



Annual Review 2019

BACD
British Academy of
Childhood Disability



British Academy of Childhood Disability

- Encouraging and supporting research for the public benefit, publishing and disseminating the useful results thereof, in child development and disability
- Working to improve health services for children with disability and their families
- Providing a forum for all professional disciplines, agencies and professional bodies involved in childhood disability
- Providing technical advice to national government and local authorities and representing child health on committees
- Considering matters relating to child development and disability and providing training and teaching for those involved with children with disability



Chair's Report

I am delighted to be able to introduce our first annual report as a newly registered charity. This marks an incredible journey from the establishment of BACD's predecessor, the Child Development and Disability Group (CDDG) in 1993, through recognition of paediatric neurodisability as a specialty in its own right in 2004, to this exciting new milestone as we become a young charity.

Over the last year there has been growing recognition of the importance of the specialty, as the number of children with disability and life limiting conditions continues to grow. This is in no small part down to improved care and novel treatment approaches, but it also highlights the importance of our work in supporting and educating generalists as well as specialists in the field.

Our research profile continues to grow, and we are proud of our cohort of Castang Fellows, who really represent the multi-disciplinary nature of our specialty and the importance of growing research capacity across the many different professionals involved in our work.

Our Annual Scientific meetings really reflected this philosophy that disability is everyone's business as we discussed the changing face of the specialty and the complex ethical and practical challenges that now face both families and clinical teams.

We have been proud to be represented through many different bodies and committees involved in the care of children with disabilities. We have been able to influence, whether directly or through partnerships with other organisations, on a wide range of important topics ranging from management of medication in those with severe learning disability to consultations on cannabis-base products for medicinal use.

We continue as the only organisation open to all professionals working in the field of paediatric disability, and as a well-recognised source of advice to regional and national bodies.

I am confident that the organisation will go from strength to strength and that our new charitable status will enable us to grow our reach and influence in the coming years.

Dr Hilary Cass, OBE
BACD Chair



Education & Training

BACD will enhance the skills and competence of the neurodisability workforce

Paediatric Disability Distance Learning Courses (PDDL)

BACD and Sheffield Children's NHS Foundation Trust (SCH) have established a partnership to deliver web-based distance learning courses to professionals supporting disabled children and young people and their families. BACD members are eligible for discounted fees on all PDDL courses:

- Paediatric Neurodisability Diploma
- Introduction to Paediatric Disability and Clinical Assessment Course
- ADHD Distance Learning Course
- Epilepsy: Diagnosis, Management and Disability Course

Paediatric Neurodisability Specialty Training

As the Royal College of Paediatrics & Child Health specialty group for paediatric neurodisability, BACD is involved in the development and delivery of sub-specialty training for paediatric neurodisability, and works closely with the College Specialty Advisory Committee (CSAC). The chair of the Paediatric Neurodisability CSAC sits on the BACD Executive Committee.

Continuing Professional Development

BACD continues to deliver high quality scientific and practice-based education through national events as well as regional meetings.

Annual Scientific Meeting

Thursday 21st March 2019 saw over 200 professionals from across the spectrum of the multi-disciplinary team head to the historic city of Leicester for BACD's conference, which this year focused on the changing face of paediatric neurodisability. The programme featured an excellent group of keynote speakers, from both local services as well as from further afield in the UK, covering a wide range of topics from genetics and ethics, to CPIP and complex care needs from both the therapists and parents point of view.

Trainees Meeting

The BACD Trainees' Meeting was held on 1st November 2018 at the Royal Victoria Infirmary, Newcastle. The main topics of the day were feeding problems in children with neurodisability in the morning session and the upper limb in cerebral palsy in the afternoon. The day was attended by a wide range of paediatric trainees of all grades, including those in general paediatrics, community and neurodisability.



Practice

BACD will facilitate high quality clinical service delivery

Contributing to national consultations and evidence setting groups

- Input to NICE guideline consultations include: Cannabis-based products for medicinal use; Children and young people with disabilities and severe complex needs; Epilepsies in children, young people and adults.
- Consultation on mandatory training and development for staff working with those with a learning disability.

Providing representation on relevant committees and working groups

- BACD representation at the Learning Disability senate

Encouraging collection and use of clinical data to drive care improvements

Through the CDT database, researchers can apply to contact Child Development Teams which allows clinicians to undertake research, audit and activities which help us bring about improvements in the interests of children with neurodisability, their families and clinicians.

Disseminating good practice guidance

The BACD newsletter is used to share good practice and local initiatives to a wider audience. This has included:

- Summaries of keynote lectures at BACD annual scientific meeting
- Sharing innovative service delivery, including: Hafan Y Mor Children's Centre Swansea, Cerebral Palsy Integrated Pathway East Midlands, developing local partnerships in Waltham Forest
- Special edition focusing on Learning Disability
- Sharing national policy developments and research, including STOMP-STAMP; NCEPOD Each & Every Need report; priority setting partnerships (occupational therapy, speech and language therapy)



Influence

BACD will influence national and local policy

Collaborations with other relevant groups and organisations

BACD was one of over 60 organisations to sign an open letter to the Prime Minister urging the Government to do more to improve support for children and young people with speech, language and communication needs.

Disabled Children's Partnership

The DCP is a major coalition of over 70 organisations, including BACD, campaigning for improved health and social care for disabled children, young people and their families.

Using our Executive meetings to invite, hear from and inform key policy makers

Representatives from relevant Royal Colleges have a seat at the Executive Committee to enable policies to be shared and collaborations fostered. BACD has 3rd sector and parent representation through the Council for Disabled Children, Contact, and National Network of Parent Carer Forums. Key leads from the Departments of Health & Social Care, and Education are also invited. Presentations have also been received from representatives of NHS England for key policy initiatives.

Presenting data and evidence at the highest level to drive policy change

The 2018 NCEPOD *Each and Every Need* report recommended that “patients with neurodisabling conditions should have their weight and nutritional status considered at every healthcare encounter, and assessed and recorded based on clinical need.” However, not all UK healthcare providers and environments have the facility, resource or skills to accurately weigh and measure all children and young people. The NCEPOD review identified that weight and height were not recorded in all children and young people (CYP). BACD believes it is unacceptable that weight and nutritional status should not be considered and recorded during every encounter, and that all CYP health services should be able to offer the facility to record weight and height for all CYP. BACD's **Weigh to go campaign** aims to raise awareness of the need for weight and nutritional monitoring of disabled children and young people, and an audit will take place to establish if this need is being met across the UK.



Research

BACD will facilitate high quality neurodisability research so clinical evidence drives high quality care

The Strategic Research Group continues to lead national research into childhood disability. In March 2019, it recruited several new members, including its first paediatric neurodisability nurses.

BACD-RCPCH Polani Award

The Polani Award is supportis research and innovation in UK paediatric neurodisability and is awarded annually.

It is administered by BACD and funded by the Royal College of Paediatrics & Child Health. Applications are open to any individual or team in the UK. Applications are peer reviewed and the winning application is announced at the BACD annual scientific meeting.

In March 2019, the Award was presented to Dr Richard Lee-Kelland for his study *Non-invasive assessment of anaemia in children with neurodisability attending community paediatric clinics: a feasibility study*.

Dr Lee-Kelland will be invited to present the findings at the BACD annual scientific meeting in 2021.

BACD-Catang Foundation Career Development Fellowship

The Fellowship supports UK research that includes children and young people with neurodisability and their families.

We are working together to identify, support, and develop childhood neurodisability research leaders, and fund multi-disciplinary Fellowships and workshops that will aim to build childhood neurodisability academic capacity.

In 2019, ten Fellowships were awarded.

Partnership with NIHR

BACD works closely with the National Institute for Health Research (NIHR) to continue the work of the James Lind Alliance Priority Setting Partnership which identified the research priorities for childhood disability research.

For more information about research activities visit:

www.bacdis.org.uk/pages/16-research



Member Benefits

BACD is the UK's only multi-disciplinary professional organisation in childhood disability

It is important that we have a representative membership who can tell us about what is happening locally, for the children and families that we represent. Together we are stronger! Membership is open to all professionals working in childhood disability.

We currently have over 400 members from across the multi-disciplinary team and our community is growing. Join BACD to keep up to date with current practice, improve standards and influence the future of childhood disability care.

- Discounts on all BACD Conferences - annual scientific meeting, trainees' meeting, regional meetings
- Quarterly and monthly news
- Network with fellow professionals
- Publications produced by BACD
- Discounts on all Paediatric Disability Distance Learning Courses
- Reduced subscription to Developmental Medicine & Child Neurology journal
- Discounts on all Mac Keith Press publications

"I came to a BACD meeting and found myself in a room full of like-minded people who are passionate about children and young people with disabilities"

New BACD website launched May 2019

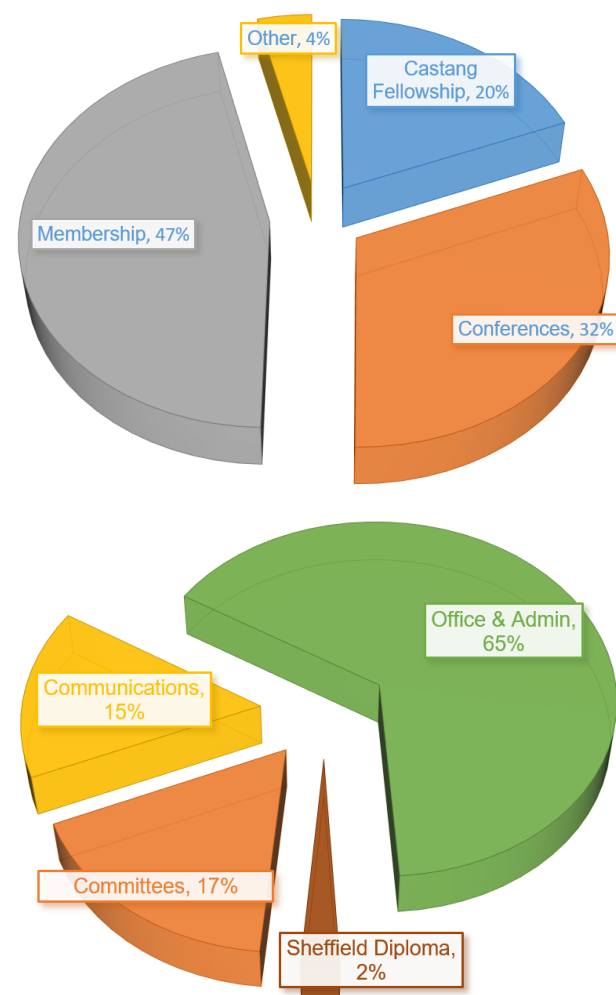
- New design and navigation
- Fully mobile friendly
- Key topics sections, resource search and related content links
- Quick-links menu to access key systems and information

www.bacdis.ac.uk

Our finances

Statement of Financial Activities For the year ended 31 August 2019

	Unrestricted funds	2018
	£	£
Income and endowments from:		
Donations and legacies	561	-
Charitable activities	62,399	44,288
Investments	55	8
Other income	1,382	650
Total	64,397	44,946
Expenditure on:		
Raising funds	(27,344)	(23,655)
Charitable activities	(34,967)	(26,620)
Total	(62,311)	(50,275)
Net income/expenditure	2,086	(5,329)
Reconciliation of funds		
Total funds brought forward	75,307	80,636
Total funds carried forward	77,393	75,307



Key Points

Income:

- BACD is reliant on membership subscriptions and income from educational events, namely the annual scientific meeting, to fund its charitable activities
- Castang Fellowship income covers all costs relating to the programme

Expenditure:

- Office & Admin comprises office rent and service charges, and part-time BACD administrator
- Communications are the quarterly newsletter and redeveloped website

BACD

British Academy of Childhood Disability

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