with us. The four hours of support a week has had a positive impact on everyone, but mostly Farrah which is amazing.

As soon as I contacted Cerebra I felt heard and validated. Without the guidance we received we wouldn't have got there. This was a long and challenging case, and I cannot thank Cerebra's Legal Rights team enough for their commitment, empathy, knowledge and support".



4. Together we are helping families who have a child with a brain condition to discover a better life.

Thank you for joining us on our journey in 2024.

Number of individuals who supported our income streams in 2024:

Raffle	7,838
Lottery	17,153
Regular Giving	1,930
Donation Card	11,555
Gift Aid	10,587
Trusts & Foundations	10
Corporate	33
Legacies	56
Other	339
<b>Total</b>	<b>49,501</b>

Support from a number of Trusts and Foundations along with corporate grants has meant that even more children are able to discover a better life with their families.

Thanks to:

Abbie, Active Spaces Fund, Allen & Overy Foundation, Alpkit Foundation, Atsain Fund, B&Q, Blakemoore, Broome Family Trust, Charles S French Trust, Churchill Foundation, Hospital Saturday Fund, JAZZ Apple Foundation, Media Cymru Seed Fund, Mercian Community Trust (The West Brom), Monmouthshire Building Society, Morrisons Foundation, Motability Foundation, Percy Bilton, Tata Steel, Tesco Community Grant, The Henry Sale Foundation, Toy Trust, Unum, Valero Golf Day, Welsh Water, Westfield Health, W & M Morris CT, Frazer Trust, Jaffe Family Relief Fund, Douglas Health Eaves CT, Pilkington Trust, Foundation Scotland, Anthony Hart CT.

We are grateful for:

The financial support given by the following solicitors who specialise in accident or clinical negligence cases relating to brain conditions or Court of Protection Deputyships and personal Injury Trusts.

Over the past 12 months these solicitors have provided support to a number of families Cerebra work with. They have also provided detailed and insightful articles and interviews across a wide range of topics, which are available to view on the News section of our website.

Bolt Burdon Kemp, CL Medilaw, Irwin Mitchell, Irvings Law, Leigh Day, Fletchers Solicitors



How it helped:

Research Projects	30%
CIC	26%
Sleep	18%
Support Services	12%
Health & Wellbeing	8%
LEaP	7%

If you would like a financial breakdown, please do contact us directly. You can also view our published accounts on the Charity Commission website.

Thanks to everyone who signed up to Team Cerebra this year. You are all Superheroes!



11 year-old Skylar took on a mighty 125,000 steps challenge throughout May.



We partnered with theatre company Grand Ambition

This year we were proud to partner with theatre company Grand Ambition to bring a play with a powerful message to the stage. MumFighter explored the obstacles faced by the mother of a disabled child, fighting for the support needed for them to reach their potential.

Cerebra Trustee and parent, Isabel Shapiro, explains why the play is so powerful and why it struck a chord with so many families:

*"Life as a parent-carer is a rollercoaster. The everyday experience of caring for a disabled child is full of love and joy. But there can also be isolation and despair – daily battles for the care that your child needs and for the wellbeing of the whole family. To see these ups and downs brought to life so powerfully on stage is rare. By putting the spotlight on the shared experience of parent-carers, Mumfighter brings hope through solidarity, motivating anyone who is lucky enough to see the play to demand change."*



Superhero Duo

Superhero Harry (aka Phoenix Fire) and his brother Tommy (Super-Farmer-Ted) completed the epic challenge of the Superheroes Tri at Dorney Lake. Harry lives with Dyskinetic Cerebral Palsy, which significantly affects his movement and coordination.

Harry and Tommy described the whole event as 'the Best Day Ever' and cannot wait to take part again next year.



Louise Astill and Fabienne Cuthbert, from Fieldfisher took part in the Parallel Festival of Inclusivity for Cerebra at Windsor.



63 miles and still smiling!

James Atkinson, set himself the almighty challenge of running the Manchester to Liverpool Ultra Marathon (50 miles) – followed by the London Landmarks Half Marathon (13.1 miles). All in the space of just nine days!

James daughter, Isabella, suffered a brain injury in August 2022. He and his wife, May, who is a Trustee for Cerebra, found that Cerebra helped them navigate a whole new world of life with a disabled child. Our Toy Library helped meet Isabella's sensory needs and our Innovation Centre provided a specially adapted swing harness so that she could safely enjoy her one of her favourite activities.

*"We are so thankful for Cerebra, the work they do and continue to do is amazing and I am so happy to run for this amazing cause."*



- Join our lottery and for just £1.20 a week you have the chance to win £1,500 every Thursday!
- Enter our raffle prize draws to be in with a chance to win £5,000!
- Leave a very special legacy by including a gift to Cerebra in your Will.

We look forward to where the journey takes us next.

Why not join us?

Be a fundraising superhero and help families discover a better life together.

Just give us a call on 01267 240850 or visit [www.cerebra.org.uk](http://www.cerebra.org.uk)



Thank you for working wonders  
for children with brain conditions

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