

# BACD

British Academy of  
Childhood Disability

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## **A History of the CDDG and BACD**

## **Background**

“Children are not just small adults” has been the familiar cry of those keen to recognise the completely different medical needs of young people from adults in the mid part of the last century, a movement that led to the development of Paediatrics as a specialty. Expertise steadily evolved within the various fields of this new, broad discipline. Whilst paediatrics as a whole was represented by the British Paediatric Association (BPA), the forerunner to the Royal College of Paediatrics and Child Health (RCPCH), other organisations were established to support and promote special interests within paediatrics, such as the British Paediatric Neurology Association (BPNA), and the British Association for Community Child Health (BACCH).

Visionaries like Ronnie MacKeith recognised the particular needs of disabled children, and promoted activities and research that is now enshrined in the MacKeith press, which continues to make an enormous contribution. Tertiary Paediatric Neurologists excelled as diagnosticians and provided expert advice on aspects of the medical needs of children and adolescents with a neurodisability. However, it was recognised that those with a neurodisability required co-ordinated assessment and long term support provided by general community or hospital paediatricians working in collaboration with local therapy disciplines, nursing, psychology, education and social services.

The expansion of child development centres from the 1970s onwards facilitated multi-disciplinary support of children with neurodisabilities. Such centres were not established in all localities (and some that were set up have since closed), but it was acknowledged that effective assessment and support for those with neurodisabilities depended on a well co-ordinated, multi-disciplinary, inter-agency team approach. In 1985, Brian Neville and colleagues founded the European Academy of Childhood Disability (EACD) to promote research, provide teaching and foster co-operation between those working in the field of childhood disability throughout Europe and beyond.

Inspired by the EACD, a number of paediatricians met in Derby in 1990 to consider the formation of a UK multi-disciplinary group to set standards and provide learning opportunities for professionals working collaboratively to support those with a neurodisability, and to advocate for appropriate resources for these children and young people. This led to the inauguration of the Child Development and Disability Group (CDDG) in 1993, with Andrew Lloyd Evans (from the Royal Free Hospital) as Chair, Richard Morton (from Derby) as Honorary Secretary, and Diane Smyth (from St Mary's, London), as Honorary Treasurer. From the beginning the CDDG included within its membership, and executive committee, allied health professionals as well as colleagues from education and social care involved in supporting children and adolescents with a neurodisability. Links with these other professionals have been steadily strengthened over the years. The inclusion of representatives from families and ‘third sector’ groups has greatly enhanced the CDDG since its foundation.

The birth of any new organisation is often accompanied by labour pains arising from the considerable effort required to establish the group and the resistance of other bodies that may not perceive a need for such a venture. The founding of the CDDG was no exception. There was initial scepticism over

whether the CDDG was really necessary from those paediatric organisations with an interest in this area, namely the BPNA, BACCH and even the BPA (later to become the RCPCH). These organisations felt that, to varying extents, they already catered for paediatricians with an interest in neurodisability. Those who founded the CDDG believed strongly that these other organisations only provided for some of the professional needs of paediatricians working within neurodisability. Furthermore, CDDG's sole focus on neurodisability, as well as its multi-disciplinary multi-agency ethos, were enormous strengths that clearly set it apart from those other organisations. Fortunately, the unique status of CDDG soon came to be appreciated and various collaborations have been formed with those other paediatric organisations with many CDDG paediatricians also being members of these other groups.

The CCDG, then BACD, has been fortunate to have been chaired by individuals whose leadership, inspiration and sheer hard work has helped the organisation to thrive (see Table 1). Various officers, individuals holding other portfolio roles, members of the executive committee and regional representatives have also been instrumental in supporting the work of CDDG/BACD and helping it to grow and develop. A key feature of CDDG activity has been the annual conference that has been held in various venues, mostly in the Midlands (for ease of access within the UK), although there have been the occasional forays to London and to Durham. The themes of each BACD Annual Conference are shown in Table 2.

***Dr John Gibbs***

***Dr Karen Horridge***

***Nicola Jolleff***

***Dr Andrew Lloyd Evans***

***Dr Richard Morton***

***Dr Jeremy Parr***

***Gail Trembl***

***Dr Gabriel Whitlingum***

***(December 2016)***

## **Paediatric Neurodisability Specialty Training**

The recognition of specialty training in paediatric neurodisability by the Specialist Training Authority of the Medical Royal Colleges (STA) (the body that oversaw training before the Postgraduate Medical Education Training Board (PMETB), which was then taken over by the General Medical Council (GMC)), in 2004 was a milestone in the history of the CDDG. In fact, it marked the end of the CDDG! Far from there being any negative connotations, this was a highly positive move as it represented a carefully planned development as the CDDG evolved into the British Academy of Childhood Disability (BACD). Until 2004, the RCPCH had a Standing Committee on Disability (SCOD).

The Education and Training Subcommittee of the SCOD put together the successful bid to the STA for paediatric neurodisability to be recognised as a separate subspecialty of paediatrics. This bid was underpinned by a competency-based training programme, supported by an extensive training resource pack for trainees and trainers. The stated goal in the original application to the STA for subspecialty status was for there to be a paediatric neurodisability consultant with all of the competences detailed in the training pack for every 100,000 total population in the UK.

Following the official recognition of paediatric neurodisability as a specialty, the SCOD was disbanded and its role as the College's advisory group on neurodisability was handed over to CDDG, whilst a separate committee was set up to oversee the training needs of paediatricians specialising in neurodisability: the paediatric neurodisability College Specialty Advisory Committee (CSAC) of the Royal College of Paediatrics and Child Health. In recognition of these additional responsibilities, and to cement its status as the UK branch of the EACD, the CDDG changed its name and amended its constitution to become the BACD.

The recognition of neurodisability as a subspecialty meant that paediatricians could now specialise in neurodisability during their training, and receive a dual Paediatrics, and Paediatric Neurodisability Certificate of Specialist Training (CST). There was no new money to develop specialist neurodisability Grid training programmes, which were put together by using posts from existing training programmes. Training programmes were assessed in detail by the neurodisability CSAC using a process of 'virtual visits' to decide if they reached the standards required to deliver subspecialty training (or not). The first grid programmes started in September 2005. Some paediatricians who complete specialty neurodisability training are appointed to tertiary, regional hospitals, others to local district general hospitals or community services. Many paediatricians who were trained before grid training was established continue to maintain neurodisability as their main professional activity in district general hospitals or in tertiary children's hospitals. Other general, community and specialist neurology paediatricians have a particular interest and involvement in childhood neurodisability and continue to make a substantial contribution to this field.

## **Research**

One of the aims of BACD is “to encourage debate and promote research into the many outstanding questions in childhood disability”. In 2008, the Strategic Research Group (SRG) was formed with the aims:

- To identify and encourage high quality clinical research in childhood disability in Britain; in particular collaborative multi-disciplinary projects
- To encourage and assist people in the field, including families, young people and clinicians, to identify research priorities
- To facilitate and support the development of major research applications to Wellcome, Medical Research Council, National Institute for Health Research and national charitable funding bodies
- To encourage and help clinicians, who are interested, to participate in research, and potentially pursue an academic career path

An anonymous donor gave £150,000 in 2007 to the RCPCH to be used for the benefit of child health. The College decided to call this the Paul Polani Fund in memory of Paul Polani (1914-2006), who was the first director of the Paediatric Research Unit at Guy’s Hospital, where he was also Prince Philip Professor of Paediatric Research. The College decided that BACD should have the responsibility for using the money and BACD decided that its Strategic Research Group should administer the Polani Award. The Polani Award aims to encourage research and innovation in the field of Paediatric Neurodisability and up to £7,500 is awarded each year to teams or individuals to pilot or complete a research project in paediatric neurodisability. The award allows the team to access National Institute for Health Research support through the NIHR portfolio, giving the award additional value.

Following a funding award from BACD, from 2012 to 2014 the Strategic Research Group collaborated with the James Lind Alliance to identify and prioritise unanswered questions about the effectiveness of interventions for children and young people with neurodisability from patient, carer and clinical perspectives. This resulted in the identification of a Top 25 ‘shared research priority’ topics that are now referred to by research funding bodies when determining which neurodisability projects to support. The BACD Priority Setting Partnership was highly successful and led directly to the SRG working in partnership with the NIHR in the subsequent years. NIHR subsequently prioritised some of the Top 25 topics for research funding, leading to new evidence that could be used by clinicians, parents and young people. Following the success of the BACD funded process, other neurodisability organisations also funded priority setting partnerships, for example in autism research.

Between 2010 and 2015, the SRG conceived, part funded and delivered a multisite randomised controlled trial, to address the uncertainty around the management of drooling, and also to show the feasibility of delivering multisite, multidisciplinary team trials in the UK. <https://trialsjournal.biomedcentral.com/articles/10.1186/1745-6215-15-60> From 2016, the Strategic Research Group partnered with the Castang Foundation to support UK research that includes children with neurodisability and their families, and invite research applications to improve the evidence around which treatments and interventions are most effective for children and families. The aim of the award is to gather pilot and feasibility data that leads to an application for a large definitive

National Institute for Health Research, Medical Research Council, Wellcome Trust, or Charity funded study into treatments or interventions for children with any type of neurodisability

*BACD & Castang Foundation Research Fellows*

From 2017, the first BACD Castang Foundation 'Capacity Building' Fellowships will be awarded. Recognising the importance of research for our clinical practice, the awards will support attendance at two multidisciplinary research workshops run by the SRG, and will aim to foster research collaboration and increase researchers core skills.

**For more details about the SRG, see**

**[http://www.bacdis.org.uk/research/strategic\\_research\\_committee.htm](http://www.bacdis.org.uk/research/strategic_research_committee.htm)**

## **Office Administration**

In the early years, there was no dedicated administrator and so separate organisations were contracted to arrange the annual conference whilst the Hon. Secretary provided administrative support to the executive committee. From 2003 it was realised that for CDDG/BACD to function efficiently, a dedicated administrator was required to organise the annual conference and to support the work of CDDG/BACD throughout the rest of the year. The advantages of a dedicated administrator were, unfortunately, partially offset early on by there being 4 different administrators over 4 years. The members of the executive committee became adept at supporting a new administrator to 'learn the ropes' and organise their first annual conference, because it was such a regular occurrence. BACD has benefitted greatly from the consistency enjoyed by having Kelly Robinson as its very effective administrator since 2007.

## **Summary**

Throughout its existence, BACD (and its forerunner CDDG), has supported innovation and provided regular advice and opinions on national guidelines or standards related to neurodisability. Other than organising an annual conference, BACD's key activities are summarised in Table 3. In addition, BACD regional representatives organise local education events across the UK to encourage, support and inspire colleagues in their work. Despite these achievements, there are still many challenges in endeavouring to meet the needs of children and adolescents with neurodisabilities. The surveys conducted by BACD over the years have demonstrated that although much good work is being undertaken by neurodisability teams, not all agreed standards are being met, workloads are high and resources are stretched - severely so in some localities. BACD has been a highly successful organisation, justifying the belief of its founders that it had a vital role to play in supporting neurodisability work. As BACD moves forward, and continues to benefit from the commitment of its administrator, executive committee, regional and trainee representatives, it will become even more relevant and important to its members, and other professionals, parents and young people with neurodisabilities.

Table 1: Chairs of CDDG and BACD

CDDG Chairs

1993 – 1998                      Andrew Lloyd Evans

1998 – 2004                      Alison Salt

BACD Chairs

2004 - 2007                      Val Harpin

2007 – 2011                      Jane Williams

2011 – 2013                      Gillian Baird

2013 – 2017                      Karen Horridge

2017 – 2020                      Hilary Cass & Ian Male



Table 2: Annual Conference Themes

|      |  |
|------|--|
| 1994 | Treatment approaches in cerebral palsy   |
| 1995 | Standards of service for children with disability  |
| 1996 | Multiprofessional support for disabled children and their families – the role of counselling   |
| 1997 | The evaluation of intervention in childhood disability   |
| 1998 | Evaluating therapeutic approaches to autism  |
| 1999 | Sensory impairment – a multidisciplinary approach  |
| 2000 | Rehabilitation in acquired brain injury in children – the challenge for local and specialist services  |
| 2001 | Specific learning difficulty – overlapping syndromes. Theory and practical management – dyslexia, dyspraxia, language disorder, ADHD, autism |
| 2002 | Children with complex health care needs  |
| 2003 | Management of challenging childhood behaviour  |
| 2004 | Hot topics in autism   |
| 2005 | The earlier the better – is early intervention effective?  |
| 2006 | Advances in managing children and young people with motor disorders  |
| 2007 | Autism spectrum disorder – the evidence  |
| 2008 | Living with disability as a teenager   |
| 2009 | Intervention in neurodisability – what works?  |
| 2010 | Managing cerebral palsy – how to do it   |
| 2011 | Autism spectrum disorder – co-morbidities and outcome  |
| 2012 | What's new in neurodisability?   |
| 2013 | Brain Injury   |
| 2014 | Technological advances in supporting neurodisability   |
| 2015 | Autism Service delivery  |
| 2016 | Behavioural aspects in neurodisability   |
| 2017 | Updates in neurodisability   |

Table 3: Key Activities Undertaken by CDDG/BACD

|               |   |
|---------------|---|
| 1990s onwards | Directory of Child Development Teams, updated approximately every 10 years.   |
| 1999          | UK wide survey of child development teams revealed variation in care (published in Child: Care, Health and Development).  |
| 1999 – 2001   | Val Harpin (CDDG Chair) member of National Advisory Group for SEN (provided advice to Education Ministers especially relating to SEN Code of Practice).   |
| 2000          | Standards for Child Development Services: A Guide for Commissioners and Providers.  |
| 2000          | Advice provided to Department of Education's SEN Toolkit by Dr Andrew Lloyd-Evans   |
| 2003/4        | BACD extended executive committee to include representatives of parents and Department for Education. Links to 3 <sup>rd</sup> sector organisations strengthened (especially the Council for Disabled Children and Contact a Family).   |
| 2004/5        | Network of regional representatives (one paediatrician and, wherever possible, also another member of the multidisciplinary neurodisability team), set up throughout the UK to liaise between the regions and BACD EC and to organise regional neurodisability meetings.  |
| 2006          | BACD asked to oversee the bequest from Prof. Paul Polani, founder of the genetics unit at Guys Hospital, to advance the field of neurodisability. This fund has subsequently been used to offer an annual research grant for small neurodisability studies and to pay the expenses of an invited speaker to give the Paul Polani lecture at the BACD annual conference. First Paediatric Neurodisability CSTs awarded.  |
| 2007          | First Neurodisability Trainees national conference (has continued annually)   |
| 2007          | Worked with the RPPCH and the Council for Disabled Children to highlight the failure of payment by results to adequately fund a multi-disciplinary style of working.  |
| 2007          | First BACD/RCPCH Paul Polani Research Award   |
| 2008          | Provided information to inform the Bercow report into Speech and Language Therapy services (John Bercow MP, attended a meeting of the BACD EC).   |
| 2008          | Strategic Research Network (Childhood Neurodisability), established by Professor Allan Colver   |
| 2008          | Agreement with MacKeith Press for reduced subscription to the Developmental Medicine and Child Neurology journal for BACD members. Establishment of the MacKeith Press poster presentation award at the BACD annual conference.   |
| 2009          | Supported Mencap's campaign related to the relatively poor provision of care for those with a learning disability in hospital.  |
| 2009          | UK wide survey of child development teams revealed continuation of variation in care provided and in compliance with standards (summarised in two publications in Child: Care, Health and Development). <a href="https://www.ncbi.nlm.nih.gov/pubmed/23425219">https://www.ncbi.nlm.nih.gov/pubmed/23425219</a> and <a href="https://www.ncbi.nlm.nih.gov/pubmed/26184744">https://www.ncbi.nlm.nih.gov/pubmed/26184744</a> . Survey enabled an electronic database of child development teams to be established as a replacement for the former paper directory. |
| 2010          | Highlighted concerns over the steady reduction in the provision of school nurses (the same issue was raised again in 2013).   |

- 2010-15 BACD SRG conceived, part funded and delivered a multisite medication trial of drooling management for children with neurodisability, showing the feasibility of such trials in the UK
- 2011-12 Contributed to the on-line 'Spotting the Sick Child' educational and training resource commissioned by DoH and aimed at primary care and 'first responders'.
- 2012 onwards Worked with BACCH and DoH to improve the collection of accurate data on the provision of care to children and young people with a neurodisability (evolved into Data Matters)
- 2013 Successfully worked with Contact a Family to oppose the 'bedroom tax' for children with a neurodisability, resulting in the Government agreeing to exempt such children.
- 2014-15 Contributed to Disability Matters Education and Training resource commissioned from the RCPCH by the DoH (BACD chair led this project at the RCPCH).
- 2015 BACD James Lind Alliance Research Priorities published  
<http://bmjopen.bmj.com/content/5/1/e006233.full>
- 2015 Report published jointly with BACCH and Contact a Family on the impact of austerity measures on families with disabled children (Counting the Cost).
- 2015 Contributed to the RCPCH 'Paediatric Care on Line' education and training resource.
- 2015 First joint conference arranged in collaboration with the Council for Disabled Children (in addition to the BACD annual conference).
- 2016 First BACD/Castang Foundation Funding Award made by the SRG
- 2017 First BACD/Castang Foundation Fellowships awarded