



Impact Report 2022

CEREBRA 
Working wonders for children
with brain conditions



Together we are working wonders for children with brain conditions

Our **vision** is that every family that includes a child with a brain condition will have the chance to discover a better life together.

Our **mission** is to listen to families that have a child with a brain condition.

We use what they tell us to inspire the best research and innovation.

Then we help them put the knowledge into practice so they can discover a better life together.

Our families, researchers and supporters go further when they travel together:

Families play a vital role in their children's lives and in everything we do. We want the families we work with to feel valued, listened to and part of our work.

A spirit of enquiry and innovation drives our research teams. The potential for discovery in their work and in the families whose lives they will touch is truly exciting.

We want to inspire people to give, raise funds, and get behind us by not just reminding them of the need for what we do, but also the positive outcomes they could help families achieve.

This report reflects what we achieved together in 2022

2022 at a glance:



804 families got a good night's sleep thanks to our Sleep Service.



Our Legal Rights Service helped 138 families access public services.



We lent 1,062 books and toys to help families learn and play.



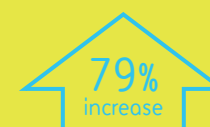
Our information resources were downloaded 58,786 times.



We spent £925,280 on life changing research.



Our Innovation Centre helped 209 children discover life and have fun with their friends.



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.

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

Research & Information Strategy

We continue to focus explicitly on supporting research to benefit the families of children with multiple and complex needs or rare conditions. In other words, needs characterised by a combination of physical disability, learning disability, development delay, physical and/or mental health problems, genetic diagnosis and/or autistic spectrum condition.

In our experience, this community is poorly understood and provided for within the research environment. Our services will continue to reflect and align with our research ambitions.

Ultimately, through our research and associated services, we want to promote understanding and to see a world where neurodiversity is respected and celebrated, and where children with neurodevelopmental conditions get to fulfil their greatest potential without barriers to their complete participation in society.

In 2022 we've continued to work towards:

- Seeing research translated into policy and practice at a local, national and international level.
- Developing evidence-based resources for families to help them tackle some of the challenges they face.
- Promoting understanding of neurodevelopmental conditions, particularly rare conditions and associated complex support needs, among professionals and within society.
- Developing the next generation of researchers who will champion the needs of children with neurodevelopmental conditions.

Read our Research Strategy in full on our website.

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES





Summary of key research in 2022:

You can read more in the 2022 Annual Reports for all of our Research Partners on our website.



University of Leeds,
Mr Nigel Simpson and
University of Barcelona,
Professor Eduard Gratacós.

1 in 5 women will experience complications in their pregnancy that can result in childhood disability. We want to better understand the causes of these complications, develop new tools to identify women at risk of experiencing them and investigate how we can prevent them or minimise their impact on mother and baby.

2022 Highlights:

- Investigation on assisted reproductive technologies shows that infants conceived with these technologies are more prone to have impaired neurodevelopment
- A study on fetal cortical development in pre-eclampsia has shown that this adverse condition during pregnancy predisposes the fetal brain to a poor development
- Completion of all the preparatory steps for the FETAL BRAIN CARE study. Recruitment to start in 2023.



Dr Hayley Crawford



Dr Jo Moss



Dr Caroline Richards



Dr Jane Waite

Cerebra Network for Neurodevelopmental Disorders:

Dr Hayley Crawford, University of Warwick; Dr Jo Moss, University of Surrey; Dr Caroline Richards, University of Birmingham; Dr Jane Waite, Aston University.

The Cerebra Network for Neurodevelopmental Disorders is a unique collaborative research network that truly integrates knowledge, expertise and resources across four leading institutions to deliver greater insight into children with rare and complex syndromes. The aim of the Cerebra Network is to improve the evidence that underpins better assessment and support which in turn leads to improved outcomes for children with complex needs and their families.

2022 Highlights:

- We launched the Be-Well Checklist – an accessible summary of factors that are important to assess when considering behaviour and wellbeing in children with severe learning disability and complex needs. The Be-Well Checklist has been extremely well received by both parents/carers of children with rare and complex needs and healthcare professionals. We have received feedback that parents have used it to structure their conversations with Clinical Psychologists during their consultation appointments and that it has led to identification of areas for future monitoring.
- We launched the BEOND survey which will explore outcomes in more than 30 rare genetic syndrome groups.
- Our Cerebra funded PhD students are now in their second and third years of study and have been sharing findings at national and international conferences (see page 7).
- Our Network Directors have been invited to present to a number of clinical groups including the Royal Society of Medicine, the Council for Disabled Children, Birmingham and Solihull Mental Health Foundation Trust, and Evelina London Children's Hospital.
- Our key dissemination platform, FIND, continues to maintain a steady number of visitors (approx. 4,000 per month). Our audience is global, with 74.5% of users being outside of the UK. Over 120 NHS professionals remain registered through the site for updates.



University of Warwick, Professor Richard Hastings.

Our partnership with the Centre for Educational Development, Appraisal and Research (CEDAR) at the University of Warwick focuses on family research that aims to better understand and improve family well-being.

2022 Highlights:

Online Wellbeing interventions for family carers – A Systematic Review

We began a new study to review what research evidence there is available on online or virtual wellbeing interventions for family carers of people with a learning disability, autism/who are autistic, or both (family carers).

Family carers can experience additional stress and have a higher chance of poorer mental health than other family carers. The project will run until early 2024.

Positive Family Connections Project

This project focuses on helping families to build positive relationships within their family, and is delivered online in six sessions. It was co-produced by family carers, and is designed for family carers of children with a learning disability, autism, or both.

In 2022 we ran a feasibility study to test out the co-produced programme with family carers to see if it will be possible to run a much larger study in the future. The final stages of data collection will be completed in early 2023 and will be followed by data analysis and dissemination of the project's findings.

1 000 Families Study

This project is a longitudinal study involving a large cohort of families of children with a learning disability living in the UK. The aim of the study is to explore the wellbeing of children with learning disability, siblings, caregivers, and families overall. Wave 3 of the Study was completed in December 2022.

Above, left to right: Dr Richard Hastings, Dr Paul Thompson, Dr Joanna Griffin, Dr Samantha Flynn

Centre for Law & Social Justice, The School of Law, Leeds University, Professor Luke Clements

Research evidence suggests children and their families experience considerable difficulties in accessing their rights to education, health and social care support. The Legal Entitlements and Problem-Solving (LEaP) Project helps families of children with brain conditions cope with the legal barriers they face.

2022 Highlights:

Disabled children and their families are one of the most severely disadvantaged groups in the UK. A major research report published by Professor Clements and his team in 2021 found that most English Children's Services Authorities operate a 'one size-fits-all' approach to families – regardless of whether it is a parent carer seeking support for a disabled child or a family where the evidence suggests there to be neglect or abuse. The effect of this approach is to create an institutional culture of 'parent blame'.

In October 2022 the team published follow up research 'Challenging Parent Carer Blame: Disability and human rights training and guidance' which identified a troubling failure by English Children's Services Authorities to adequately resource and train their staff who have responsibility for assessing and supporting disabled children and their families.

These findings include:

- That on average only 2.5% of disabled children are (at any one time) receiving support from a Disabled Children's social work team
- That there was no evidence that Children's Services authorities were providing training courses of a depth or weight that would provide assessors with an understanding of:
 - their statutory obligations to provide care and support to disabled children and their families
 - the disability related challenges that disabled children and their families encounter
 - their obligations under the Human Rights Act 1998 including their duties to respect private and family life
- That the training provided to assessors of disabled children had an overriding focus on 'safeguarding' rather than on support.

The report concludes that the Secretary of State for Education must now be aware that local authorities have failed to develop and implement fit-for-purpose local assessment protocols, despite being instructed to do this in 2013.

In October 2022, Professor Clements and his team hosted the Cerebra Legal Entitlements and Problem-Solving Project Conference: 'Addressing commonly occurring social care difficulties encountered by disabled children and their families'.



Developing the Next Generation of Researchers

As part of our Research Strategy we are committed to developing the next generation of researchers who will champion the needs of children with neurodevelopmental conditions, particularly those with multiple and complex needs or rare conditions.

We fund the following PhD students within our research teams. You can read more about their journey into research and why the studies they are working on are so important on our website

Above left to right:
Top: Caitlin Williams, Daniel Sutherland, Lauren Jenner.
Bottom: Caitlin Murray, Jessica Mingins, Rory O'Sullivan.

Caitlin Williams University of Warwick

"My research follows families over time to understand how things change within the family system, as part of our 1000 Families Project. In my future PhD research, I hope to look at the family system more broadly; focusing on grandparental support for example".

Daniel Sutherland University of Warwick

"My PhD involves working on a project to develop and evaluate an intervention for families of children with developmental disabilities like learning disabilities or autism. My PhD involves working on this Positive Family Connections feasibility study, as well as some other research looking at what existing interventions are available for families".

Lauren Jenner University of Surrey

"I am researching social abilities and autism among children and young people (4-19-years-old) with Prader-Willi syndrome and Down syndrome. I am particularly interested in how individuals with these syndromes process and understand social information".

Caitlin Murray University of Warwick

"My primary role has involved working on the Cerebra 1000 Families study. Most of my research is related to the mental health and well-being of children and adults with learning disabilities and their families. I feel very proud to be speaking and learning from families, and to focus on the impact of research for people with learning disabilities and the people who support them".

Jessica Mingins Aston University

"My research focuses on tailoring and validating assessment measures for anxiety in children with rare genetic syndromes. My PhD will also involve examining factors that give rise to anxiety in these populations. I will also collect background information and data on other factors which can influence anxiety such as autistic traits, sensory processing, low mood and more".

Rory O'Sullivan University of Birmingham

"My PhD involves exploring the characteristics and significance of sleep in children with rare genetic conditions. I will explore whether our understanding of sleep in children with neurodevelopmental disorders is affected by how we measure sleep. This should tell us what future research should do in order to most accurately measure sleep in children with neurodevelopmental disorders".



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

From physical and mental health, dealing with social services, financial and legal affairs and education, all of our **Information Resources** offer expert advice and research-driven strategies to help families deal with issues we know they may be facing.

All of our information resources are free to download from our website.

83% of users who gave feedback rated our guides as excellent.

Our top 10 downloaded guides and factsheets for 2022 were:



1. Disability Living Allowance Guide	21,145
2. Sleep Guide	6,884
3. Sleep Cards	3,190
5. FLACC Pain Infographic	1,869
4. Sleep Tips	1,462
6. Be-well Checklist	764
7. Introduction to DLA Factsheet	748
8. Challenging Behaviour Factsheet	704
9. Accessing Public Services Toolkit	602
10. Emotional Outbursts Parent Guide	539



Our Sleep Advice Service offers a range of information and support to help children – and everyone in the family – get a good night's sleep.

How Our Sleep Service Helped:



In 2022:

We helped 804 families on a one-to-one basis

We held 7 online sleep seminars and 11 face-to-face workshops

158 families were helped through our seminars and workshops

Our Sleep Guide was downloaded 6,844 times

Our Sleep Tips booklet was downloaded 1,462 Times

Our Sleep Cards were downloaded 3,190 times



Hugo

"My son Hugo is 3 years old and has autism. He loves going out for walks and to the play park. He also loves playing with spinning toys but he doesn't like having his hair washed or his nails cut! As he doesn't have any awareness of danger he needs to be watched all the time.

Hugo wasn't sleeping very well so I got in touch with Cerebra's Sleep Service. It was just simply amazing! There was great communication and I felt very well looked after. Hugo did manage to improve his sleep and I just wanted to say that you're doing an amazing job"

Beatta

Elijah

Three year old Elijah was waking numerous times in the night. Sometimes he'd scream uncontrollably, other times he'd be wide awake and talking. Elijah has cerebral palsy and needs someone to aid him and move him all day. It's tiring, exhausting and frustrating for Elijah and his family. They were all in need of better sleep.

His mum, Claire, got in touch with our Sleep Service for some one-to-one support. She told us:

"The sleep practitioner advised us on what to do. She explained how sleep works and about routine and we tried different methods using her support. Elijah now sleeps and, when he is awake at night, he is having night terrors which we feel equipped to deal with. We all now enjoy amazing sleep".

Having better sleep means that Elijah is more able to enjoy his books and reading, which he loves, and to play with his favourite cars, Happyland and Bluey figures.

"The service was amazing and I can't thank you enough".

Claire

Tyler

"Our son Tyler is six years old and has a lot of sensory issues which affects us all in our every-day family life. His favourite things are Lego and numbers but he dislikes social settings such as parties. Tyler experiences a huge amount of anxiety and it can be difficult to get him to school.

It was taking Tyler a very long time to settle at night-time and then he wouldn't sleep for more than a couple of hours. He wasn't able to self soothe. Tyler's paediatrician prescribed melatonin and also referred us to Cerebra's sleep service.

Our Sleep Practitioner was really good and understanding. She gave advice and suggested different strategies and physical tools to try – starting small with baby steps. She was also very caring and a good listener – I felt like she really understood. I've gained a lot of knowledge, found new ways to cope and to help Tyler.

I am really happy with the service and I would recommend it to anyone. Thank you for understanding and not judging".

Chelsea

Zach

Four year-old Zach enjoys playing outside, especially climbing. He likes music, lights and bubbles and his favourite things are his peekaboo blocks. Because of his autism, global development delay and sensory processing disorder he needs constant care. He's constantly on the go and has no understanding of the environment and people around him. It's difficult to visit places or people as Zach cannot cope with change.

With such busy days the whole family really needed their sleep. But Zach wasn't sleeping well at night. The main challenge was getting him to fall asleep, which would often take several hours.

Zach's mother Claire found out about our Sleep Service and got in touch for some support. She told us: "The different strategies suggested by the Sleep Team and the constant support made a massive difference. As long as we keep to the same routine Zach now falls asleep within 15 minutes. I'm so grateful for the friendly support we received and I've recommended the service to other parents with children with SEN".

Claire



We published our new Be-Well Checklist

The Be-Well Checklist can help to reduce challenging behaviour and improve the wellbeing of people with severe learning disability and complex needs.

The Checklist can be used by parents, carers and professionals when they are trying to work out why someone is showing a behaviour or might be distressed, angry, upset or appear to have very low mood.

It can also be used at regular review meetings or any other time to make sure someone's quality of life is as good as it can be.

It can help make sure the right things are discussed and thought about and help everyone to agree on the most important things to do next. Carers, parents and professionals can then decide together which assessments and treatments might be helpful



Our Legal Rights Service provides families of children with brain conditions with help when facing difficulties accessing support services they are entitled to.

Parents told us:

"Thank you so much for all your help and support! It truly means a lot not just to me but to my boys as well. This will make home life so much easier once it's all finished."

"Having a knowledgeable professional who has similar problems to us, describe issues that are generic to many parents of children with disabilities."

"Thank you very much for your quick and helpful response, and for the Cerebra-funded document which will be really useful in all sorts of instances: it's so practical and takes the sting out of the strong feelings that I sometimes get distracted by, when arguing our sons' cases. Also what a relief to read something clearly explained."

In 2022:

Our Accessing Public Services Toolkit was downloaded **602** times

Our legal rights template letters were viewed **1,269** times

We held **20** Problem-Solving Accessing Public Services Toolkit Workshops

A total of **223** people attended

88% of attendees reported that after attending the workshop they now had the confidence to try this at home

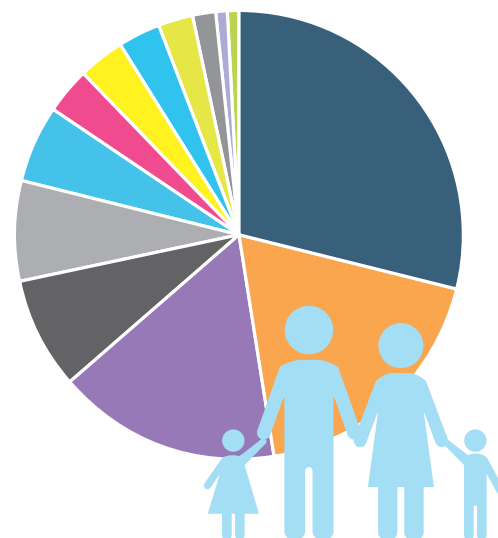
97% said the workshop improved their knowledge on how to access public services

Direct Payments for 1:1 Support – How Our Legal Rights Service Helped

"Our son is 6 years old and is a determined individual who knows what he wants, and what he doesn't want to do. He has a vivid imagination, is very caring towards other children and would love to make a friend – he'd also love to have a dog!"

Ben has Autism, ADHD, sensory issues and epilepsy. He has behavioural problems, and this can be very hard to manage. He is impulsive and can lash out which has led to him being excluded from activities at school and even expelled twice. An ordinary family life isn't possible for us; we can't take holidays together or even pop out for a coffee as things often get thrown around the coffee shop. At night he needs us to sleep with him and in the day he's always full of energy – it's impossible to wear him out. We both need to work and have no family support around us.

We helped 124 families with specific information:



Social care	36
SEN provision	23
Disabled Facilities Grant	20
Health services	10
School transport	9
Safeguarding	7
Transition	4
Welfare benefits	4
Housing	4
Continence services	3
Home adaptations	2
Discrimination	1
Other	1

I spent almost a year seeking help from the council to have 1:1 support put in place over the holidays and after school but with no success. It was an incredibly long winded, frustrating process only to be told that we couldn't have the support our son needed and was entitled to. It was then that I got in touch with Cerebra's Legal Rights Service.

I found the service very effective and helpful, and it has made a significant difference to our quality of life. The team helped us to understand our rights and consolidate our issues into a letter of complaint to the council. They also gave me positive guidance over the telephone. Being dyslexic myself, it's not that easy to write and summarise all of the issues and Cerebra really did an excellent job in helping me through this.

The complaint led to tangible action and a meeting with the Assistant Director of Children's Services who agreed to the support package I was asking for. This will enable our son to attend holiday clubs over the holidays with 1:1 support. He will be able to safely enjoy all of the activities on offer as well as develop his social and emotional skills. It will also enable us to continue to work so that we can provide for our son.

Our son has begun to have his 1:1 support and it's going well so far. I cannot recommend the service enough and I am extremely grateful for the help and support provided".

* Names have been changed

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 2022:

We loaned **277** toys

We added **15** new toys to the library

91% of our library users told us that the toy they'd borrowed had met their child's sensory needs

79% said the toy had improved their child's skills

93% said the toy had helped their child's enjoyment of life

81% said the toy had helped their child to interact with family and friends

85% had decided to purchase their own following the loan

Our most popular toys were:

1. Sensory in a Suitcase
2. Bouncy Lily Pads/
Hip Hop Jumping Mats
3. Fibre Optics

Parents told us:

"The library enables us to use something that we would in no other way be able to afford. The toy loan gave such joy, not only to our child, but the family as a whole, and that money can't buy, and is sometimes very difficult to achieve".

"The book loan gave me more insight and help in how to communicate with my son".



Our **Postal Lending Library** helps families to play and learn.

In 2022:

We helped **534** families

We loaned a total of **1,062** items.

In 2022:

We loaned **539** books

We added **89** new books to the library (54 for children and 35 for parents/carers)

81% told us that their book loan had helped them to meet their child's needs.

98% who rated our service as excellent.

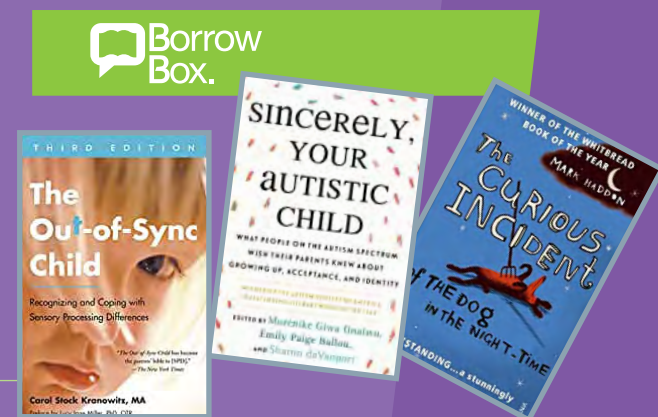
Families can also borrow ebooks and audiobooks using the **BorrowBox** app and website.

In 2022:

We loaned **246** BorrowBox books

Most popular BorrowBox loans:

1. The Out of Sync Child
by Carol Stock Kranowitz
2. Sincerely, Your Autistic Child
by Emily Paige Ballou
3. The Curious Incident of the Dog in the Night Time by Mark Haddon



Our library has books on a wide range of topics with titles for both adults and children.

Our most popular books were:

1. Understanding Autism
by Katrina Williams & Jacqueline Roberts
2. Day by Day by Joanna Griffin
3. My Social Stories Book
by Carol Gray



Our Library Assistant Ffion was awarded a Champion Award for her added contribution to the Engage to Change Project. Ffion's passion and enjoyment for her work really comes through and she has been a huge inspiration to other young people and employers alike.

Ffion told us: "I love everything about my new job with Cerebra. After months of lockdown the routine of working is making a huge difference to my mental wellbeing and I feel more confident and self-sufficient".



Our Innovation Centre (CIC) designs and builds innovative, bespoke products to help disabled children discover and engage with the world around them.



Some of our great designs in 2022:

Our ethos is simple – if you can dream big, we can do big. Never accept it's not possible!

In 2022

we helped 209 families:

52 with unique designs

127 with repeat designs

18 with advice



Pod Chair

Our Pod chair is designed for children that love to spin, sometimes all day! Our highly stylized design looks at home in any family living room while providing a comfortable and safe space for a child to spin freely. We're now working on a hood that pulls up and over the child, creating a secret space to hide in with sensory lighting and music/sound, which can be reactive (encouraging the child to move stiff muscles), relaxing, or stimulating depending on their requirements.



Medical Stands

Our Medical Stands are a fun and colourful alternative to the stainless steel apparatus currently offered to children needing any portable medical equipment such as food pumps or intravenous drips. So far, we've prototyped a giraffe, rocket, and a tree, but the possibilities are endless! Maybe we should make a dinosaur next?



Oxy-Gem

For children who constantly need to have their oxygen cylinder, ventilator, or food pump to hand, just going out for a simple walk with Mum and Dad can be a real struggle. We created Oxy-Gem to ensure these children don't have to face barriers when wanting to spend precious time outdoors or have fun running around the house! Now they are free to explore without constant adult help while being the envy of all the other children in school.



Rocking Chair

Our Rocking Chair is proving a big hit with many families. It offers support in a fun, beautiful, and robust rocking chair to keep kids moving. Children love the calming rocking motion, which helps build their core strength while they enjoy a fun and engaging indoor activity.



Lucas



Megan



Fraser and Mirren



Luca

Our drums were a big hit!

Our sensory drum may look like a traditional Cajon drum for group music therapy use, but we've built in a few extra features.

Created from locally sourced hardwood, the removable back panel has tactile textures carved into the surface so children can use it to make noise or provide sensory input through touch and smell.

On the sides, we've included a selection of shakers made from various natural timbers and textures, each creating a unique sound. Inside is a customisable space for housing all manner of small musical equipment. We've included a small xylophone, drum sticks, and brushes to get them started.

"**Megan** really loves the sensory drums she received from Cerebra. She has Hemiplegic cerebral palsy, so this drum set encourages the use of both hands and she can access the set herself without assistance. She plays the

drums by themselves and sometimes uses it to accompany music she listens to. We like the way the accessories are stored inside too. Megan happily amusing herself with the drum kit is lovely to see".

"**Lucas** doesn't have many play skills. This is something we are working on and hopefully the drums will help with his communication in the long run. Lucas' new favourite pastime is banging on the tambourine with the recorder out of his new Cerebra drum kit, he even takes it in the car with him when he goes anywhere".

"**Luca** loves opening the drum to get all the instruments out, he likes to look and explore the drum, he especially loves it if I put sensory lights inside. He laughs and flaps his hands in excitement".

"The benefits for **Maddison** are fantastic. Not only is it visually stimulating, she is learning to hold instruments in her hemiplegic hand. They are the right size and weight for her to try to hold for short periods. The drum is easy to move around and the craftsmanship is beautiful. Maddison is often found sitting with the drum, making sounds and singing. It has been of huge benefit to her".

"**Fraser and Mirren** love it and it is great seeing them play together. Fraser is a big fan of the wooden instruments and really responds to the vibration and physical feedback, especially when using the textured lid. He struggles to hold toys but the shaker, bells and beater are the perfect size for him. We can't wait to use the bells on Christmas Eve!"



Madison



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 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 in 2022:





Something Super Light and Super Strong for Superstar Henry

Henry is 9 and a $\frac{1}{4}$ although, as a massive Harry Potter fan, he will tell you that he is in fact 9 and $\frac{3}{4}$! He's very artistic and loves to be out and about, taking part in activities like, wheelchair basketball, power-chair football and frame running!

As Henry has Cerebral Palsy, he relies on his wheelchair or his crutches to get around. Henry wanted to spend more time out of his wheelchair, but he's a growing boy and his crutches had become too small for him. That meant he was hunching over them when walking and this was not good for his posture as well as being uncomfortable.

Mum, Lara had tried for some time to find suitable replacements. Henry needed something lightweight, but the ones they tried were either too wide or too heavy and very expensive. Lara had come across our Innovation Centre after they had made products for the children of some of her friends and so decided to drop us a line. She told us: "Before we got in touch with the Cerebra Innovation Centre, I thought we were going backwards rather than forwards. It's really important that Henry's crutches can support him for longer distances, to help improve his stamina. We're so pleased that we got in touch."

Lara spoke to our Head of Product Design, Ross Head, and he and his team set about this tricky problem. Firstly, they started thinking about any lightweight materials they might be able to use and how that might influence the design. Lara's communication was great. She sent Ross and the team examples and explanations, dimensions and drawings, so they were quickly able to start sketching ideas.

Working with some of our other colleagues at the Centre for Advanced Batch Manufacture (CBM), we were able to get hold of 3D printed titanium. This is the material that they make space rockets and Formula 1 cars from!

These parts are so strong it defies belief. The titanium was so tough that it was even difficult to finish the parts and make them smooth. Fortunately, the team were able to sand blast them, which leaves a beautiful matt grey finish and contrasts nicely with the shiny carbon fibre. A few tubes of super specialist epoxy resin (and a little sweat and tears later), Henry's crutches were ready!"

Ross and his team went to deliver them personally to Henry and Lara: "Henry was a very satisfied customer! He took to them no problem at all".

Since then the team at CIC have improved the design of the original crutches and Henry's new ones are now even better: "This set of crutches for Henry is a slight modification to the last set. Previously we were lucky enough to be helped by CBM (Centre of Batch Manufacture) within University Wales Trinity Saint David. They manufactured some parts from titanium for us to make a strong, yet lightweight set of crutches. This time, however, we worked closely with them to help 'lightweight' the parts even more! Due to the incredible strength-to-weight ratio of titanium, we were able to further reduce the weight of the parts, resulting in possibly the lightest and coolest, 3D printed titanium and carbon fibre crutches in the world!

"We're delighted that Henry and Lara are so pleased with the finished product. It is so important to us when we produce a product for a child, that it enhances their life in more than just a functional way. The product has to look amazing, it has to draw positive attention and be equal or better than the rest. I feel we have succeeded in this mission and look forward to developing this product further and helping more children."

Henry enjoyed a fun packed summer - a 100m race, followed by a ski trip, followed by a 5k race! We can't wait to hear what Henry does next!



Toys for Thomas and Information for Mum

"My son Thomas is 4 years old. He was diagnosed autistic around his 3rd birthday. Thomas also has sensory processing difficulties and speech delay, but is catching up quickly now.

Thomas is such a pleasant, well-mannered and happy little boy. Buses are his absolute passion! Whether it's playing with one of his diecast collection (he has over 50), sitting in the bus stop together watching his favourite number 14 drive past, or carefully turning the pages of

one of his many bus magazines, there is usually always something bus related happening in our household!

I first became aware of Cerebra on a popular parenting forum when I was searching for help completing forms for Disability Living Allowance. The forms looked very intimidating but once I downloaded the information pack provided on the Cerebra website and used this to help complete the forms, Thomas was successfully awarded the allowance.

Following on, I have borrowed many books from the Cerebra library. It's been a real help as I have been able to put strategies into place with Thomas and our family that I have learned from the guide books borrowed. This has helped in being able to recognise Thomas's meltdown triggers and therefore being able to avoid that situation.

I have also borrowed a few books written by autistic authors, which has educated me more about the condition and made us as a family aware that not all autistic people are the same, therefore one strategy that works well for one may not work well for Thomas. The Cerebra library and website has also been a gateway into reading about other families experiences and positive stories.

The Cerebra toy library has also been a great joy for Thomas. The sensory suitcase really helped as we found that Thomas engaged a lot with the light up toys, especially the fibre optics. He wasn't too fussed on the fragrance diffuser but then he does have a very heightened sense of smell. The relaxation music was especially helpful at bedtime as it helped him to wind down and it's something that we have continued to use. The acrylic and bell mobile was also one of the items that Thomas gravitated toward. This suitcase

helped us to choose some items and activities to purchase for Thomas that he was actually interested in.

The bouncy lily pad is also another resource that we borrowed from Cerebra and although we haven't the space for our own lily pad, we have purchased a peanut ball for Thomas as he found the bouncing of the lily pad soothing. We have built bouncing on his peanut ball into his daily routine as we find that this regulates him.

We have had to fight to gain a place for Thomas within a specialist school, and I honestly feel that Cerebra has helped me become confident in appealing for his well-deserved place. As a family we feel a lot more confident with this transition from nursery to primary school partly because of the guidance from the Cerebra website and its library. This will be a new journey for Thomas and we look forward to continuing it with the help of Cerebra. Cerebra is an absolute hub of knowledge, guidance and support.

Thomas is our gorgeous boy, every day we tell him how proud we are of him. Thank you Cerebra, you're a part of our extended family!"

Rachael, Thomas' mum

A Good Night's Sleep for Bertie - and his Family



My son Bertie is nine years old and a big fan of all things computing. He has his own gaming museum with retro consoles and loves to learn about the history of computers and their development. He also loves anything to do with science, history, and geography. He has a great memory and can tell you so many facts about his favourite subjects, from Nikola Tesla to Ancient Egypt!

He is a very fussy eater and has a really limited diet, which causes problems when we go out. His best friends are his big sister and cousin and he loves spending time with them. At the weekend we like to do things as a family, like exploring the outdoors, visiting National Trust properties, going to the cinema, or going ice skating.

My son is a quiet and thoughtful boy. He suffers from separation anxiety and began to show signs of OCD over lockdown. He became withdrawn and refused to leave my side. He was only 6 at the time. He began to have persistent nightmares, waking up 10+ times a night. I have chronic illnesses so in the end, it was easier to have him with me. Once we were seen by CAMHs his appointments were over the phone, and he doesn't communicate over the phone, so we waited again to be seen.

Before we saw his new key worker I began working with Laura from Cerebra. Her guidance was wonderful. She understood the issues surrounding his anxiety and worries and encouraged us to go very slowly at first, encouraging my son just to go into another room on his own to get something (which he would not do at the time). We worked slowly building this up, each time seeing if he could stay in the room on his own for a little longer.

I also bought a cushion with a message on it from me. I kept the cushion with me at all times, bringing it around the house. The whole process took several months, which was definitely what my son needed if we'd tried to push it quicker it would've been too much for him.

Eventually, he felt ready to try sleeping in his own bed. The plan was for me to sleep in with him, then sleep on the floor, then gradually get out of eye contact distance, and so on. However, because we'd been practicing grounding, breathing exercises, and relaxation techniques, he decided on the first night to try and sleep on his own with his cushion. I thought it would be like before with him only lasting a short while, but he slept all night on his own – the first time in two and a half years!

Since then, he's slept on his own every single night in his own bed. A few times, he has gotten out of bed, we've had a quick cuddle or done one of the relaxation techniques or reassured him and he's gone back to sleep.

I cannot thank Laura and Cerebra enough. By taking it slowly, following my son's lead, and going at a pace that was right for him we have finally cracked it. The difference in my son is amazing, he is so proud of himself and we are so proud of him too. Thank you so much, Laura, we will forever be grateful for your support!

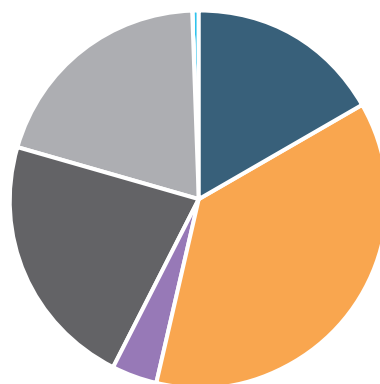
Chante, Bertie's mum



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 2022.

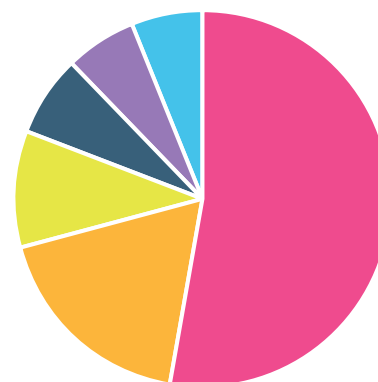
Number of individuals who supported our income streams in 2022:

Raffle	9,470
Lottery	20,851
Regular Giving	2,128
Donation Card	12,445
Gift Aid	11,146
Trusts & Foundations	36
Corporate	27
Legacies	7
Other	216
Total	56,326



How it helped:

Research Projects	53%
CIC	18%
Support Services	10%
Sleep	7%
LEaP	6%
Health & Wellbeing	6%



Support from a number of Trusts and Foundations and Corporate Grants towards the work of our Innovation Centre meant that even more children are able to have fun with their family and friends.

Thanks to:

Westfield Health, Blackwood Engineering Trust, Swinton Paterson Trust, Audemar Piguet, Morrisons, Hays Travel Foundation, The de Brie Charitable Trust, The Hobson Charity, The Childwick Trust, The D'Oyly Carte Charitable Trust, The Moondance Foundation, Nationwide, Bolt Burdon Kemp, Percy Bilton, Next Plc, Candis Club.

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.

Enable Law,
Pryers Solicitors,
Alderstone Solicitors,
Bolt Burdon Kemp,
CL Medilaw.



Stacey Bryant



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

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

Stacey Bryant from Enable Law trekked 90km over 5 days in Cambodia and raised an incredible £1,505. Stacey told us "The work that the Cerebra Innovation Centre does is so inspirational, you can't be anything other than impressed and drawn into the wonderful stuff Cerebra achieves. I had always wanted to visit Angkor Wat so it seemed a good opportunity to combine that trip with the desire to have a personal challenge. Angkor Wat is simply breathtaking in its size and beauty and the Cambodian people are simply the smileiest people I have ever met! I will definitely look at another trek in the future although perhaps not next year! I like the sound of the trek in India".

Swiftly, from PCB Radio based in Worcester, cycled 300 plus miles along the whole of the A38 from Mansfield to Bodmin! He raised £700.

Team Cerebra took on the London Landmarks Half Marathon. Our thanks go to: Sam Hitchcock, Sophie Burgess, Amanda Sellar, Caroline Klage, Ellen Hitchcock, Natasha Price, Orla McGowan and Fiona Cozens and Nicholas Bell: "My son, Alex was born with an undiagnosed condition. When I researched charities, I found Cerebra do a fantastic job helping many families and young people with the support they need. This is very important and personal to me".

We also held several fundraising challenges throughout the year. Our 10k Steps a Day in May raised £1,200, our Hula Hoop Challenge raised £1,600 and the Big Give raised £8,200. Thanks to everyone who took part.

We look forward to where the journey takes us next. Why not join us?



- Join our 'Count Me In' lottery. It costs just £1.20 a week and gives you the chance to win £1,500 in our weekly draw.
- Buy some winning tickets for our summer and winter raffle draws.
- Leave a very special legacy by making a gift in your Will to Cerebra.



Thank you for working wonders for
children with brain conditions

Cerebra

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