The BACD 2015 ASM leads on the theme of Autism. Following the recent updates in diagnostic criteria and educational reforms, this meeting will help tie the new research in autism to service delivery.

The speakers are expert researchers and clinicians in Autism and will provide an evidence base to current thinking and practices in Autism.

This conference is suitable for clinicians, allied health professionals, parents and carers and professionals from social care, education and charity services, who are involved with the management of children with Autism.

**Lectures**

- **Polani Lecture:** Early Identification  
  **Prof Tony Charman, London**
- **DSMV and NICE guidelines: implication for service delivery in Autism**  
  **Prof Ann Le-Couteur, Newcastle**
- **Attachment Disorders & Autism**  
  **Dr Margret DeJong, London**
- **Autism in Girls**  
  **Prof David Skuse, London**
- **The role of medication in Autism Management**  
  **Prof Jeremy Turk, London**

**Presentations**

- **Polani Research Award 2013 presentation:** Identification of behavioural risk markers for Challenging Behaviour in very young children with intellectual disabilities  
  **Dr Dawn Adams, Birmingham**
- **Strategic Research Group: Update on research activities**  
  **Dr Jeremy Parr, Chair of the SRG**

**Workshops**

- Managing feeding difficulties in Autism
- Managing autism after diagnosis - Autism Outreach Teams: implementing the SEN reforms
- ADOS
- Interventions for Autism

**Abstract Submission**
The Mac Keith Poster Prize is awarded to the best poster presentation at the ASM each year. We are seeking abstracts that report innovative multi-disciplinary working for children with neurodisability and their families. We encourage submissions from medical and therapy undergraduate students, and foundation doctors, and if their abstract is selected for presentation BACD will provide complimentary registration fees.

**Registration**
Registration Fees for BACD Members have been reduced and we are offering a very early bird, as well as an early bird registration:

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*Waived if presenting a poster

See BACD website for non-member fees

**Venue**
The ASM 2015 will take place at the Radisson Blu Hotel, which is situated alongside the banks of the River Wear. The hotel is located near to to Durham city centre, affords easy access to major motorways as well as being a short walk to the railway station. It is also a short drive from the Durham Tees Valley and Newcastle airports.

**Dates for your diary!**

- 1 December - Very early bird registration
- 18 December - abstract submission deadline
- 28 January - accommodation booking deadline
- 1 February - early bird registration deadline

Visit the BACD website for information on: registration, programme, accommodation, and abstract submission

http://bacdis.org.uk/conferences/annual_scientific_meeting.htm
EXECUTIVE COMMITTEE VACANCIES

We have three vacancies on the committee: Honorary Treasurer, Honorary Secretary, and Newsletter Editor.

Honorary Treasurer

The Hon. Treasurer is one of three officers of the BACD executive committee, and works closely with the chair and honorary secretary.

The successful candidate will act as a Deputy to the current Treasurer until March 2015, after which they will serve as Treasurer for a further three years. The key roles of the Treasurer are:

• Maintain and strengthen the financial base of BACD, to enable it to fulfil its responsibilities to its members.
• Prepare financial reports for the executive committee and present the annual accounts at the BACD Annual General Meeting.
• Monitor BACD finances and make recommendations to executive committee on the annual subscription, any major expenditure and any investment decisions.
• In consultation with the Academic Convenor and the Executive, to advise on the delegate fees and various costs associated with the annual conference.
• Negotiate any financial arrangements needed with other organisations.
• Ensure that the organisation’s arrangements for financial probity are sound and transparent.
• Attend executive committee meetings whenever possible (3 per year).

Suitable candidates should have skills with basic accounting, internet banking capabilities, good time management and organisation skills. They should be able to support and advise the executive committee on matters of finance and develop strategies to ensure the long term success and survival of the organisation.

Honorary Secretary

The Hon. Secretary is one of three officers of the BACD executive committee, and works closely with the chair and honorary treasurer.

The successful candidate will act as a Deputy to the current Secretary until September 2015, after which they will serve as Secretary for a further three years. The key roles of the Secretary are:

Supporting the administrator in the day-to-day running of the organisation and also linking with other external organisations.

• Regular contact with the BACD office.
• Policy development in consultation with the other officers and members of the Executive.
• Links with voluntary agencies.
• Coordinating (with the administrator) the distribution of consultations on guidelines and standards from NICE and other relevant bodies.
• Coordinating BACD’s response to the consultations and other relevant documents.
• Attend executive committee meetings whenever possible (3 per year).

Suitable candidates should have experience of responding promptly to deadlines (timescales for NICE and other consultations are often tight), summarising the views of a range of colleagues and working with colleagues to help set policy.

Newsletter Editor

The key roles of the Newsletter Editor are:

• Receive all copy for the news, check for accuracy and proof read copy.
• Encourage the submission of copy both from executive committee members and also via those working within the field of childhood disability.
• Consult with fellow executive committee members regarding material which may be contentious.
• In liaison with the editorial committee, develop topics for themed-editions and commission articles.
• Produce four editions of Newsletter per year.
• Attend executive committee meetings whenever possible (3 per year).
• Work with the BACD Administrator regarding the layout of the newsletter (the administrator puts together the newsletter using a publishing programme).

The editor’s role would suit someone with the ability to proof read, edit and adapt written articles, often within a short timescale, who enjoys writing and who would be able to liaise with others in order to bring together articles for each edition.

To apply for a role

• Send a CV (three pages max) along with a brief statement (250 words max) outlining your experience and reasons for wanting to take up the role.
• Send applications and queries to the BACD office at bacd@rcpch.ac.uk
• Deadline to apply: Friday 31 October 2014

If more than one candidate applies for the positions of treasurer or secretary, the officers of the BACD will review the applications. If there is more than one suitable candidate, an election of the whole BACD membership will take place.

In the event of more than one candidate applying for the Newsletter Editor position, the executive committee will convene and discuss the applications to select the most suitable candidate.

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EDITORIAL

Dr Katherine Martin

We’ve enjoyed a surprisingly sunny summer this year. If you are feeling full of vigour after a summer break there are a number of opportunities for channelling your energies into more involvement with BACD – we are currently seeking candidates for the treasurer, secretary and newsletter editor roles – see page 2 for details. Being involved with the BACD executive committee is an excellent way of keeping abreast of and having opportunities to input to or comment on current developments in policy, clinical and wider issues in neurodisability. We also advertise two forthcoming meetings and in particular encourage early registration for the BACD Annual Scientific Meeting on 13th March 2015, to be held in Durham.

Our tour of Child Development Centres takes us to Milton Keynes CDC where pathways and processes are frequently reviewed in order to maintain a flexible and integrated service that is able to respond appropriately to the needs of children accessing the service through different routes. Following an open survey and a workshop involving a range of participants, the James Lind Alliance Research Priority Setting Partnership announce the Top Ten Shared Priority Research Questions in Paediatric Neurodisability, with further information about this piece of work available on the BACD website (page 5).

We also offer, as usual, a round-up of government updates, including the SEND Reform timetable, and review a comprehensive article covering many of the issues surrounding palliative care in children.

Many thanks to all those who have contributed to this and past editions – it is great to have input from across our membership. If you have an idea for an article or would like to feature your CDC please do contact us at bacd@rcpch.ac.uk. Please also give some thought as to whether you might like to take on one of the forthcoming vacant roles on the executive committee. And we look forward to receiving your registration for the ASM in March – remember there is a very early bird as well as early bird discount this time...!

Katherine

SEND REFORM TIMETABLE

On 1st September 2014 Part 3 of the Children and Families Act 2014 was implemented replacing the previous SEN statutory framework. Alongside the Act, the SEN and Disability Code of Practice: 0 – 25 Years 2014 and the SEN and Disability Regulations 2014 are now in force.

From 1 September 2014:
- Education, health and care (EHC) plans will co-ordinate support for all CYP aged up to 25, replacing statements of SEN. Statutory EHC assessments must be carried out within 20 weeks.
- CYP with SEN, and their families, will be offered personal budgets to carry out their EHC plans.
- Local authorities must publish a "local offer” with details of all the support available to disabled CYP and their families in the area.
- High-quality mediation services; and independent advice and support for parents and children across education, health and care must be available.
- All state schools including academies, free schools and PRUs must make arrangements to support all pupils with medical conditions, whether or not they have SEN or are disabled.

From April 2015:
- The home LA of a young person in custody will be responsible for arranging appropriate support as outlined in the EHC plan.

End of spring term 2015:
- Pupils should transfer from School Action and School Action Plus to SEN Support.

1 September 2016:
- All those in further education or training assessed as having a learning disability should have an EHC plan where needed.

1 April 2018:
- All CYP with statements should be transferred to EHC plans.
An excellent guide to palliative care for children and young people with disabilities written by Karen Horridge and Toni Wolff was published in the August 2014 edition of the Paediatrics and Child Health Journal. It defines palliative care, highlighting its holistic nature and emphasising the need for high-quality, evidence based best practice with multidisciplinary team involvement, not only to control symptoms, but also to acknowledge when dying is a possibility and to ensure open communication around such issues. Key issues addressed by the article:

What is palliative care? Paediatric palliative care and neurodisability sit comfortably together, sharing many common values. Both involve the active, holistic management of children and young people in partnership with families to ensure their needs are fully met, from the time of initial diagnosis or when difficulties are first recognised, throughout the child’s life span and beyond.

Data matters Improved data capture regarding children and young people with disabilities and/or at risk of early death or requiring palliative care is essential in order to define needs, secure funding and ensure equality of service provision across the UK and there is an ongoing government drive to move towards this.

Networks for paediatric palliative care The UK’s leading charity that supports children with life-limiting and life threatening conditions and all those involved in their care, Together for Short Lives the provision of children and young people’s palliative care via managed regional networks.

Specialist services and transition NHS England has produced a service specification for paediatric palliative care. Transition services vary geographically and are often unsatisfactory. A Transitions Taskforce has been launched by Together for Short Lives to share information via a national information hub and promote good practice.

Using care pathways The care pathway approach advocated by Craft and Killen following their independent review of paediatric palliative care in 2007 utilises best practice principles in paediatric palliative care, embracing cultural diversity and considering the best interests of children and young people at all times, whilst considering the important issues of capacity, consent and confidentiality.

The article also covers key practice points including recognition and discussion of death and dying, action to take if death seems probable or imminent, practical, legal and ethical considerations and elements pertaining to mental capacity and ‘best interests’ decisions. There is information about drawing up emergency healthcare plans and about symptom control.

Key Learning Points:
- Palliative care for disabled children and young people with disabilities should be delivered by or in partnership with paediatricians with appropriate expertise in order to ensure participation, quality of life and appropriate treatments are optimized. It is important to recognise early when death may be a possibility and to discuss this openly and honestly with children, young people and families, to ensure full involvement in decision making, including regarding end of life care.
- We must always be mindful of the ethical and legal frameworks governing decision-making about appropriate levels of care and follow these appropriately.


For the full review of this article visit the BACD website www.bacdis.org.uk/publications/newsletters.htm
The aim of the JLA Childhood Disability Research Priority Setting Partnership was to identify and prioritise unanswered questions about the effectiveness of interventions for children and young people with neurodisability from patient, carer and clinical perspectives.

A wide range of professional and family organisations were contacted and many signed up as partners in the project. Suggestions were gathered in an open survey that was advertised widely by partners. The suggested topics were aggregated and framed as research questions, then checked against existing systematic reviews of research evidence to ensure they were unanswered.

The topics were initially prioritised in a preliminary vote with partner organisations and survey participants, and then discussed and rank ordered by a group of young people, parent carers and clinicians at a one-day workshop held at the RCPCH.

The Top 10 represents the ‘shared priority’ topics selected by participants at the workshop. We have also made available the topics ranked 11-25 and all the issues identified in the survey through the BACD website: http://ow.ly/B4tAM

These data are catalogued in the UK Database of Uncertainties about the Effects of Treatments (UK DUETs): http://ow.ly/B4tM2

The JLA process produces broad research topics that represent the issues identified. To design research studies to address the priorities, interventions and comparators, target populations and outcome measures would need to be carefully defined.

The project has gained considerable interest from the NIHR and, as well as identifying priority topics, it has raised the profile of childhood neurodisability generally with the main UK government agency that fund health research.

The Top 10 ‘shared priority’ research questions

1. Does the timing and intensity of therapies (e.g. physical, occupational and speech and language therapy, ‘early intervention’, providing information etc.) alter the effectiveness of therapies for infants and young children with neurodisability, including those without specific diagnosis? What is the appropriate age of onset/ strategies/ dosage/ direction of therapy interventions?

2. To improve communication for children and young people with neurodisability: (a) what is the best way to select the most appropriate communication strategies? And (b) how to encourage staff/careers to use these strategies to enable communication?

3. Are child-centred strategies to improve children’s (i.e. peers) attitudes towards disability (e.g. buddy or Circle of Friends etc) effective to improve inclusion and participation within educational, social and community settings?

4. Does appropriate provision of wheelchairs to enable independent mobility for very young children improve their self-efficacy?

5. Are counselling/psychological strategies (e.g. talking therapies) effective to promote the mental health of children and young people with neurodisability?

6. What is the (long term) comparative safety and effectiveness of medical and surgical spasticity management techniques (Botulinum neurotoxin A (BoNT-A), Selective Dorsal Rhizotomy (SDR), Intrathecal Baclofen (ITB), orally administered medicines) in children and young people with neurodisability?

7. Does a structured training programme, medicines and/or surgery speed up the achievement of continence (either/ or faecal or urinary) for children and young people with neurodisability?

8. What strategies are effective to improve engagement in physical activity (to improve fitness, reduce obesity etc.) for children and young people with neurodisability?

9. Which school characteristics (e.g. policies, attitudes of staff etc.) are most effective to promote inclusion of children and young people with neurodisability in education and after-school clubs?

10. What is the long term safety, effectiveness and sustainability of behavioural strategies and/or drugs (e.g. melatonin) to manage sleep disturbance in children and young people with neurodisability (outcomes include time to onset, duration, and reducing impact on family)

The project has gained considerable interest from the NIHR and, as well as identifying priority topics, it has raised the profile of childhood neurodisability generally with the main UK government agency that fund health research.
MILTON KEYNES CHILD DEVELOPMENT CENTRE
DR CHINWE OSUCHUKWU, CONSULTANT PAEDIATRICIAN ON BEHALF OF THE SPECIALIST CHILDREN SERVICE TEAM

Milton Keynes is a unitary authority with a rapidly growing estimated population of 255,000 people in 2013. The age group for 0-19 years in 2013 was approximately 71,000. The Milton Keynes Child Health Department located in the CNWL-MK NHS Trust Headquarters within the main hospital campus was established in 1960/70s and predated the opening of the local hospital in 1984. The department consisted of SCMO/CMOs until 1993, when the first Consultant Community Paediatrician was appointed.

Over the years, the department has expanded and continues to evolve; the department now consists of; 4.3 WTE Community Paediatricians, Higher Specialist and Core Community Paediatric Trainees, Medical Secretaries, Complex Needs Nurses (palliative care, epilepsy, special needs school), Looked After Children Nurses, Departmental Manager, Clinical Psychologist and administrative staff. This integration of services has enabled us to provide coordinated packages of care.

Child Development Centre
The Child Development Centre (CDC) was built within the main hospital campus in the 1980s and has areas for our paediatric therapy teams (SALT, Occupational Therapy, Physiotherapy), two clinic rooms for medical consultations and is the base for our Service Co-ordinator.

The Paediatric Neurologists and Orthopaedic Surgeons hold joint clinics with the Paediatricians in the CDC and a weekly joint orthotist-physiotherapist clinic.

The Child Development Centre is centrally located and has the added advantage that all the specialist services are located on a single hospital site. We share common medical records with our acute hospital colleagues. Most of the clinical work is carried out in the CDC. Other appropriate hospital sites and special needs schools are also used.

Referral Pathways
We continually review our pathways to ensure excellent patient care and streamline services to avoid duplications.

Early Years Workers, such as Portage, Children and Family Practice and Health Visitors can telephone Paediatricians directly for advice, where parental consent has been secured. Practitioners (in schools, private and voluntary sector, nurseries, pre-schools, child minders, etc) can also refer directly to specialist teachers who have direct links with the Educational Psychologists or recommend that parents see Health Visitors or their GP in the first instance; who will then refer to Paediatrician/therapy teams if appropriate. The Speech and Language Therapy Team can be accessed directly and without referral through the drop-in clinic held on the hospital campus and within local Children’s Centres.

The Health Visitors undertake the Schedule of Growing Skills II development assessment before referral to our service. This reduces consultation time.

Weekly referral meetings are held and if appropriate allocation to a member of the paediatric team is made. We aim to see the child within 16 weeks.

Referral routes are sufficiently flexible to enable children who are already known to a service, to be seen by Paediatricians if a diagnosis or further investigation is required. This can reduce waiting times for parents and helps to smooth the route towards diagnosis.

Assessment Process/Pathway
Following referral and allocation to the appropriate professionals and pathways, the child is seen in clinic, school and/or home, if appropriate. Milton Keynes Community Paediatrics Team has developed an integrated pathway to ensure joint working between professionals in health and
other partner agencies such as educational authorities, specialist teachers and Health Visitors. Therapists are co-located in the CDC where most of Paediatricians clinics are held.

The assessment pathway includes:
- Pre-school development delay/ neurodevelopmental disorders
- Pre-school Autistic Spectrum Disorder
- School age Autistic Spectrum Disorder pathways

Pre-school /school age Autistic Spectrum Disorder (ASD) assessment pathways
Milton Keynes Community Paediatrics service is commissioned to provide pre-school and school age ASD assessment. The pre-school assessment process includes an Educational Psychologist, Speech Therapist and Paediatrician, while the school age assessment team includes a Clinical Psychologist, Speech Therapist and Paediatrician. Individual professionals conduct their own assessment.

With parental consent, health professionals are able to request information from early years’ settings about the child’s development and progress. The Health Visitors, Speech and Language Therapists and specialist teachers are also involved with Children’s Centres, running clinics on site and offering group sessions with parents. This information is valued as providing a more holistic approach towards a child’s assessment than just clinic visits.

At the end of pre-school ASD individual assessment a diagnostic, feedback and planning meeting is arranged. The Milton Keynes Local Educational Authority supports us with planning of the pre-school ASD professional meetings, where professionals share the outcome of their assessment and discuss strategies for supporting the child; an information pack is provided to parents/ carers with information of appropriate support and services available. Parents may be joined by the nursery staff as well as by the Health Visitors during feedback. A summary report and plan is sent to all parties within 1-6 weeks of the meeting.

The school age children will see a Paediatrician, a Speech and Language Therapist and/or Clinical Psychologist. Once the conclusion is reached by the Multi Disciplinary Team (MDT), feedback is given to parents by the Paediatrician. We aim to conclude both pre-school and school age ASD within 6 months.

Challenges and the Future
The challenges for pre-school are that meetings can only be organised during term time because of the specialist teachers’ involvement in the diagnostic process. Professional meetings are organised six months in advance for pre-school and this works well.

Another challenge is post diagnosis intervention. The ASD Parents Training Programme relies on the good will of staff to deliver it. There is ‘The Early Bird Programme’ delivered by the local authority (which occasionally has long waiting times) and the ‘More Than Words Programme’ delivered by the Speech and Language Therapy team.

We have experienced significant increase in volume as well as complexity of referrals which is having an impact on existing resources.

There is also an Autistic Spectrum Disorder (ASD) coordinators meeting involving Health and Education. Other parenting programmes are available for a range of specific groups and concerns commissioned by the Local Authority.

Our department was successful in securing the funding for the first wave pilot for the Newborn Hearing Screening Programme. We have been involved and continue to be involved in a number of national projects/research such as the Child Health Review: Coordinating Epilepsy Care in 2013, Obstructive Sleep Apnoea in children with Down Syndrome and recruitment into the ASD database. One member of the team is in the process of publishing a Cochrane review on the treatment of respiratory morbidity in children with severe global developmental delay. Our team members have won awards at local and national levels e.g. Queen’s Award for their contribution to patient care. This is also reflected in our monthly NET promoter questionnaire where >80% of families have said that they are more likely to recommend or use our services again.

We continue to review our pathways incorporating research and NICE guidelines in our practice, striving for efficiency and excellent care for children and families, in a timely and coordinated approach.

If you would like your CDC to feature in the newsletter, please contact us at bacd@rcpch.ac.uk!
DfE Analysis of Children with Special Educational Needs 2014

The number of pupils with SEN decreased from 1.55 million pupils (18.7%) in 2013 to 1.49 million pupils (17.9%) in 2014. This is part of a continuing decline since 2010 when 21.1% of pupils had SEN. Boys are two and a half times more likely to have statements of SEN at primary schools and nearly three times more likely at the secondary phase compared with girls.

Child protection IT system imminent

DH has confirmed that the Child Protection Information Sharing (CPIS) to help child protection and health professionals share information about children at risk of abuse and neglect will shortly be available for use in the first wave of NHS organisations and councils taking part in the project. The system aims to improve information sharing on safeguarding between health and children’s services, and comes four years after the closure of ContactPoint, the previous Labour government’s database of children and young people.

Quality of serious case reviews

The quality of child death reviews are “disturbingly variable” with far too many failing to find out what went wrong. The National Panel of Independent Experts on Serious Case Reviews said that the number of good serious case review reports is outnumbered by the number that fails on key points. Problems included reports containing “irrelevant detail, jargon and acronyms that made it difficult to distinguish key events”. Reports also repeatedly listing what happened rather than why. The panel also expressed concern about decisions taken over whether or not to initiate a serious case review.

More health visitors needed

More than 1,800 health visitors must be recruited within 12 months in order for the government to achieve its five-year pledge to boost numbers by 4,200 by May 2015. Latest NHS statistics show that, a further 1,868 health visitors must be recruited by April 2015 if the government pledge is to be met.

Insufficient childcare places

The government’s expansion of free childcare seeks to double the number of disadvantaged two-year-olds eligible to receive 15 hours of care. However over 50% of LAs are unable to provide all disadvantaged two-year-olds with access to free childcare as the scheme expands. As from 1st September, the number of eligible two-year-olds eligible doubled from 130,000 to 260,000. But there is a predicted nationwide shortfall of at least 41,218 places, so only 185,000 of the 219,854 eligible two-year-olds will have access to a free childcare place.

Children’s social care spending rises 5%

LA spending on children’s social care increased by more than 5% in a single year. In contrast, spending on education dropped by 3.4%. Figures from the Department for Communities and Local Government show that councils spent a combined £6.95bn on children’s social care services between April 2013 and March 2014. This figure is £340m (5.1 per cent) higher than spending in 2012/13.

Rising School Population

The number of pupils in English schools will reach its highest level in almost half a century by 2023. The government estimates the number of schoolchildren will top eight million in the next nine years, with an estimated 4.6 million pupils in state primary schools, 9% higher than in 2014. Secondary pupil numbers are expected to start rising from 2016 - from 2.7 million to 3.2 million in 2023.

The rising school population is putting pressure on LA budgets, with councils funding a £1bn shortfall in the funding for school places. Many schools are adding temporary classrooms or building extensions. LAs provided an extra 90,000 places last year, with another 130,000 needed in the next three years, as the birth rate continues to climb.

Fried Food only twice a week

School meals in England must include at least one portion of vegetables a day - and no more than two portions of fried food each week. New regulations for school food in state schools apply from January 2015; they promote drinking water and limit fruit juice servings to 150ml. Schools will also have to provide a choice of fruit and vegetables. The school food plan is designed to promote healthy eating, and will be mandatory for LA schools, new free schools and schools converting to academies.

Hot meals in primary schools

20% of primary schools will not be able to provide hot meals to pupils due to a lack of kitchen facilities. Schools will instead serve children sandwiches or reheated meals in order to fulfil the government’s universal free school meals promise.

Screening Test unavailable to all Welsh mothers

A new screening test for Down’s syndrome is still not available across the Welsh NHS, six years after NICE said all pregnant women should be offered the ultrasound scan and blood test. Currently only patients in north Wales are offered screening. The Welsh Assembly said introducing the test across Wales had been “challenging”.

GOVERNMENT NEWS

Gail Treml, SEN Advisor