



BACD NEWS

The official newsletter of the British Academy of Childhood Disability

WINTER 2020

BACD

British Academy of
Childhood Disability

5-11 Theobalds Road
London WC1X 8SH

www.bacdis.org.uk

*BACD is registered in England and Wales
under charity number 1177868*

The aims of BACD are:

- Mutual support for all those working in district and tertiary level services for children with neurodevelopmental disability
- Promote communication between Child Development Teams
- Organise regular national multidisciplinary meetings on child development and disability
- Good practice in child development and disability
- Encourage debate and promote research into the many outstanding questions in childhood disability
- Work closely with voluntary organisations and others to advocate for children with disabilities and their families
- Encourage and support research in childhood disability

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London - North	Dr Madhumita Mukherjee
London - South	Vacant
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South West	Dr Tom Allport & Dr Caroline Bodey
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Wales	Dawn Forbes & Rina van der Walt
Wessex	Dr Catherine Tuffrey
West Midlands	Dr Manjeet Raina
Yorkshire & The Humber	Dr Pam Ghosh

BACD has close links with the following organisations:

- Association of Paediatric Chartered Physiotherapists
- British Association for Community Child Health
- Contact
- Council for Disabled Children
- National Network of Parent Carer Forums
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Occupational Therapists
- Royal College of Paediatrics & Child Health
- Royal College of Psychiatrists
- Royal College of Speech & Language Therapists

Dear fellow members,

I am pleased to bring you the winter edition of BACD albeit during the 3rd Lockdown in the UK. I hope you all had a restful holiday and that some of you may have had the opportunity to meet others on Christmas day.

We are now almost at the end of January and yet this deadly pandemic shows no signs of abating. Despite it all, we carry on delivering the best quality services, research, training and education as evident by the articles from this newsletter. We have learnt much from the first lockdown, and the November edition of the APCP journal and the July RCOT survey are exemplars of such learning. The succinctly written pieces on page 5 are just tasters and I encourage you to click on the links to read more. Some of us may have been re-deployed yet again or returning back to virtual clinics. However, the statement from Parliamentary under-secretary of state for Children and families saying that children's therapists should not be redeployed and should provide interventions as usual was no doubt reassuring to many.

On a lighter note, Kelly Robinson had the brilliant idea of using a seasonal, joyful photo as our cover for this edition. The beautiful winter cover credits go to the daughter of Madhu Dasarathi, our deputy academic convenor. A winter's day in a small village in North Yorkshire.

Stay safe, stay warm and best wishes,

Yasmin de Alwis



PAUL POLANI RESEARCH AWARD

The Royal College of Paediatrics and Child Health (RCPCH) and BACD, through the Paul Polani Fund, supports research and innovation in UK Paediatric Neurodisability. Research to build a robust evidence-base is essential to provide optimal services for Children and Young People with Disabilities and their families.

Up to £15,000 is available through the Paul Polani Research Award to enable a team to pilot, undertake, or complete a paediatric neurodisability original research project. 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.

Application deadline Midday, Friday 5 February 2021
www.bacdis.org.uk/pages/24-paul-polani-research-award

Happy New Year everyone. I hope you're keeping well, both physically and mentally despite the ongoing strain of working in the current difficult circumstances. The Covid-19 vaccines are giving us hope for a return to some normality later this year, perhaps in the Autumn. The speed of vaccine development and authorisation for use has been amazing and I feel really privileged to be among those who have already had a first dose.

Some parents and professionals are asking about vaccination for children. The [Green Book](#) which has the latest Public Health England information on vaccines and vaccination procedures in the UK was updated with a chapter on Covid-19 in December 2020.

The evidence continues to indicate that children including those with medical complexity are at low risk of serious illness from Covid-19. Currently the [Joint Committee on Vaccination and Immunisation](#) (JCVI) advises that increasing age is the greatest risk factor for serious illness from Covid-19 and data on safety and effectiveness of the vaccines in children is very limited; therefore children under 16 years are not in any of the priority groups for vaccination in the first phase.

People 16 years and over who are deemed to be clinically extremely vulnerable will be offered vaccination alongside people aged 70-74 years, i.e. group 4. People 16 years and over with underlying health conditions will be offered vaccination after those who are 65 years and over, i.e. group 6. The Green Book says that vaccination may be considered for older children with severe neurodisability who live in specialised residential settings, but this would be outside the terms of the MHRA approval and therefore unlicensed use. There is further information on the [Royal College of Paediatrics and Child Health website](#).

Meanwhile we are looking forward to our Annual Scientific Meeting which will be virtual via Zoom on Thursday 11th March. The theme is Physical Activity and Movement and we have an exciting programme including Dido Green, Professor of Occupational Therapy talking on the evidence base for new technologies in rehabilitation for children. So please register via the BACD website and encourage your medical, nursing and therapy colleagues to do so too.

The most important thing is to look after ourselves for the very long haul this is turning out to be. There are some useful wellbeing resources on the [RCPCH website](#). Personally I'm finding 15 minutes of yoga a day with the help of a YouTube channel beneficial for my backache, screen fatigue and general frustration. And seeing my colleagues once a week at virtual team meetings always lifts my spirits.

Best wishes,

Toni Wolff

BACD Regions

We have revised the names of the BACD regions to bring them in line with the Royal College of Paediatrics & Child Health and the NHS deanery regions - we hope that this makes it less confusing than using very outdated NHS regions (from the mid-90's!).

For most members, this simply means a name change of your region; for others it means moving into a brand new region:

- East Midlands (was Trent)
- East of England (was Eastern, now includes Essex)
- Kent, Surrey & Sussex (was Thames SE/SW)
- London - North (was Thames NE/NW)
- London - South (was Thames SE/SW)
- Mersey
- North East (was Northern)
- Northern Ireland
- North West
- Scotland
- South West
- Thames Valley (was Oxford)
- Wales
- Wessex
- West Midlands
- Yorkshire & The Humber

Would you like to be a regional representative?

BACD is looking to recruit regional reps to the following regions:

- East of England
- London - South

Regional representatives promoting communication, mutual learning and support between professionals within child development teams and others with an interest in neurodisability through:

- Local Networking - liaise with local leads for child development teams and/or neurodisability services;
- Education and Training - support the development of regional neurodisability training programmes and act as the local points of contact for interested paediatric trainees to find out more about neurodisability training routes, neurodisability as a future career option
- Policy - contribute to BACD response to consultation documents
- Committee Meetings - present colleagues' opinions, concerns or achievements and represent BACD in the region

We welcome joint applications to job share the role. If you are interested, please contact the BACD office via kelly.robinson@rcpch.ac.uk by **28 February 2021**.



The Advisory Committee on Clinical Excellence Awards (ACCEA) is now accepting applications to the 2021 national Clinical Excellence Awards competition. Consultants and academic GPs working for the NHS in England and Wales can apply for new national awards and for renewals due in 2021. This includes those who were due to renew in 2020 and whose awards were extended by one year.

ACCEA wants to hear from applicants who have delivered patient or NHS system benefit that is 'over and above' their contracted activities, particularly where it has had a demonstrable national and international impact. ACCEA specifically encourages applications from female and BAME consultants, who are underrepresented as a proportion of total applicants but have similar success rates to male and white consultants when they apply.

Award holders will need to submit a renewal application if: they received their current award in the 2017 round; their award was last renewed in 2016 (awarded in 2012, 2007, 2002); or their award was due to be renewed in 2020 and was extended by one year

To apply to ACCEA

Applicants should read the latest guidance before starting an application. All applications must be submitted via the [official ACCEA online application system](#). You MUST submit your application to ACCEA via the online system by 5pm, Thursday 18 March.

To apply for BACD support

As a recognised specialist society, BACD is able to provide citation support to accompany members' application. BACD is required to submit a ranking of candidates for each award category - therefore you must submit to BACD the following:

- Your ACCEA application form (using [this offline form](#))
- Your [contribution to BACD](#)

These two forms must be emailed to bacd@rcpch.ac.uk by **5pm, Thursday 25 February**.

If you are applying for BACD support, you should submit your final application to ACCEA in advance of the final ACCEA deadline so that we can upload the citation of support before the online system closes.

<https://www.bacdis.org.uk/articles/172-accea-awards-2021>

Update from Paediatric Allied Health Professionals



Royal College of
Occupational
Therapists



2020 was a rollercoaster of a year and now seems a good time to reflect on the response of the allied health professions to the pandemic and what this meant for the delivery of therapy services to children, their families and carers.

In March 2020 children's therapy services were directed to stop routine work and provide urgent care only. Schools closed to most children and many children's therapists were redeployed to other parts of the NHS. As a consequence, over half of parents who responded to a Disabled Children's Partnership survey in May 2020 said their children's therapy had stopped.

Children's therapists had to adapt and develop new ways to support children, young people and families. The professional bodies have also been proactive in providing information and support in what has been a rapidly changing situation. BACD members may be interested to learn how the allied health professions have responded.

Physiotherapy

The Association of Paediatric Chartered Physiotherapists (APCP) published a special edition journal in November 2020 - [Practice and Experiences of Paediatric Physiotherapists during the COVID-19 Pandemic](#). This was created with contributions from 472 paediatric physiotherapists who shared their experiences of the first wave of the COVID-19 pandemic. Feedback was captured in the form of a survey which was circulated to all APCP members in June 2020. The main survey headings and subthemes were as follows:

- **Role changes** Role transformation, fulfilling new roles, common barriers and facilitators to fulfilling roles and Impact of role change.
- **Caseload Management** Caseload responsibilities, methods of assessment and intervention, caseload prioritisation, supporting children/young people and their families, risk assessment and safety.
- **Technology** Capability using technology, technology and service delivery, technology to support professional communication and clinical education, technology use in future practice.
- **Continuing Professional Development** Forms of CPD, virtual Learning and practice pattern change.

- **Education and Research** A move towards virtual teaching and assessment, cancellation of clinical education, and taking a step back from research activity.
- **Wellbeing** The emotional impact of the COVID-19 pandemic, relationships and maintaining wellbeing through COVID-19
- **Moving Forwards** Future of digital practice, formulation of new working models, leadership and factors enabling coping with change.

The Chartered Society of Physiotherapy (CSP) have a wealth of COVID-19 resources which can be access via www.csp.org.uk/news/coronavirus

Occupational Therapy

Over 1500 occupational therapists (including 175 working with children/young people/families) responded to Royal College of Occupational Therapists (RCOT) survey in July 2020 exploring how the pandemic affected members' roles/responsibilities/duties, education and research. Key findings from the [report](#) include the following:

- 97% experienced a change to their role/responsibilities, including changes to working patterns, location/base, duties and service demands.
- Redeployment to another team occurred for one-third of respondents: *"As a service of three occupational therapists, two of us were redeployed to adult wards and this meant that valuable work we could have carried out to support families and engage with them while they were at home was not possible."*
- Increased use of digital technologies has driven innovation and service benefits in many cases, but more support is required for this technological shift for others.
- 85% respondents indicated that their service was being delivered differently, for example people being seen less frequently and/or by remote/telephone consultations.
- Almost two-thirds of respondents said that the pandemic brought about changes they would like to see continue into the future, for example more streamlined services, better communication and improved team working.

RCOT produced [guidance](#) to help families maintain their children's health, development and well-being during the first lockdown, and [information](#) to help prepare children for a return to school. These documents were shared widely on departmental, Local Offer and other websites. Brief case studies some of which illustrate how occupational therapists have adapted in response to the pandemic can be found [here](#).

Speech and Language Therapy

The [Royal College of Speech and Language Therapists](#) (RCSLT) produced a range of guidance and information to support members. This includes links to guidance from government and other organisations, FAQs, research, information about telehealth for children, and support for members' resilience and self-care. The Royal College is also gathering information about the impact of coronavirus on access to speech and language therapy.

Case studies illustrating how speech and language therapists are meeting the challenges presented by Covid-19 can be found [here](#), while this [Special Needs Jungle](#) article highlights the need for local and national recovery plans, extra resources and clear guidance to ensure speech and language therapists can support children whose therapy has been affected by the pandemic.

What next?

Concerned about the impact of Covid-19 on therapy services for children and young people, the professional bodies together with Disabled Children's Partnership and BACD [wrote](#) in October to Vicky Ford, Parliamentary Under-Secretary of State for Children and Families, asking that children's therapists be protected from redeployment during the next phase of the pandemic. The Minister's unambiguous [response](#) was that the expectation was that children's therapists should not be redeployed and should provide interventions as usual. This message was reinforced by Suzanne Rastrick, Chief Allied Health Professions Officer in December. We know that many challenges remain in providing therapy to children and young people over the coming months, and anticipate an increase in referrals for children whose needs were missed while schools were closed or who have new needs arising from the pandemic. Children's therapists will continue to adapt, working creatively and collaboratively, doing their best to provide children and families with the therapy they need and deserve.

Dr Sally Payne

Royal College of Occupational Therapists Professional Adviser – Children, Young People and Families

Ms Jemma Bell

Clinical Specialist Physiotherapist (Neonates) & NIHR/HEE Pre-doctoral Clinical Academic Fellow

Dr Penny Williams

Consultant Speech and Language Therapist



International Alliance
of Academies of
Childhood Disability

The impact of the COVID pandemic on children with disabilities, their families and on professionals involved in providing care and support has been very significant. The EACD conducted a Europe wide survey in 18 languages and the survey analysis is available at <http://edu.eacd.org/eacd-covid-19-surveys-report>. There is country specific data also available in the report, including recommendations for policy makers and provider organisations. Please use the data to advocate for our services and for our children and families.

The Global Professional Education Committee (GPEC) of the International Alliance of Academies of Childhood Disability (IAACD) commissioned a COVID-19 Task Force (<https://iaacd.net/iaacd-covid-19-task-force/>). The Task Force had three sub-groups, namely Global COVID-19 Data Co-ordination, Listening & Sharing and COVID-19 Inspired Resources. There is a wealth of useful data available and I invite you to explore the site link.

For those of you who may not have come across the IAACD, it is a collaboration of academies of childhood disability, bringing together the global community of people interested in childhood development and childhood-onset neurodevelopmental disorders. One of the major initiatives of the IAACD is to help develop networks and academies in regions where such networks are lacking and help promote ideas in keeping with 21st century practice in our field. There are sub-committees focused on knowledge transfer, research, best practice and much more. The IAACD website hosts a Knowledge Hub (co-created with CanChild) where good quality peer reviewed resources are available, free to download, use and adapt (<https://iaacd.net/search-knowledge-hub/>).

There is information on all the other activities of the IAACD, including on how you can contribute and get involved. I welcome you to explore <https://iaacd.net/> and join the initiative.

Dr Arnab Seal

Chairperson, EACD

Chair, GPEC, IAACD & Steering Group member, IAACD



Programme

- 10.00 Welcome and housekeeping
- 10.05 **Paul Polani Lecture: Evidence base for new technologies in rehabilitation for children**
Prof Dido Green, Professor in Occupational Therapy, Brunel University London
- 11.00 **Tree Fu Tom**
Dr Sally Payne, Professional Adviser – Children, Young People and Families, Royal College of Occupational Therapists
- 11.15 Morning Break
- 11.30 **SRG Update**
Prof Jeremy Parr, Chair, BACD Strategic Research Group
- 11.45 **Exercise as an intervention for children with neurodevelopmental disorders and sleep-related difficulties; impact on sleep and wellbeing**
Dr Jess Turnbull, Consultant Community Paediatrician, Clinical Lead for Community Sleep Clinic, Guy's and St Thomas' NHS Foundation Trust and Glyn Davies, Joint manager of PE & School Sports Network, PE consultant, lead on SEND & Health & Wellbeing
- 12.25 Lunch Break
- 13.00 **Young People's experiences of Disability Sport**
- 13.50 **Evidence-based Interventions for Developmental verbal dyspraxia**
Dr Pam Williams, Honorary Lecturer in Speech and Language Therapy, University College London Hospitals NHS Foundation Trust
- 14.30 Afternoon Break
- 14.45 **Complex motor stereotypies and management**
Dr Tammy Hedderly, Consultant Paediatric Neurologist, Guys & St Thomas' NHS Foundation Trust and Hon. Senior Lecturer, Kings College London
- 15.25 Summing up, Poster Prize Presentation
- 15.35 Close
- The BACD Annual General Meeting will take place at 15.40-16.00 for BACD Members*

Poster Presentations

We have now peer reviewed the abstracts submitted to the conference, and authors have been contacted to invite them to present at the annual scientific meeting.

We were very pleased to see so many submissions from across the multi-disciplinary team and different grades in all professions. You may recall that BACD is committed to encouraging submissions from undergraduate students and foundation doctors, and three of the lead authors selected to present a poster come from this category, and they will receive free registration.

The best poster presentation will win the Mac Keith Press Poster Prize of £250.

Registration

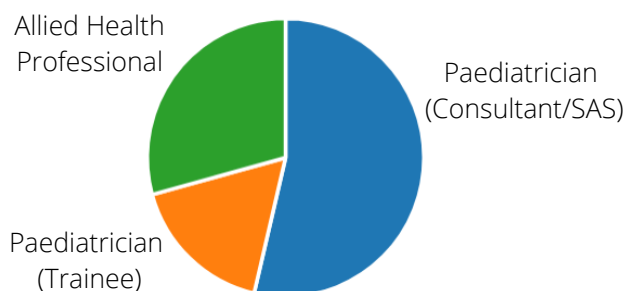
BACD member registration fees are as follows:

- Consultants & SAS Drs - £30
- Non-medical practitioners - £15 (e.g. therapists, nurses)
- Trainee Drs (ST1-8 or equivalent grade) - £20

Register at www.bacdis.org.uk/events/65

North East Regional Meeting

In December 2020, BACD dipped its toe into the world of virtual conferencing - fortunately the day went ahead with no technical hitches! Hosted by the North East region and focusing on Sleep in Neurodisability, over 150 delegates signed up to the event.



Feedback has been positive with 81% feeling that the quality of education was excellent and 81% also scoring that their learning from the event would change their practice in a large or significant way.

"This was an excellent study day and very thought provoking."

"Made me think a lot today on how services can be improved and ways in the future we could do more joint working."

"Absolutely excellent! Best virtual course in a while."

BACD is hoping to arrange additional regionally hosted virtual study day meetings throughout 2021 - make sure you keep an eye on the website and monthly e-news for details!

Trainees' Update

We hope that everyone and their families are well and safe, during what, once again, is a very challenging and uncertain time.

Annual Trainees' Meeting

The annual trainees study day, *'Managing co-morbidities in disability and ensuring services meet needs'* was held on 16th December via Zoom. This is the first trainees meeting we have run virtually and it was great to have so many people join from across the UK. There were over 60 delegates, including a range of neurodisability, community and general ST4-8 trainees, as well a number of consultants and specialty doctors. The sessions covered a balance of clinical and training topics.

Feedback from the day was positive; 100% of delegates felt the day was good or excellent at meeting their learning needs, 91% that their learning from the day would change their practice in a large or significant way and 97% that the quality of education was good or excellent. Comments included:

"Really interesting and helpful. Great to be so trainee focused"

"Excellent teaching sessions. Will definitely try and join next BACD trainees meeting – was pleasantly surprised by how much overlap there was with community child health grid"

The day included a workshop to learn about service design using break out rooms with clinicians, service managers, commissioners and parents as facilitators. This added more of an interactive element to the day and enabled participants to share local practice and gain a broader perspective of services in other regions.

"I enjoyed the interactivity, especially talking to people from other regions with varying service experiences"

"Very useful. Excellent to share good practice and think about 'gold standard'"

"I really enjoy the smaller group work... I think we need more of this across paediatrics"

We will look to include sessions using similar formats in future trainee days.

We both came away with lots of inspiration, ideas and awareness of sources of resources to use with children, young people and their families, and have already put some of this new knowledge from the day into practice.

We would like to thank Kelly Robinson for all of her help in organising and running the day and all of the speakers for making this such a valuable learning opportunity.

Neurodisability training and career resources

We plan to develop the information and resources that are available on the BACD website for trainees, in particular about training in neurodisability and career pathways. We hope this will support both junior trainees

who are considering neurodisability as a career, as well as those further on with their training. If you would like to get involved with developing these resources or have any ideas to contribute, please get in touch.

One of the issues that was highlighted in the trainees survey, undertaken last year, was variation in accessibility to advice and information from more senior clinicians and that not all trainees knew who they could approach for this. The BACD regional representatives are now local points of contact for interested trainees to find out more about neurodisability training routes, neurodisability as a future career option and to find out more about what is happening in your local area. This is now signposted to on the BACD website. For more information and to contact your regional rep, please see www.bacdis.org.uk/pages/8-regional-representatives

Neurodisability online webinars

These online teaching sessions were initially set up over the summer in response to the first wave of COVID to enable trainees to keep connected to neurodisability and the grid curriculum, and also to have more of a face-to-face connection between trainees. In response to positive feedback, these sessions are continuing monthly, on the 4th Wednesday of the month, 1-2pm.

We are aware from discussions with colleagues and from survey results that, for a large number of trainees, COVID had impacted on neurodisability and community child health sub-specialty training opportunities and experiences. With the current situation for many trainees, this is likely to be ongoing to some extent. We hope that the online webinars will continue to provide opportunities for peer support and to connect with other trainees over the coming months, as well as neurodisability focused learning.

To enable a more co-ordinated approach, the paediatric neurodisability and CCH teams are working more closely together to bring a monthly theme to the sessions:

- February – Safeguarding
- March – Inequalities, advocacy and action
- April – Medical complexity
- 1st, 2nd and 3rd Wednesday of the month, 1-2pm – Community Child Health webinar
- 4th Wednesday of the month, 1-2pm – Neurodisability webinar

For more information and to be added to the MS Team to access the webinars, email theneurodisabilitycommunity@gmail.com

If there is anything we can help with or if you have any questions, please get in touch – bacd@rcpch.ac.uk

Dr Katy Wood and Dr Kate Harvey
BACD Trainee Reps

Trainees' Meeting Review

2020, a pandemic of unprecedented proportion. 2020, a year of unprecedented challenge for healthcare, social care, education and the economy. 2020, a year that continues to take its toll on the health, development and wellbeing of children and young people. But also a year of collaboration, ingenuity and innovation in so many ways. December 16th 2020 saw the first virtual BACD Trainees' Meeting held on Zoom, a platform that allowed health professionals, paediatric trainees and voluntary services from around the country to teach, learn and share experiences. And what a day it was!

We started with an informative talk about sleep difficulties in children with neurodisability from Dr Desaline Joseph based at Guys and St Thomas' NHS Foundation Trust with case discussions which I felt really grasped the breadth of this concern. She followed with models of care for the development of a sleep service. Vicki Dawson, CEO and founder of the Sleep Charity, brought this even more in context, highlighting the invaluable work of the voluntary sector in supporting families and the collaborative work with health professionals.

Dr Veronica Kelly and her team (also from Guys and St Thomas') updated us on feeding difficulties and Avoidant Restrictive Food Intake Disorder and strategies that they use in their specialist clinic. This not only highlighted the medical and physical concerns to explore but also the importance of multidisciplinary work in supporting this serious difficulty faced by many children with neurodevelopmental conditions. It included practical advice which I know I will use in my day to day practice.

Personally, as I am currently preparing for my START assessment and gearing my training more towards a consultant role, I found Dr Hannah Nicholson's and Dr Rebecca Gumm's talk on this topic really valuable, including very useful advice regarding applying for a consultant position.

After a CSAC and training update which highlighted the work of the Neurodisability Community and the BACD "Weigh to go!" campaign, the afternoon sessions centred largely around governance and service planning.

Dr Jane Williams from Nottingham University Hospital NHS Trust updated us on the NHS England mandated implementation of SNOMED-CT. The use of standard terminology as a tool to gather data inspired me to start thinking more broadly on ways to improve our efficiency in clinical audit and research to help quantify issues faced by our patient population, thereby powering potential business cases for service development and quality improvement.

The day ended with an incredible small group session in Zoom break-out rooms on actual service development inspired by Dr Venkat Reddy's and Dr Ian Male's Autism Diagnostic Service Re-design work. Participants were given specific priorities and funding and worked together to design a service for children and young people referred for Autism assessment.

Aside from valuable clinical practices, a big learning point for me was about having an awareness of targets for the health of children and working towards these through multi-agency collaboration. All in all, I felt the day had a timely undercurrent of preparing us trainees for the challenges in service provision at a time of economic strain; challenges which we are likely to face as consultants in our endeavour to continue to deliver quality healthcare for vulnerable children and young people.

Dr Navdha R Ramchurn
ST7 in Community Child Health, Northern Deanery

Developmental Medicine & Child Neurology

Are you looking for up to date information on how to improve management and care pathways for children with disability?

DMCN is a multidisciplinary journal that has defined the fields of childhood-onset neurodisability and paediatric neurology for over 60 years. DMCN disseminates the latest clinical research globally to enhance the care and improve the lives of disabled children and their families.

Key features

- Podcasts by Editor in Chief Bernard Dan and authors
- Virtual Issues on key topics

For authors

- Fast decision and publication times
- High quality peer review
- Statistical reviews of original articles
- Open access publishing options
- All articles are free to read 12 months after publication
- High impact factor (4.406) and wide readership

Official journal of BACD

BACD members are eligible for reduced subscription rates to DMCN, which are in addition to BACD membership. For the 2021 subscription period (January-December) this is £100 - subscribers will receive each edition (12 per year) in print, and also be provided with online access. Contact bacd@rcpch.ac.uk to subscribe!

Read the journal: onlinelibrary.wiley.com/journal/14698749

Find out more: www.macketh.co.uk/journal

EACD Europe 2021 - Childhood Disability in a Changing World



People with childhood-onset disabilities and their families are living in challenging times. COVID-19 has hit our European society very hard and will keep our health care and economy for a long time in a stranglehold. Budgetary deficits are raging and savings are likely on the way.

By taking a truly European perspective, EACD Europe 2021 has the ideal timing for EACD to conduct the discussion with local and European stakeholders on how to keep health service for people with childhood-onset disabilities affordable with acceptable quality and to place the most urgent challenges on the European agenda.

Under the meeting theme 'Childhood Disability in a Changing World', we will look back on the direct and indirect effects of COVID-19 on the area of childhood disability, from the use of remote consultation methods and tele-medicine up to the mental health impact. But also look forward to the newest trends in rehabilitation and care and the latest development in technology and innovation.

20 May 2021

Childhood Disability in the Era of COVID-19

- Direct and indirect impacts of COVID-19
- Which lessons did we learn on how to support individuals with a childhood-onset disability
- What can we do to be better prepared to provide the best possible care and support as society recovers?

3 June 2021

Global Partnerships: opportunities and challenges

- Productive partnerships within Europe.
- How can we take full advantage of the current opportunities
- Meeting the emergent challenges that our improved web connectivity and flourishing international networks offer.

27 May 2021

Care, Research and Innovation, the new Landscape of User-professional Partnership

- How have new relations and input emerged through partnership in care, research and innovation?
- How do we operate, find the ways and capitalize on the willingness of users and professionals to help the child and the family to reach their goals throughout the life course?
- How do we train to be a partner, whether a user or a professional?

10 June 2021

The Future of Childhood Disability

- What does the future hold for children with a disability, their families and the professionals who care for them?
- How could future scientific and societal developments affect the lives, participation and rights of children with a disability and their families?
- How will we practice our professions in 10 to 20 years?

Abstract submission closes 31 January 2021!

<https://eacd2021.com/>



All-Party Parliamentary Group (APPG) on cerebral palsy

The first All-Party Parliamentary Group (APPG) on cerebral palsy has been formed and the first two sessions took place in November and December 2020, chaired by Mary Foy MP and Paul Maynard MP. The APPG was sponsored by Action Cerebral Palsy, a campaigning charity which works to raise awareness of cerebral palsy and the challenges faced by children with the condition and their families. The Secretariat was provided by Connect Public Affairs agency.

The first two sessions examined the issues of early identification and pathways of care for infants at risk or with cerebral palsy. Following extensive discussion with stakeholders to establish priorities for discussion, the call for evidence invited submissions on the following themes:

- The importance of surveillance of infants at risk of cerebral palsy, the early identification of signs of cerebral palsy and onward referral for assessment and intervention
- Why infants at risk of cerebral palsy are not being referred quickly enough for assessment and intervention
- The state of health visiting, primary health care and local paediatric services and their role in the early identification, referral and intervention of infants and young children at risk of cerebral palsy, and how their services could be improved
- Workforce skills and knowledge of cerebral palsy and abnormal motor development in primary healthcare, health visitors and early years practitioners
- How could communication and support networks around the family during the assessment and diagnostic process and beyond be strengthened
- Why and how the Cerebral Palsy in Children and Young People Quality Standard [QS162] October 2017 should be implemented as standard across all regions and the impact of this not being the case on children with or at risk of cerebral palsy and their families

- What changes are required so that care for infants and young children at risk of or with cerebral palsy and their families provides a continuum of swift and seamless pathways between local paediatric services and centres of excellence in which multi or trans disciplinary teams of cerebral palsy specialists work together on assessment, monitoring, therapy and treatment
- Why it is crucial that such pathways are centrally funded rather than reliant on regional commissioning models
- What the Government can do to ensure national standard best practice pathways of care for all infants and young children at risk or with cerebral palsy across the UK

The APPG was delighted with the response to the call for evidence and expert speakers for the sessions. Speakers included Prof Simon Kelly, National Clinical Director for Children and Young People, NHS England, Dr Charlie Fairhurst, Chair of the NICE Guidelines and Quality Standards on the Management of Cerebral Palsy in Children and Young People and several members of the BACD including Dr Jill Cadwgan, Honorary Secretary. Other speakers included Alison Moreton, Deputy Director, Institute of Health Visiting and individuals with lived experience of cerebral palsy.

Over 60 participants attended the virtual sessions including policy makers, clinicians, practitioners, voluntary sector agencies, parents and researchers. The sessions can be viewed at:

www.youtube.com/watch?v=vG4YQ7ER23c&feature=youtu.be
www.youtube.com/watch?v=H7NS3GI_pUw&feature=youtu.be

Key themes raised at the APPG sessions included the continuing variations in levels of care across the UK and the need for best practice pathways of care between primary and tertiary care as standard. Examples of best practice were described, but also the urgent need to address the reduced capacity of the paediatric workforce across both primary and tertiary healthcare and to improve the quality of screening processes for motor impairments for infants was raised by a number of contributors.

The report and recommendations from these first two sessions of the APPG on Cerebral Palsy will be completed by mid-February 2021 and will then be available to the public. Some members of BACD who participated in the APPG sessions have indicated that they would like to be involved in potential follow-on work with the APPG.

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Balancing the Pressures: A review of the quality of care provided to children and young people receiving long-term Ventilation (LTV)

National Confidential Enquiry into Patient Outcome and Death; 2020



In 2020 the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published 'Balancing the Pressures?'. This report reviews the quality of care provided to children and young people receiving long-term ventilation (LTV). Data were collected across the whole LTV care pathway, from a number of sources including patients, parent carers, and health and social care professionals working in the LTV community. Twelve recommendations were made, seven of which relate to service planning and commissioning and five which relate to routine care.

From the outset it was apparent that case identification would be difficult as there is no national procedure code which can be used to identify people receiving LTV. To assist with case identification, study contacts were established in all participating organisations across the UK. These study contacts collated the details of all children and young people aged 0-24 years receiving either invasive or non-invasive ventilation, over a two year period from 1st April 2016 – 31st March 2018.

Over the two-year period, the details of 3,061 people were reported; this demonstrates a three-fold increase in the number of children and young people receiving LTV since the last review published in 2010 (Wallis et al, 2010). 60% of the population were male with an average age of 12 years, and 40% female with an average of 11 (Figure 1); 22% were ventilated invasively and 77% non-invasively.

Underlying conditions which led to the need for respiratory support were grouped into five categories (Table 1). This revealed a change in the relative contribution of particular diagnostic groups in this population over the last ten years, with a decrease in the number of young people with musculoskeletal conditions, and an increase in the number with underlying neurological conditions, and in particular the appearance of people with the cerebral palsies in this subgroup which was not present in the previous data.

Table 1. Underlying condition

Wallis et al, 2010			NCEPOD 2020		
	Number of people	%		Number of people	%
Upper Airway Obstruction	256	27.4	Upper Airway Obstruction	791	30.9
Musculoskeletal	402	43.1	Musculoskeletal	751	29.4
Central nervous system	168	18.0	Central Nervous System	630	24.6
Chronic Respiratory Disease	37	4.0	Chronic Respiratory Disease	227	8.9
Other respiratory	50	5.4	NA	0	0.0
Unclassified	20	2.1	Other	157	6.1
Subtotal	933		Subtotal	2556	
Not answered	0		Not answered	505	
Total	933		Total	3061	

One of the key recommendations of the report is to ensure standardisation of the planning/commissioning of integrated care pathways for long-term ventilation services, which bridge child and adult health services, social care services, respite care and any other partnerships relevant to the local network. Health and social care professionals identified aspects of LTV services that could be improved. Survey responses that illustrated this included the need for better access to the wider multidisciplinary team (115/219; 52.5%); and an improvement in clinical knowledge and skills about LTV (48/219; 21.9%).

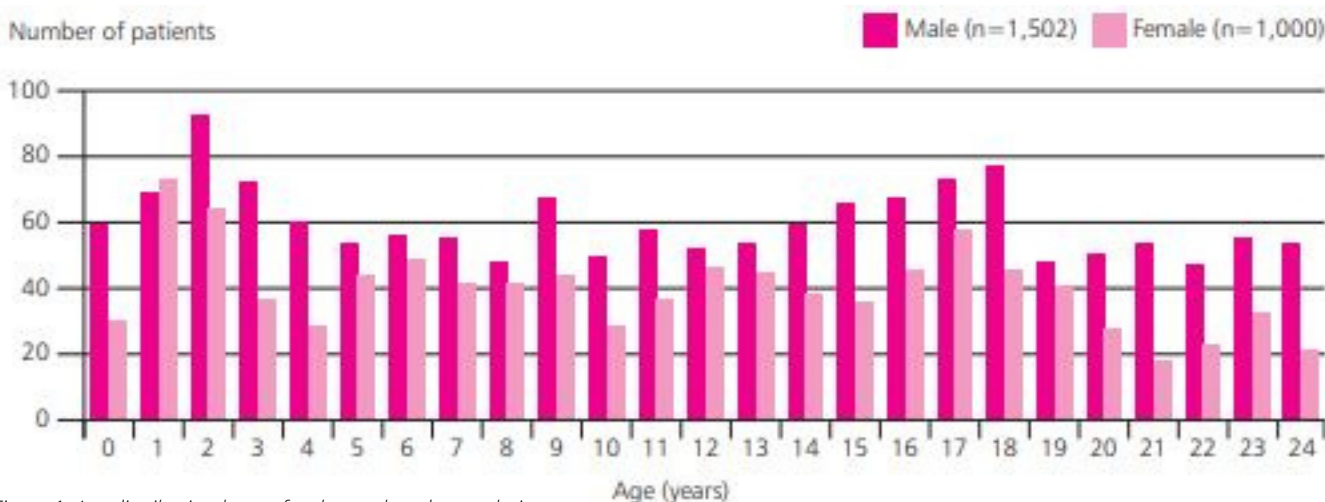


Figure 1. Age distribution by sex for the total study population (where both age and sex available)

The role of the multidisciplinary team was subsequently highlighted as an important aspect of the integrated care pathway. Data from the clinical and organisational questionnaires indicated there was variation in access to specialist help in the community, in the presence of identified leads for people receiving LTV, and in the constitution of specialties within the LTV service.

Training was an area of care also explored in more detail. This was reported as having been received by 63/80 (78.8%) parent carers for common healthcare situations at home. Organisational data indicated that formal structured training programmes for parent carers as well as community staff were more likely to be in place in LTV centres providing care to patients <18 years of age in comparison to organisations providing care to young people ≥18 years. Based on these data NCEPOD has recommended that organisations provide structured training programmes and associated resources which prepare people on LTV and parent carers for home care; community providers for routine care; and non-specialist clinicians for hospital admissions.

NCEPOD found that admission to hospital was relatively common, particularly for people recently established on LTV. Admitting clinicians indicated that a fast-track admission plan was in place for 63/135 (46.7%) people admitted during the two-year study period. It was also reported that an Emergency Healthcare Plan (EHP) was in place for 52/75 (69.3%) people, however there were a further 77 people where this was unknown or the clinician indicated it was not applicable. When the associated case notes were reviewed a copy of this plan was only available in 232/149 (15.4%) sets of notes.

Transition was a key aspect of this study, with 688/2,980 (23.1%) of the total population of people receiving LTV between the ages of 14-18 years. Transition to adult services was identified by parent carers and healthcare professionals as an area for improvement. Parent carers felt that often little or no information or support was provided. Furthermore they reported that the professionals involved sometimes had a poor understanding of what the change meant in practice. Clinicians also noted that the arrangements for transition to adult services were not consistent. The pathway was often disjointed and the level of available support reduced as soon as transition took place. Subsequently it was recommended that the planning for transition from child to adult services, includes the provision of joint transition clinics, has clearly identifiable clinical and executive leadership and forms part of an integrated care pathway for people on long-term ventilation.

The full report and supporting information is available to download at <https://www.ncepod.org.uk/2020ltv.html>

Our thanks to BACD members that helped with data collection. We would be glad to receive comments and questions and/or present to local networks.

References

- National Confidential Enquiry into Patient Outcome and Death. Balancing the Pressures. A review of the quality of care provided to children and young people aged 0-24 years who were receiving long-term ventilation. 2020; NCEPOD London.
- Wallis C, Paton JY, Beaton S et al. Children on long-term ventilatory support: 10 years of progress. Arch Dis Child, 2010; 96(11): 998-1002



Guy's and St Thomas'
NHS Foundation Trust

Clinical Fellow in Neurodisability

An opportunity has arisen for a Senior Clinical Fellow in Paediatric Neurodisability at the Evelina London Children's Hospital.

The post will commence in March 2021 for a 6 month period.

The trainee will work closely with the wider multidisciplinary teams within the paediatric neurology and neurodisability services including behavioural paediatrics, feeding disorders, saliva control, neuropathic bowel and bladder, epilepsy, spinal, neurorehabilitation and movement disorder pathways. They will gain exposure to interventions with Botulinum Toxin A, Intra-thecal Baclofen Pump insertion and review and Deep Brain Stimulation.

Within the Evelina there are a wide variety of other specialties that the trainee will work with including combined orthopaedic clinics, genetics, complex communication, audiology and ophthalmic and palliative care clinics.

For more information on the role and how to apply [click here](#).

Closing date: 29 January 2021

Paediatric Disability Distance Learning Courses

Online learning resources to support professionals working with disabled children and their families

PAEDIATRIC NEURODISABILITY DIPLOMA

This course is recommended for all Paediatric Neurodisability grid trainees in the UK to complement the grid training programme and provides a useful framework to gain the expected competencies. It would also be excellent training for any medical specialist in Paediatric Neurodisability in the UK and overseas.

EPILEPSY: DIAGNOSIS, DESCRIPTION, MANAGEMENT AND DISABILITY

This course is for any member of the multidisciplinary healthcare team who wants to improve their knowledge and understanding of epilepsies, their assessment, description, management and associated conditions, and to improve their awareness of resources to better inform and support children, young people and their families.

ADHD AND COMORBID CONDITIONS

This course is intended to support learning for specialist nurses, paediatricians and other health professionals working with children and young people with ADHD and their families.

AN INTRODUCTION TO PAEDIATRIC DISABILITY AND CLINICAL ASSESSMENT

This course is intended to support learning for specialist nurses, paediatricians and professionals working with disabled children and young people and those following different developmental pathways.

AUTISM, SPEECH, LANGUAGE AND COMMUNICATION NEEDS IN CHILDHOOD

This course is for professionals involved with assessment and support for children and young people with speech, language and communication needs, including autism spectrum. This includes community, general or specialist paediatricians and allied health professionals, particularly speech and language therapists, school nurses, teachers, SENCO's, educational psychologists and classroom support assistants.

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www.sheffieldchildrens.nhs.uk/about-us/careers-and-opportunities/courses/paediatric-disability-distance-learning/