

# Research and Information Strategy 2019 - 2024



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# INTRODUCTION

Cerebra is a charity dedicated to improving the life opportunities of children with brain conditions through our investment in research. 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.

In the UK today there are around half a million children and young people with such conditions that, together with barriers to participation, result in complex medical, educational and social support needs. Our work across neurodevelopmental conditions, many of which occur together and/or share similar risk factors, behaviours and challenges gives us a unique perspective within the charity research sector, one that we aim to utilise to achieve our goals.

We want our children to have the maximum opportunity to achieve and participate in society. To that end we support research aimed at reducing the prevalence of disabling conditions that have their origin in pregnancy and research that gives families access to the highest quality evidence based information and support so they can begin to tackle the challenges they face and make informed decisions about what is right for them. We work with university researchers and advocate for families to achieve this.

Having evaluated our previous research activity, our direct work with families and considered the findings of consultation exercises carried out by researchers in the childhood disability field, we want to focus more explicitly on supporting research to benefit the families of children with multiple and complex needs, rare or poorly understood conditions. We reflect this desire in our priorities for 2019 -2024, which are to support research in the following areas:

- Outcomes in pregnancy
- Family research
- Legal entitlements
- Mental health
- Sleep
- Creative design

Funding for our vital work comes in a variety of ways, with us benefiting from many gifts, some small, some large. Many people give regularly, take part in our lottery or just buy a raffle ticket twice a year. Others, generously, leave a gift in their will. We also enjoy the support of grant giving bodies and businesses who enable us to make a real and lasting difference to the lives of others through grants, donations, sponsorship and gifts in kind.

For more information about how you or your organisation can help our children and their families discover a better life together please visit our website [www.cerebra.org.uk/fundraise](http://www.cerebra.org.uk/fundraise) or call Terry Osborn on 01267 244223.

Chris Jones

CEO

In the UK 8% of children and young people are disabled, up from 5% in 2006/07 (Department for Work and Pensions: Family Resources Survey 2016/17). The range of impairments and conditions that are associated with childhood disability is wide, with neurodevelopmental conditions forming the largest group. The UK does not have a single survey that can provide data on the number of children and young people with specific neurodevelopmental conditions. Nevertheless, the estimated prevalence is around 3 to 4%, which equates to around half a million children and young people (Chief Medical Officers Report 2012). Many of these children experience a number of impairments and co-morbidities, which together with limitations placed on participation, result in complex medical, educational and social support needs.



At Cerebra we approach, fund and help to develop research in a unique way that expresses our key values. We support, and will continue to do so, high quality discovery research that can improve the quality of life for children with neurodevelopmental conditions and their families.

Alongside our research programme, we provide a number of services to families of children with neurodevelopmental conditions. Those services are aligned with our research and are in areas that are less well supported by other charities or public services; they are our Sleep Service; The Cerebra Innovation Centre and our Legal Entitlements service that focuses on health and social care.

Through our support of families within these services, we bridge the gap between them and the academic community, providing researchers with valuable information on the difficulties families face in their everyday life.

We utilise our research findings and links with universities to provide evidence based information for families. We aim to provide the highest quality evidence based information and support, so families can begin to tackle the challenges they face and make informed decisions about what is right for them.

## OUR VISION, MISSION AND VALUES

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 brain conditions. 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.

Everything we do is underlined by three words:



### Positive:

Our optimism helps families see past every barrier.



### Inquisitive:

A spirit of relentless discovery drives everything we do.



### Together:

Our researchers, practitioners and families go further when they travel together.

We work in partnership with universities and families in a productive, engaging and collaborative way to find answers to some of the questions and most persistent problems families face.

# OUR GOALS

Our work across neurodevelopmental (brain) conditions, many of which occur together and/or share similar risk factors, behaviours and challenges, gives us a unique perspective within the charity research sector, one that we aim to utilise to achieve our goals. We support research aimed at reducing the prevalence of disabling conditions that have their origin in pregnancy and research that gives families access to the highest quality evidence based Information and support so they can begin to tackle the challenges they face and make informed decisions about what is right for them. We work with university researchers and advocate for families to achieve this.

Over the next five years, we will focus more explicitly on supporting research to benefit the families of children with multiple and complex needs rare or poorly understood neurodevelopmental conditions.

**We want to achieve significant outcomes from our research that include:**

- Seeing research translated into policy and clinical practice that will improve pregnancy outcomes and the quality of life of families.
- Being able to use our research to advocate for families.
- Developing evidence based resources for families to help them tackle some of the challenges they face and make decisions about what is best for them.
- 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.
- Collaborating more in funding, designing, implementing and communicating research outcomes.
- Supporting and developing new innovative ideas that may lead to more extensive research programmes.
- Leveraging more research funding to support research that will benefit the families of children with multiple and complex needs.
- All bids for research funding from us must meet one or more of our priorities and help us achieve our goals.

# OUR ACHIEVEMENTS

We have been funding research at leading universities since December 2001, investing over nine million pounds. In that time, we have made a significant contribution to improving knowledge that benefits children with neurodevelopmental conditions and their families. Our investment has achieved important results in the following areas.



# Pregnancy

For most mothers, pregnancy is a safe and straightforward process, but for 1 in 5 unexpected complications can occur and are a major cause of childhood disability. We want to focus on understanding the causes of these complications, what can be done to improve outcomes for mother and baby and see research translated into clinical practice.

Our achievements so far are:

A close-up photograph of a pregnant woman's lower abdomen and belly. Her skin is fair, and she is wearing a grey textured top. A purple circular callout is positioned to the left of her belly.

Contributed to a reduction in still and preterm birth rates in the Leeds area, with 500 fewer babies being stillborn or being born pre-term over the course of Cerebra's funding.

A close-up photograph of a pregnant woman's lower abdomen and belly. Her skin is fair, and she is wearing a grey textured top. A yellow circular callout is positioned to the right of her belly.

Improved current knowledge of growth restriction in late pregnancy, its association with impaired foetal brain development, links to childhood disability and interventions to reduce risk.

A close-up photograph of a pregnant woman's lower abdomen and belly. Her skin is fair, and she is wearing a grey textured top. A blue circular callout is positioned to the left of her belly.

Helped to achieve a better understanding of the causes of pregnancy complications, the serious consequences for mother and baby and preventative strategies for the main conditions complicating pregnancy.

A close-up photograph of a pregnant woman's lower abdomen and belly. Her skin is fair, and she is wearing a grey textured top. A green circular callout is positioned to the right of her belly.

Participated in drawing up current government targets to halve pre-term birth rates by 2030.



Contributed  
to local, national  
and international  
guidance for best practice  
in managing pregnancy  
complications.

Facilitated  
participation  
in national and  
international research  
collaborations, helping  
research progress  
faster and better.

Established  
the Thousand  
Women Study, a biobank  
that collected more than 2,000  
blood samples from women  
during the course of their pregnancy,  
with associated demographic and  
clinical information, creating an  
internationally unique resource  
for research into the obstetric  
causes of preterm birth.

# Family research

Families of children with intellectual disability, autism and genetic disorders face considerable stresses and challenges, while also experiencing positive times with their children. We want to understand children's behaviour; the role of the family and how to better support families. We want to use that knowledge to influence public policy around supporting families. Our achievements so far are:

A photograph of a person sitting cross-legged in a field of green grass and small purple flowers. The person is wearing orange shorts and brown shoes. A purple circle contains the following text:

Developed the UK's first longitudinal study following over 1,000 families of children with intellectual disability and/or autism in order to understand the role of the family in influencing outcomes for children.

A photograph of a person sitting cross-legged in a field of green grass and small purple flowers. The person is wearing orange shorts and brown shoes. An orange circle contains the following text:

Developed cross-syndrome work and documentation providing a unique platform for research, leading to a new understanding of behaviours resulting from disorders, their impact on the quality of life of children and their families, and potential effective interventions.

A photograph of a person sitting cross-legged in a field of green grass and small purple flowers. The person is wearing orange shorts and brown shoes. A pink circle contains the following text:

Pioneered ways of working with families and involving them in deciding research questions, designing and conducting studies and telling people the results.

A photograph of a person sitting cross-legged in a field of green grass and small purple flowers. The person is wearing orange shorts and brown shoes. A yellow circle contains the following text:

Influenced local, national and international guidance for best practice in managing a range of rare syndromes; on challenging behaviour in people with learning disabilities; and family support.



Developed and shared evidence based information for families around key topics.

Contributed towards the development of the FIND website, that provides parents and professionals with information about rare and poorly understood conditions.

Trained the researchers of the future by supporting PhD students who are now active researchers and leaders in their field.

Established a lending library stocking reliable information to help families get the answers to the questions they have about their child's condition or to borrow and try out some sensory toys.

# Legal entitlements

The laws of the four nations of the UK place enforceable duties on public bodies to provide education, health and social care support for disabled children, yet the research evidence suggests children and their families experience considerable difficulties in accessing these rights. We want to help families overcome barriers to legal entitlements to public services, in particular health and social care services. Our achievements so far are:

A photograph of a woman with long dark hair, wearing a dark t-shirt, sitting at a desk and looking at a laptop screen. Behind her is a red bookshelf filled with books. Three colored circles with text are overlaid on the image.

Provided legal information and advice to help families understand their legal rights.

Supported families in getting the right support for their children and changing local authority policy and practice.

Developing an understanding of why families struggle to get the support they are entitled to, the common problems they encounter and ways families might best address these problems.



Published research reports on Short Term Breaks, Disabled Facilities Grants and School Transport.

Contributed to government policy reviews and the updating of government guidance.

Published guidance, factsheets and template letters on our website that helps families navigate the complexities of the social and health care systems.

Developed and successfully delivered accredited workshops for parents around the UK, based on resources developed in partnership with our research team at The University of Leeds Law School.

# Mental health

Research tells us that children with autism, intellectual disability and some genetic conditions are often predisposed to experiencing diagnosable mental health problems. At the same time, their needs often go unrecognised or unmet. We want to understand the different types, causes and effects of mental health problems on children and young people with multiple and complex needs or rare conditions; to develop resources for parents and work with clinicians to improve understanding. Our achievements so far are:

A close-up photograph of a young child's face, showing a wide, joyful smile. The child has light-colored hair and is wearing a white top. The background is slightly blurred, suggesting an outdoor setting.

Developed an evidenced based, highly commended guide for parents on how to spot the signs of anxiety and anxiety disorders and what can be done.

Hosted a highly regarded mental health and wellbeing conference.



Succeeded  
in a bid with Cardiff  
University for a Knowledge  
Transfer Project based around  
the needs of children with rare  
neurodevelopmental disorders,  
with a genetic cause, that carry a  
high risk of children developing  
conditions such as ADHD,  
autism or Schizophrenia.

Developed  
guidance  
for parents on  
looking after their  
own emotional  
wellbeing.

# Sleep

Sleep disorders are common, different in nature and problematic for children and families living with autism, intellectual disability and some rare genetic conditions. We want to understand why these sleep problems occur and the interventions that can help families get a better night's sleep. Families told us that lack of sleep has a major impact on their family life and they struggle to get support to address sleep problems. Our achievements so far are:

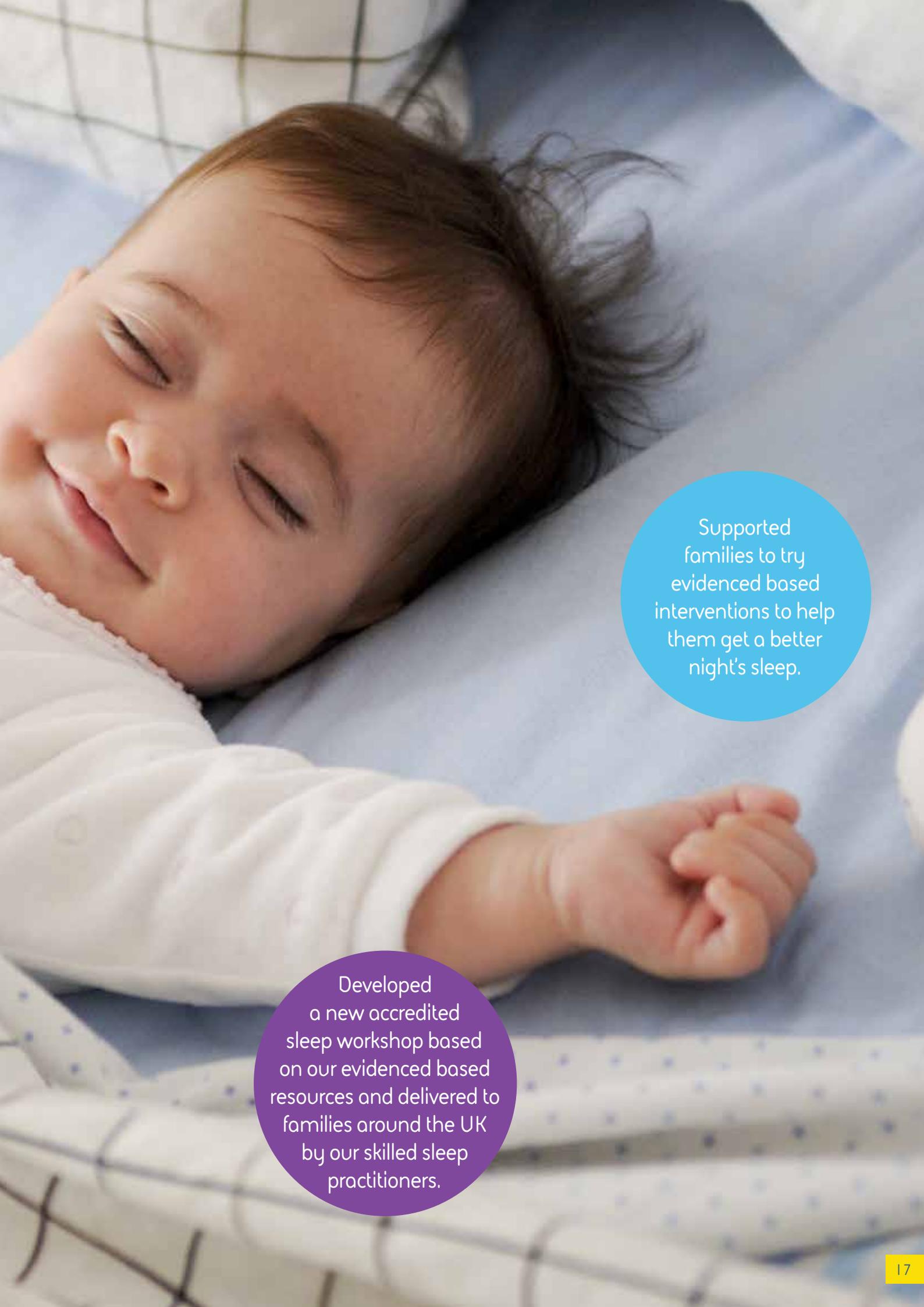
A background photograph showing a close-up of a child's head and shoulders. The child is wearing a white hospital-style gown and has several grey electroencephalogram (EEG) electrodes attached to their scalp via wires. A dark grey rectangular object, possibly a monitor or a piece of equipment, is visible in the lower-left corner of the frame.

Achieved  
a better  
understanding  
of the impact of  
disturbed sleep on  
children and their  
families.

Achieved  
a better  
understanding of  
the nature and causes  
of sleep problems in  
children with rare or  
complex needs.

Developed  
and shared  
evidenced based  
resources to help  
families get a better  
night's sleep.

Trained  
the researchers  
of the future by  
supporting research  
students and early  
career research  
leaders.



Supported families to try evidenced based interventions to help them get a better night's sleep.

Developed a new accredited sleep workshop based on our evidenced based resources and delivered to families around the UK by our skilled sleep practitioners.

# Creative design

Disabled children often encounter barriers to taking part in activities that their typically developing peers take for granted. We want to promote creative, inclusive and innovative design solutions to enable participation through the growth and development of our Cerebra Innovation Centre. Our achievements so far are:



Developed logical, innovative and, above all, fun design solutions to tackle issues families raised with us.

Had designs taken on and made commercially available by companies who support our work.



Reduced some of the social stigma attached to disability by making not only functional but also beautiful products for our amazing young people.

Developed, evaluated and shared new inclusive approaches to design problems.

Across all these areas, we have leveraged millions of pounds of additional funding to support research at our Cerebra Centres.

## Our focus for 2019 to 2024

Over the next five years, we will focus more 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 disorder. Research in this area is often more complex and is poorly financed.



# Our priorities for 2019 to 2024

We have identified the following priorities, which reflect our vision and mission, by evaluating our previous research activity, our direct work with families and considering the findings of consultation exercises carried out by researchers in the childhood disability field, such as those carried out by The James Lind Alliance. We will prioritise research that aims to:



Identify women at risk of experiencing complications in pregnancy and preventing or minimising the impact of those complications on mother and baby.



Study early years support for families to avoid or minimise problems later on. Focusing on children's behaviour, the role of the family, appropriate support for families and understanding and overcoming the difficulties associated with multiple and profound difficulties.



Overcome barriers to legal entitlements to public services, in particular health and social care services.



Understand the different types, causes and effects of mental health problems for children and young people with multiple and complex needs or rare and poorly understood neurodevelopmental conditions.



Understand the different types, causes and effects of sleep problems in children with neurodevelopmental conditions and the actions that can help families get a better night's sleep.



Promote creative, inclusive and innovative design solutions through the growth and development of our Cerebra Innovation Centre.



*"We do not need magic to change the world, we carry all the power we need inside ourselves already: we have the power to imagine better."*

*- JK Rowling*

## Our funding of research

We support research at universities in line with our charitable research priorities. We fund research for the public benefit that will improve the health and wellbeing of children with neurological conditions and their families. We do not seek to own the intellectual property arising from the research. We do not fund major items of capital expenditure such as buildings and equipment. Cerebra cover the direct costs of the research only; we will not meet the full economic costs of the research nor pay towards overheads that support general university infrastructure. We fund research at universities, which can demonstrate a track record of publishing world leading research and participation in the development of clinical guidance or policy development. Principal Investigators should be able to demonstrate accomplishment and leadership in their field of research.

Over the life span of this strategy, we will launch schemes to support the best research for families. Schemes will be openly advertised and bids invited through an open tender process. All bids will be subject to independent peer review via our Research Advisory Committee and review by families via our Research Support Network. We will advertise funding opportunities on our website, through social media and any other channels trustees deem appropriate.

# Our funding streams

## Research programmes

We want to fund a small number of research programmes, typically for up to a 4-year period that address our vision, values and priorities and help us achieve our goals. Some of these programmes must specifically benefit the families of children with rare and/or multiple and complex needs.

We will particularly welcome coordinated collaborative bids, making use of skill sets across universities and work sectors and we are especially open to discussing funding alongside other funders.

We will aim to allocate a minimum of £2,500,000 to this area of work over the life span of this strategy with additional monies allocated to other funding streams.

## Short term task and finish projects

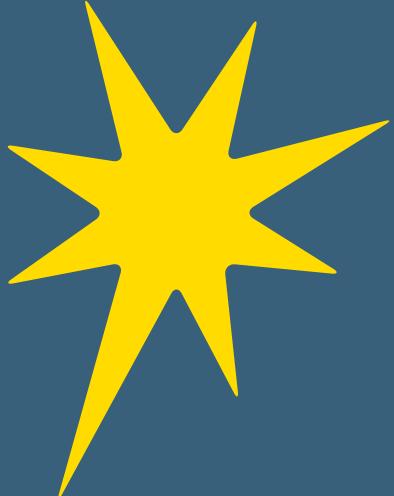
Our task and finish research projects will last between 6 and 18 months and would be for a maximum of £45,000 per project. We would invite bids that address our priorities and allow research or clinical teams to:

- Carry out a systematic review of research evidence behind innovative approaches to supporting families or interventions for particular neurological conditions.
- Run a small scale 'proof of principle pilot', which if successful, will allow the team to gather enough evidence to pursue a bid for a larger project from mainstream funders like NIHR (National Institute for Health Research);
- Produce information resources for parents based on their research/practice evidence;
- Run conferences or seminars to inform practitioners of new findings and best practice that can benefit families.

## Small bursaries and paid internships

Small bursaries and paid internships, up to £3,000 per application, for early career researchers. Preference will be given to those who have a neurodevelopmental condition— for example cerebral palsy, ADHD, epilepsy or autism. Bursaries will support, for example, work placements or enable presentation of work at high profile academic or professional conferences that applicants can demonstrate will help their career development and highlight the needs of the children and families we support.

Full details of our funding opportunities and how to apply can be downloaded from our website.



We're the charity dedicated  
to helping families with  
children with brain  
conditions discover a better  
life together.

#### Postal Address

Cerebra  
2nd Floor Offices  
Lyric Building  
King Street  
Carmarthen  
SA31 1BD

Tel: 01267 244200

Freephone: 0800 328 1159

[www.cerebra.org.uk](http://www.cerebra.org.uk)