

Research and Information Strategy 2023 - 2028



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SUMMARY

Cerebra is a charity dedicated to improving the life chances of children with neurodevelopmental conditions through our investment in research. 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 focus on supporting research to benefit the families of children with multiple and complex needs, rare or poorly understood conditions. Our aim is to give 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. Our services align with our research goals and help get current research findings to families in a timely and supportive way.

Our current research portfolio focuses on a number of lines of inquiry, these are:

- The role of the family in influencing the long-term outcomes for children. We want to study the family and early years support for families to see what will improve outcomes for children, with particular emphasis on children with multiple and complex needs.
- Research tells us that children with neurodevelopmental conditions are more likely to experience mental health problems than their typically developing peers, 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 for children and young people with multiple and complex needs or rare conditions and the things that can be done to help.
- Understanding 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.
- 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.
- 1 in 5 women will experience complications in their pregnancy that can result in childhood disability. We want to identify women at risk of experiencing these complications and investigate how we can prevent them or minimise their impact on mother and baby.
- Promote creative, inclusive and innovative design solutions through the growth and development of our Cerebra Innovation Centre.

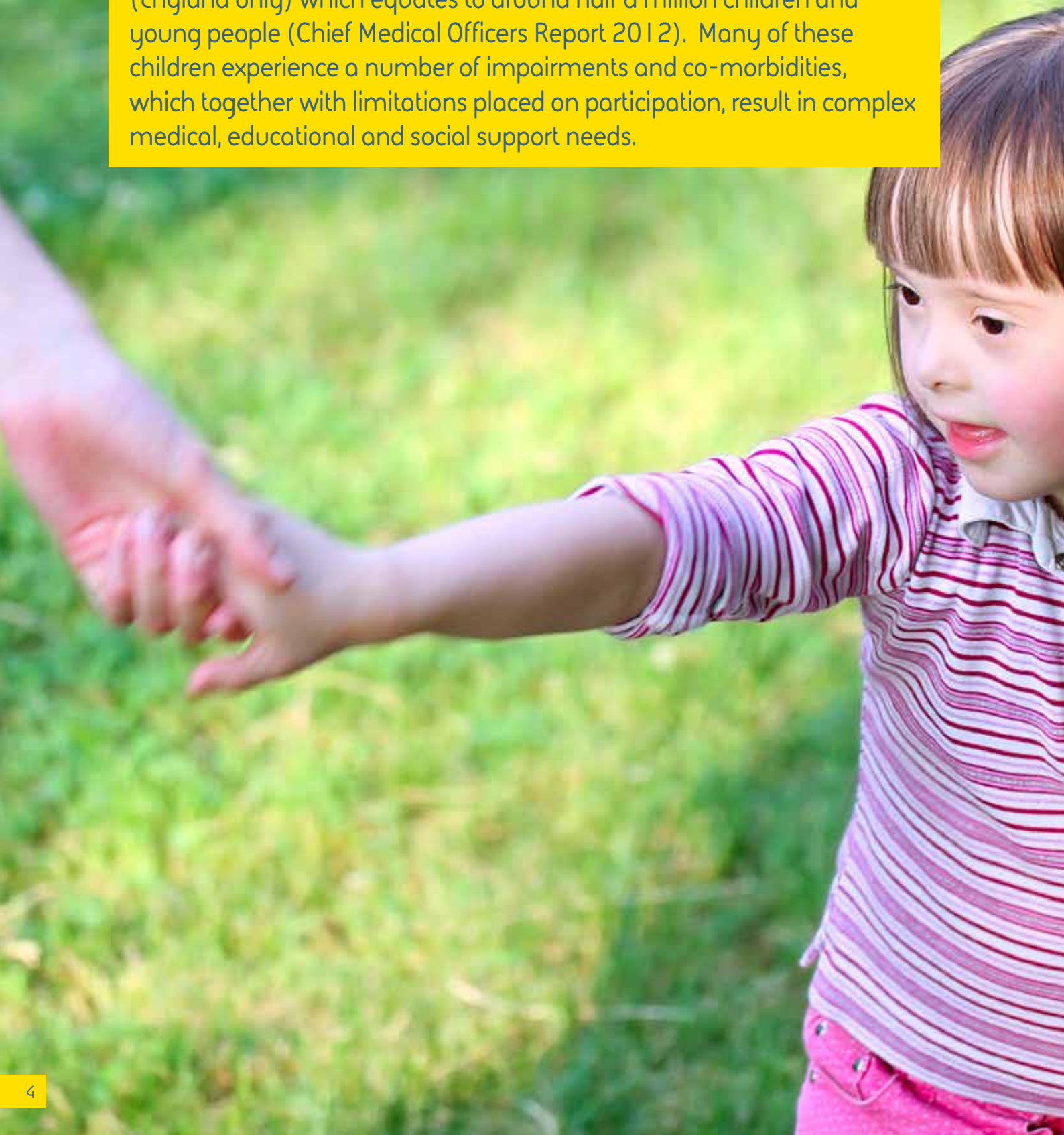
Our ultimate aim through our research and associated services is to promote understanding and to see a world where neurodiversity is respected and celebrated, where children with neurodevelopmental conditions get to fulfil their greatest potential without barriers to their complete participation in society.

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 businesses and grant-giving bodies 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 company can help our children and their families discover a better life together please visit our website www.cerebra.org.uk/fundraise.

Jess Camburn-Rahmani
CEO

In the UK 9% of children and young people are disabled, up from 5% in 2006/07. (UK disability statistics: Prevalence and life experiences House of Commons Library Research Briefing July 2022). 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% (England only) 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.



ABOUT US

We are a research charity and 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 support 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 families to achieve this.

OUR VISION AND OUR MISSION

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.

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.

OUR ACHIEVEMENTS

We have been funding research at leading universities since December 2001, investing over eleven million pounds and leveraged millions of pounds of additional funding to support research at our Cerebra Centres. 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, many of which are set out in our [impact reports](#).

Our focus for 2023 to 2028

Over the next five years, we will 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 is a community that is poorly understood and provided for within the research environment, hence our desire to focus more of our activity in this area. 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, where children with neurodevelopmental conditions get to fulfil their greatest potential without barriers to their complete participation in society.



Our priorities for 2023 to 2028

We will continue to 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.

During the next five years we want to:

- Develop deeper partnerships with universities and other charities where we can work together to improve impact for families.
- Achieve a greater understanding of the causes of pregnancy complications, with the aim of identifying women at risk of experiencing them in pregnancy and preventing or minimising their impact on mother and baby.
- Become leaders in the field of providing sleep support to families of children with neurodevelopmental conditions.
- Increase understanding of rare genetic conditions and the support needs of children and families affected.
- Increase understanding of neurodevelopmental conditions and mental health, particularly in relation to rare genetic conditions.
- Help families overcome barriers to legal entitlements to public services, in particular health and social care services.
- 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.
- Explore how we can make the products designed by our award winning Cerebra Innovation Centre available to more families, probably through the commercialisation of our service.

OUR RESEARCH GOALS

In 2021 we joined the Association of Medical Research Charities (AMRC). This reflects our commitment to ensure our processes for commissioning research meet the highest possible standards and promote collaborative working with universities and other charities.

At Cerebra we support high-quality discovery and translational 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. Through our support of families, 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.

We want to achieve significant outcomes from our research funding, specifically to:

- See research translated into policy and practice at a local, national and international level that will improve the quality of life of families.
- Develop evidence-based resources for families to help them tackle some of the challenges they face and make decisions about what is best for them.
- Promote understanding of neurodevelopmental conditions, particularly rare conditions and associated complex support needs, among professionals and within society.
- Develop 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.
- Collaborate more, with universities and other charities, in funding, designing, implementing and communicating research outcomes.
- Leverage more research funding to support research that will benefit the families of children with multiple and complex needs.



Our funding

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. 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 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. We particularly welcome co-ordinated 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, if funds are available.



Cerebra Network for Neurodevelopmental Disorders. This programme will take forward previous research completed by the Cerebra Centre for Neurodevelopmental Disorders, led by Professor Chris Oliver. In the next phase of this research programme, the Cerebra Network for Neurodevelopmental Disorders will be making an exciting transition by expanding to comprise a collaborative and dynamic network of researchers. The Cerebra Network for Neurodevelopmental Disorders will be led by four alumni of the Cerebra Centre; Dr Caroline Richards (University of Birmingham), Dr Jo Moss (University of Surrey), Dr Jane Waite (Aston University) and Dr Hayley Crawford (University of Warwick). Network research hubs located at each university will focus on key themes that are central to improving the lives of individuals with severe and complex needs and their families including research into sleep, atypical autism and mental health, while continuing their work on self-injurious behaviour and pain in this population.

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. Collaborate more, with universities and other charities, in funding, designing, implementing and communicating research outcomes.

Funding within this stream was granted in 2022. The area of this work is funding dependent and is not planned in 2023. We review this strategy annually.



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 lived experience of a neurodevelopmental condition. 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. This area of work is funding dependent and is not planned in 2023. We review this strategy annually.

Full details of our funding opportunities and how to apply can be downloaded from our [website](#).

In addition to the programmes outlined above we also fund or have funded in the past:



In partnership with the University of Wales Trinity St David (UWTSD), our award winning [Cerebra Innovation Centre \(CIC\)](#). The CIC designs and builds innovative, bespoke products to help disabled children discover and engage with the world around them. From fish tanks to oxygen tanks via specialist buggies our team are brimming with ideas and solutions. Working with families we help breakdown some of the barriers children face, and enable their greater participation in society.



A team at the [University of Warwick](#) are undertaking a systematic review looking at what online and virtual wellbeing interventions are available for family carers of people with a learning disability who are autistic or both. Family carers can experience additional stress and have a higher chance of poorer mental health than other family carers. They need to have good mental wellbeing, and this can sometimes be done through formal programmes or “interventions”. These interventions can help to improve family carers’ wellbeing and can also have knock-on effects improving life for their children. The findings will hopefully find out what’s useful for family carers and the best way to do things based on the experiences of family carers.



In conjunction with Welsh Government and Innovate UK we have also funded a **Knowledge Transfer Partnership** between Cerebra and Cardiff University. Research showed that children diagnosed with a genetic condition are much more vulnerable to psychiatric problems than children without a genetic diagnosis. Despite having elevated risks for psychiatric illnesses, parents commonly struggle with finding helpful information and accessing mental health services for their children. We believed much more can be done to improve mental health care and support for children with rare disorders, their families, service provider and wider communities. The main aim of the project was to improve mental health support for these children and their families and with this in mind a Mental Health Toolkit was developed and we are in the process of developing a workshop based on this toolkit.



At the **University of Warwick** with Professor Richard Hastings. The role of the family in influencing the long-term outcomes for children are not fully understood. Therefore the team at Warwick studied the family and early years support for families to see what would improve outcomes for children, with particular emphasis on children with multiple and complex needs. Our funding 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. The data from this study continues to be used within other research projects.



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



University of Leeds, School of Law, Professor Luke Clements. 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.



University of Warwick, Professor Richard Hastings. The Positive Family Connections Programme 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 the Positive Family Connections feasibility study, the team will be testing out the co-produced programme with around 60 family carers to see if it will be possible to run a much larger study in the future.



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

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