BACD 10 YEARS ON
CELEBRATING OUR SUCCES

Becoming BACD
In 2003 the Royal College of Paediatrics & Child Health decided to create a College Specialty Advisory Committee (CSAC) for paediatric neurodisability specialty training. At this time it was proposed that the Child Development Disability Group be renamed the British Academy of Childhood Disability to recognise the affiliation with the European Academy of Childhood Disability and to acknowledge that it is a national academy of professional disciplines working together in the area of childhood disability. Led by then chair Dr Alison Salt, this was formally ratified at the BACD AGM in 2004.

BACD members are drawn from all the professionals working in the field of childhood disability, including paediatrics, child and adolescent psychiatry, general practice, adult medicine, specialist nursing, speech and language therapy, physiotherapy, occupational therapy, psychology, social care and education. Representatives from parents’ groups and disability charities add extra value and a different dimension to the work of the executive committee.

Making our voice heard
BACD regularly contributes to a wide variety of national consultations on topics related to disability in children and young people. The range of issues includes new or revised NICE guidelines, relevant government initiatives, policies or legislation and policies and publications from voluntary sector organisations.

Probably BACD has the greatest impact when it is involved in campaigns in collaboration with other organisations that have similar interests. In 2013, BACD joined Contact a Family and other organisations in protesting over the injustice of the Government’s proposed ‘bed-
Editorial

It is 10 years since the Child Development Disability Group was renamed the British Academy of Childhood Disability – a name that better reflects the content and work of the organisation. In this edition we reflect on previous and current work of the BACD – perhaps some of the examples can be used to entice others from your team to either join or to become more active members?

Continuing the celebratory theme we congratulate Sheila Davies, Contact a Family’s representative on the BACD executive committee, for her recent recognition in the Health Service Journal’s Top Innovators in Healthcare list. Having representation from organisations such as CaF on our executive is one of the real strengths of BACD and we are delighted to continue with such partnerships.

Unfortunately we cannot ignore the less celebratory note of CaF’s recent findings about financial struggles faced by the families of disabled children – most strikingly that financial difficulties seem to be increasing for many families, impacting on their ability to access some basic elements of everyday life such as heating and transport.

We report on the recent successful trainees’ meeting and encourage all those of you who have not yet registered for the 2015 Annual Scientific Meeting in Durham, to do so – and to encourage your colleagues to attend also. The programme is excellent and should appeal to a wide range of individuals.

Incoming Editor

I am looking forward to developing a newsletter that will message so many professionals from the statutory sector who are critical to the ‘team around the child’. This is an exciting opportunity to work with a new network of colleagues and I hope to be able to work with others in presenting the wider picture to my colleagues in the community.

I am keen to share the knowledge and information required to provide excellent services both from a clinical perspective but to also include other critical stakeholders such as commissioners; non-NHS providers; voluntary and charitable providers.

As provision in the NHS is changing, clinicians need to be aware of the multifaceted considerations that have to be made to continue to provide high quality services for children with special needs and this role gives me the chance to participate.

Dr Yasmin Khan

Finally I am delighted to hand over the reins / pen / keyboard to Yasmin who is taking over as newsletter editor from 2015. Many thanks to all those of you who have helped me over the past few years by producing articles / reviews / ideas – and to Kelly whose blood pressure seems to stand up to sailing as close as can be imagined to a deadline…!

Dr Katherine Martin
room tax’ with respect to children with disabilities, which received significant TV coverage. Following this campaign, the Government agreed that significantly disabled children would be exempt from the bedroom tax. Not all campaigns or consultations have such a clear outcome, but it is only through regularly expressing an informed opinion that BACD can hope to improve the lives of disabled children, young people and their families.

BACD generally responds to relevant consultations through the RCPCH. For certain NICE guidelines which are of special interest to BACD, such as those dealing with autism or cerebral palsy, BACD registers as a stakeholder with NICE entitling us to respond directly and to nominate individuals to attend workshops or join the guideline development group.

It is uncertain to what extent BACD’s views influence legislation, guidelines, standards, government policies or other organisations’ initiatives. Hopefully, sometimes BACD does make a difference and we shall certainly continue to put forward our collective view on behalf of professionals and parents in the best interests of the children and young people whom we support.

**Regional Representatives**

BACD is divided at the local level by 10 regions with 10 regional representatives who act as a link between the local teams and the national BACD executive body. They help develop regional networking and shape local agendas in promoting child development.

The regional representatives have helped BACD to pilot projects, such as mapping Child Development teams and collecting data for the data and coding projects. They have contributed as members of the advisory committee for the “Disability matters” project and some are authors or editors for the project.

The advice to the Executive Committee on grassroots problems in their locality such as gaps and issues with staff recruitment, job cuts and service delivery is highly valuable.

**Research**

The Strategic Research Group has developed a strong reputation in the neurodisability research field and its members now sit on a number of influential national committees – this extends BACD’s reach, and allows us to ensure that the profile of paediatric neurodisability research remains high in the UK.

The Paul Polani Fund is a ring-fenced fund held by the RCPCH to encourage research and innovation in the field of Paediatric Neurodisability. BACD administers the fund on behalf of the College as its specialty group for neurodisability. The SRG runs the annual Paul Polani Research Award, which has a prize of £7,500 to enable teams to pilot, undertake, or complete research projects based in paediatric neurodisability in the UK. The Childhood Disability Research Priority Setting Partnership followed the James Lind Alliance methods and focusing on ‘neurodisability’. The aim was to find out what research is important to children and young people with neurodisability, their families, and the healthcare professionals who work with them and then prioritised the unanswered questions into a ‘Top 10’ list of topics for research.

**Working with Parents**

BACD works effectively with parent carers by means of Consultation, Participation and Co-Production. Two members of the National Network of Parent Carer Forums sit on the BACD executive committee, contributing to discussions and to consultations jointly with other professionals.

Parent carers seek to bring the lived experience and perspective of families to discussions based on a range of experiences across the spectrum of needs and services (health, education, social care and voluntary sector). With this effective involvement BACD can demonstrate the positive benefits of co-production with parent carers and families at a national, regional and local level.

**Together we can make a difference**

At a time of huge changes in the organisation of health, social care and education together with the challenging economic climate it is really important that BACD has a wide and representative membership who can share what is happening locally, both the good things and the not so good things, for the children, young people and families that we represent. Together we are stronger! And we can and will make a difference!

*John Gibbs, Chinwe Osuchukwu, Jeremy Parr, Mary Busk, Nicola Jolleff, Kelly Robinson and Gail Treml*

**What can YOU do?**

**Support BACD by attending the annual scientific meeting**

The ASM is BACD’s main income generator. Delegate fees are greatly reduced for members and it is a great way to network with fellow professionals from across the country and catch up with friends and old colleagues as well as learning ‘what’s new’ in the world of paediatric neurodisability.

**Sign up to receive consultations**

You may have valuable experience and evidence which can inform a guideline and change national practices. Contact **bacd@rcpch.ac.uk** with your interests!

**Encourage colleagues to join BACD**

**Get involved!**

Apply for a vacancy on the executive committee or as a regional representative and make a difference at a local and national level.
COUNTING THE COSTS CAMPAIGN: HELP PUT PRESSURE ON GOVERNMENT

Sharp rise in families with disabled children going without heating and food leads to ill health

The charity Contact a Family is calling on the UK government and energy companies to urgently address the alarming trend revealed in their fourth Counting the Costs report.

On Tuesday 25th November Contact a Family launched its Counting the Costs campaign at the Houses of Parliament. The reception was hosted by Dame Anne Begg MP, chair of the Work and Pensions Select Committee. Parents attended with their children and were able to talk directly to MPs about their lives and the financial challenges they all face.

Contact a Family carried out research asking more than 3500 families with disabled children for their experiences.

There has been a sharp rise in the number of families with disabled children going without heating and food over the last 2 years, reveals charity Contact a Family. This is leading to too many disabled children and their families suffering ill health.

In one of the biggest surveys of its kind, Counting the Costs 2014, also found that:

- A third are worse off as a result of benefit changes – nearly half by £1560 a year
- 60% see their financial situation worsening in the next year (UP from 43% in 2010)

Based on what parents told us we are calling for urgent action from the government and energy companies to halt this alarming trend.

We need your help to make this happen

You can do this by writing to your local MP. On the Contact a Family website there is a template letter set up so you can do this easily. It will only take one minute, but it will make a huge difference. Nearly 1000 people have already taken action but we need your help too.

Take action at: http://bit.ly/1HQZI4h or www.cafamily.org.uk/takeaction

Amanda Batten, Chief Executive of Contact a Family, said:

“Increased living costs and cuts to financial support have left some families with disabled children reeling. Despite the economy showing signs of recovery, families with disabled children are not optimistic about the coming years. Instead they feel they are facing an increasingly precarious financial future.

“These money worries are putting huge emotional and mental strain on the families we work with. The impact is affecting their health, relationships and in some cases is making their child’s condition worse. It doesn’t have to be like this. We all have a role to play in doing something about it. That’s why we are calling on the government and energy companies to help and for more families with disabled children to get in touch with us for advice.”

It costs more to raise a disabled child. More than a quarter of families surveyed have extra costs relating to their child’s disability of £300 or more every month, with the biggest cost being heating and utility bills. When asked what would help with the extra costs they face, families called for discounts from energy companies (21%) and more support through the benefits system (24%). Some families called for advice about benefits, with almost two
thirds (61%) saying they were confused about the recent changes. That’s why Contact a Family is calling for:

- The government to ensure the benefits and tax system reflects the extra costs and barriers to work that families with disabled children face
- Energy companies to offer discounts to households with a disabled child
- More families with disabled children to get in touch with Contact a Family for benefits advice

The health of some disabled children is at risk because of their families’ stretched finances. As well as going without basics, almost a third of families (27%) told the charity they are going without specialist equipment, adaptations or therapies for their child. And 9% are missing medical appointments, due to the cost of fuel or transport to get there. Some parents say that the stress they are under is having a knock on effect on their child’s health.

Amanda Batten added:

“It is a national scandal that the health of some disabled children and their families is in jeopardy. We must act quickly to address this. There is an energy bill crisis for all families, with prices rocketing over the last few years. But families with disabled children face bigger than average bills because many conditions worsen in the cold weather or require electrical equipment for care and families are typically at home more often.”

Chantal Chaervey from Suffolk, mum to Harry who has complex needs, said:

“Harry has severe brain damage, no immunity and very complex epilepsy which means he can have between 2 and 12 seizures a day. I used to work full time and bring in a very good wage but I lost my home and business when Harry first got ill and spent the first 18 months of his life in hospital.

“Going without essentials like heating has a direct impact on Harry. His immune system is severely suppressed so he needs extra heating. He is incontinent which means he can get very cold at night if he gets wet. Through autumn and winter keeping him warm with very little money becomes increasingly difficult but is vitally important. He can catch flu very easily and this has led to pneumonia in the past – last year he had 13 lung infections. As well as needing extra heating his bedding has to be changed much more than usual. It all adds up.

“Worrying about paying the bills or paying off loans I have taken out to pay for essentials means I feel stressed and anxious and spend a lot of time feeling like a zombie. I am constantly robbing Peter to pay Paul.”

Contact a Family have produced two new guides for the campaign - money matters and help with fuel bills, order today from the helpline on 0808 808 3555.
BACD Trainees’ Meeting Review
BACK TO BASICS IN NEURODISABILITY: FOCUSING ON WHAT TRULY MATTERS

This year’s Trainees’ Meeting took place on 21st November at Friends House in London. Thirty-two delegates attended, the majority of whom were trainees, along with therapists and consultants and it was a lovely opportunity for us to come together and participate in shared learning.

The meeting began with a superb talk from Dr Deborah Hodes on “Challenges in safeguarding disabled children and young people” with many practical tips from her wealth of experience along with discussion on recent high profile child protection cases. Next Dr Richard Newton and Alexandra Lesmes spoke about Disability Matters, the excellent new e-learning programme to inform and inspire launching in February 2015. After coffee Dr Maria Clark and Christina Hawkins from the Developmental Epilepsy Service at Great Ormond Street spoke about dynamic autism presentations in the context of epilepsy and treatment challenges in Landau Kleffner syndrome, which sparked a lot of interesting discussion. Dr Vivienne Campbell from Chailey Heritage Clinical Services then delivered a fascinating talk on “Neuromuscular Scoliosis - what really matters?”

Lunch offered an opportunity for networking and discussion with Dr Neil Wimalasundera, who very kindly attended to address training issues in his role as neurodisability CSAC Quality Advisor, and we also offered advice to trainees applying for neurodisability grid posts.

Next Dr Dido Green talked about optimising outcomes for children with movement disorders from DCD to CP, showing enjoyable videos on her fantastic magic workshops for children with hemiplegia. Dr Toni Wolff held an invaluable interactive session on palliative care for disabled children and young people, covering issues such as symptom control and emergency healthcare plans. Dr Vijeya Ganesan then shared her breadth of knowledge on outcome in childhood stroke, following which the day finished on a high with an excellent session from Dr Isobel Heyman and Dr Reenee Barton on child psychiatry for the neurodisability paediatrician.

Feedback from the meeting has been extremely positive, with delegates feeling inspired to join BACD and comments on how it has changed practice e.g.: “I will now think more about participation rather than just limitations when dealing with children with disabilities” which is wonderful, as the overall aim of the meeting was to highlight the need to focus on meaningful outcomes such as participation. I would like to take this opportunity to thank all of the expert speakers who very kindly agreed to come along and share their knowledge with us.

As trainees we really are fortunate to be standing on the shoulders of giants and have been wonderfully inspired as a result.

DR BELINDA CROWE, BACD TRAINEE REPRESENTATIVE

PAUL POLANI RESEARCH AWARD 2015

BACD is calling for applications to the RCPCH Paul Polani Research Fund, which supports research in paediatric neurodisability in the UK.

The Fund aims to encourage research and innovation in the field of Paediatric Neurodisability. Research to build a robust evidence-base is essential to provide optimal service to maintain and strengthen resources for Children and Young People with Disabilities and their families.

Up to £7,500 is available to enable teams to pilot, undertake, or complete research projects based in paediatric neurodisability.

Applications may be from teams or individuals (of any discipline). BACD is a National Institute for Health Research non-commercial Partner. Polani projects that recruit through the NHS might be eligible for NIHR Portfolio project status.

To Apply
An application form should be completed having reviewed the guidance in advance. (see http://bacdis.org.uk/awards/).

The application form should describe the aims of the project, the methods to be used, and how the money will be spent.

A review panel from the BACD Executive Committee will score applications using the following criteria:

• Relevance to Neurodisability
• Methodology
• Relevance of Outcomes
• Achievability
• Multi-Disciplinary Approach

The winner will be announced at the BACD Annual Scientific Meeting on Friday 13 March 2015 in Durham, will be invited to present the findings of the project at the ASM in 2017 and will be supported in disseminating the results. The winner will also be formally announced, along with a certificate, during the RCPCH Annual Conference 2015.

This is your opportunity to start or finish that important piece of research to make a difference for your service and others.

Closing Date: noon, Friday 30 January 2015
Applications must be submitted via email to bacd@rcpch.ac.uk.
Family test for new policies
Proposed government policies will be checked against five questions to see if they are family friendly as part of efforts to strengthen support for families.

The “family test” will measure the potential impact of new policies on families and family relationships. Policies that fail the test will be scrapped. The test will be made up of five questions, which will assess how policies would impact on families in a range of situations, including those getting married or experiencing redundancy.

The questions will be:

• What kinds of impact might the policy have on family formation?
• What kind of impact will the policy have on families going through key transitions such as becoming parents, getting married, fostering or adopting, bereavement, redundancy, new caring responsibilities or the onset of a long-term health condition?
• What impacts will the policy have on all family members’ ability to play a full role in family life, including with respect to parenting and other caring responsibilities?
• How does the policy impact families before, during and after couple separation?
• How does the policy impact those families most at risk of deterioration of relationship quality and breakdown?

The government has said the aim of the test is to put families at the heart of policymaking and government departments will be required to develop an evidence base demonstrating how policies support family life.

Mandatory reporting law
The government is to launch a public consultation on whether to introduce mandatory reporting of suspected or actual child abuse for professionals working with children.

Mental Health Treatment online
Young people will be encouraged to use apps to treat themselves for depression under government plans to fight mental illness. Ministers want children and adults to be able to get treatment for mental health problems online as part of a transformation of how illnesses such as depression are dealt with by the NHS. DH said that by allowing people to bypass GP referrals to get help via the internet or over the phone would encourage more patients to seek treatment.

Children’s basic rights are threatened by widespread funding cuts
Published on the 25th anniversary of the United Nations Convention on the Rights of the Child the State of Children’s Rights in England report by the Children’s Rights Alliance for England (Crae) shows that cuts to local authority budgets are leaving children and their families without access to vital support services.

It shows that investment in early intervention services has been steadily scaled back since 2011/12 despite a 35% rise in the number of children with child protection needs since 2009/10. Crae also reports that children and young people with SEN and disabilities are left particularly vulnerable when services are cut.

We are delighted that Sheila Davies, who represents Contact a Family on the BACD executive committee, has been included in the Health Service Journal’s Top Innovators in Healthcare list.

The HSJ is a prestigious magazine for health professionals in the NHS, healthcare management and health policy, and this year celebrates fifty individuals who have taken innovative approaches to transforming healthcare.

Sheila has been recognised for the pioneering work she does with parent carer forums to improve healthcare services for disabled children. The judging panel said that Sheila is doing “fantastic work. She is starting from the perspective of patients and carers, helping to build systems around them.”

Sheila has been involved in collaborations between parents and health professionals that have made a real difference to families. This includes the Royal Manchester Children’s hospital, which introduced procedures that made visits less stressful for children with autism - fast tracking children to reduce waiting and having a quiet room to wait in. Feedback from parents showed that they are more satisfied with the hospital and savings are being made as they don’t have to rebook appointments.
Parents to get the complete picture of child development

DH and DfE have announced that from September 2015, integrated health and early years reviews for children aged 2 to 3 years will be introduced. It will mean bringing together the healthy child programme review at 2 years and the early years progress check at age 2 and a half.

By integrating the two separate reviews, it is anticipated that professionals will share information and may carry out the reviews together, giving parents a better picture of their child’s progress and reducing duplication.

The National Children’s Bureau led on a 2-year pilot of integrated reviews from 2012 to 2013. The researchers found that parents preferred this joined-up approach, and take-up of the reviews increased as a result. The approach had also been effective in identifying hard-to-reach children and engaging their parents in services.

Transfer of funding from NHS to LAs

The government has published guidance outlining the funding details for the transfer of birth to five-year-old public health services to local authorities from the NHS. The factsheet explains the timescales for NHS teams and local authorities in the run-up to the commissioning transfer and how funding will work after October 2015.

As part of the transfer, local authorities will be obliged to provide certain universal elements of the Healthy Child Programme, including antenatal health review, new baby assessments, and reviews at one and two and a half.


Early Years Funding Shortfall

Early years providers face a funding shortfall of more than £200m annually to deliver the government’s flagship free childcare policy. Research by the Pre-school Learning Alliance shows the rate paid by LAs to childcare providers for delivering free places for pre-school children is on average around 20% lower than the costs incurred for doing so. The annual shortfall for providing places for two-year-olds (£29m) and three- and four-year-olds (£177m) results in a total deficit of £206m.

Under the free childcare programme, all three- and four-year-olds are eligible to receive 15 hours of government-funded care, along with two-year-olds from the 40% most deprived families. However, the study was undertaken before the free entitlement for two-year-olds was expanded in September this year from the initial 20% most deprived children and therefore it is expected that the actual shortfall may be even greater.

The Alliance said the findings reveal the extent of under-funding of the free entitlement offer. “For every four children that access a government-funded place, providers have to fund a fifth out of their own pocket. This is clearly not sustainable.”

The amount paid to providers includes an additional element from LAs as they are being forced to top up the insufficient government funding but clearly still not to a satisfactory level.

New social worker standards

A new set of professional standards for all levels of children’s social workers will be introduced next year. The standards will see the creation of three types of children’s social worker qualification, with separate assessment and accreditation systems for each and greater emphasis put on developing frontline skills and practice.

The three children’s social worker qualifications will be:

- A new approved child and family practitioner status. They will hold cases for children in need, children at risk of harm and looked-after children.
- Assessed and accredited supervisor status.
- A social work practice leader status.

This will be a senior leadership position with accountability for the quality of frontline practice locally.

Risks to vulnerable children in Scotland

Risks to vulnerable children could be missed unless greater priority and support is given to strengthening child protection arrangements in Scotland. A report by Children in Scotland, commissioned by the Scottish government, makes a series of recommendations including adopting a more coordinated approach to supporting frontline staff, such as teachers and health visitors, in their child protection duties.

Welsh disabled children more likely to be abused

Disabled children are three times more likely to be abused than non-disabled children in Wales and are less likely to get the protection they need. The NSPCC claims people’s reluctance to believe disabled children are suffering physical, sexual and emotional abuse is to blame. The charity also says there are “barriers” for the families of disabled children in accessing the right statutory support services.

ASD in N Ireland

There has been a 67% increase in the number of school age children in Northern Ireland diagnosed as having autism across all trust areas, according to the Department of Health. The figures include children with Asperger syndrome. Boys are five times more likely to be affected, but the rate in girls has increased at a higher rate. According to the latest statistics, children living in more deprived areas appear more likely to have autism.