Birmingham Health Partners
Collaboration. Innovation. Application.

University of Birmingham · Aston University · NHS Birmingham Women's and Children's NHS Foundation Trust · NHS University Hospitals Birmingham NHS Foundation Trust · NHS Sandwell and West Birmingham Hospitals NHS Trust · NHS The Royal Orthopaedic Hospital NHS Foundation Trust · NHS Birmingham and Solihull Mental Health NHS Foundation Trust · Health Innovation West Midlands

Case study: Cerebra Network for Neurodevelopmental Disorders

The challenge

- Neurogenetic conditions are rooted in changes in genes and chromosomes but are not always inherited
- There are more than 1,700 genetic conditions associated with an intellectual disability including Angelman syndrome and Prader-Willi syndrome
- An estimated 350,000 to 750,000 people in the UK are living with a genetic condition associated with an intellectual disability
- As well as developmental difficulties, people with neurogenetic conditions may experience painful health conditions, such as severe gastrointestinal reflux in Cornelia de Lange syndrome. Mental health difficulties, such as anxiety, are also common

Our impact

- Established in 2020, the Cerebra Network – a collaboration between BHP's Aston University and the University of Birmingham, with the universities of Warwick and Surrey – aims to deliver greater insight into children with rare and complex syndromes
- The Cerebra Network developed the innovative Be-Well Checklist to help parents, carers and professionals improve the well-being of people with severe learning disability and complex needs
- LADDERS intervention for reducing anxiety in autistic children with severe intellectual disability
- Developed multiple parent guides including the Cerebra Sensory Processing Guide and Cerebra Pain Guide. Its Anxiety Guide was Highly Commended by the BMA Patient Information Awards
- Delivered 189 individualised reports to families profiling their child's needs in 2023