

Investing in Children - Size Matters

Annual Scientific Meeting of the
British Association for Community Child Health



British Association for
Community Child Health

11 & 12 October 2011
Aston University
Birmingham

Welcome from the Academic Convenor

Welcome to the 2011 BACCH Annual Scientific Meeting and to Aston University in the heart of the West Midlands. I hope you will find much over the next two days to interest, educate, inspire and help you in the challenges we all face in providing high quality services for the children we care for. We hope that the theme of this year's conference " Investing in Children – size matters" will address our need to measure what we do in order to improve the quality of our services as well as looking at one of the most frequently measured characteristic of children _ their size.

How can we have effective measures that do not result in the temptation to meet targets at the expense of quality? This is one of the issues raised by Professor Eileen Munro in her recent review of child protection services. We are delighted that that Professor Munro has agreed to deliver the BACCH annual lecture giving us the opportunity to hear how we can improve outcomes in safeguarding.

Professor Mitch Blair will start the conference looking at the size of the problem and Dr Phil Wilson will talk about the importance of investing in the pre-school years. We couldn't avoid the question of growth and obesity so thanks to Professor Mary Rudolph for addressing this, to Dr Trevor Cole for covering the genetic aspects and to Dr Dasha Nicholls for size matters in mental health.

Presentation and discussion of evidence based personal practice in workshops has been a hallmark of our meetings over recent years and I hope you will agree that this year we have an interesting mix of topics. We have tried to make them all directly relevant to clinical practice and to the theme of the meeting

The submission of free papers and personal practice papers has presented us again with great difficulty in selecting those for presentation from the large number of high quality abstracts we received. Congratulations to those who have been asked to present their papers and commiserations to those who were not successful this time. The subjects of the papers are as far ranging as you would expect from such an eclectic group as BACCH. Don't forget to look at the CATCH posters over coffee and lunch - the judges will have a hard task choosing the prize winner.

Finally, the future configuration of community child health services is important to us all and so I hope we will finish the conference with a lively debate led by Dr Zoe Dunhill who has recently reported on the system in Scotland and Dr Simon Lenton who will give the English perspective. Contributions from delegates from Northern Ireland and Wales will be very welcome.

One of the most important aspects of our annual meeting is the opportunity to get to know each other and develop peer support networks. Following the success of the ceilidh at last year's meeting in Scotland we thought we would have an English Barn Dance this year so I do hope everyone will join in and have fun.

Finally, as I come to the end of my term as Academic Convenor I would like to thank you all for your support and ask you to welcome Raghu Lingam who will take over from me after the AGM. I would also like to thank everyone in the BACCH office and particularly Kelly Robinson who was until recently our BACCH Executive Officer. Kelly has now handed over the reins to Isabelle Robinson (no relation) who has worked extremely hard to ensure the success of this meeting.

Dr Angela Moore
BACCH Academic Convenor

Programme for Tuesday 11 October

- 08.45-9.15** **Registration**
- 09.15** **Welcome and Opening of Conference**
Dr Angela Moore, BACCH Academic Convenor
- 09.20** **KEYNOTE LECTURE**
Investing in Children - priorities now and in the future
Professor Mitch Blair
- 10.00** **FREE PAPER PRESENTATIONS X 5**
- 11.20* *Morning Coffee, Posters & Exhibition*
- 12.00** **BACCH ANNUAL LECTURE**
Improving Outcomes in Safeguarding
Professor Eileen Munro
- 12.50** **Lunch, posters & Exhibition**
- 14.00** **PERSONAL PRACTICE WORKSHOPS**
- 16.00* *Afternoon Tea, Posters & Exhibition*
- 16.30** **KEYNOTE LECTURE**
Investing in the pre-school years – thinking ahead
Dr Philip Wilson
- 17.10** **Closing Comments**
- 17.15** **Day One Closes**
- 17.20** **BACCH Annual General Meeting**
- 19.45** **Annual Dinner**

Speakers, Tuesday 11 October

Professor Mitch Blair: Investing in Children - priorities now and in the future (Keynote Lecture)

Consultant Paediatrician and Specialist in Child Public Health, Imperial College London

Mitch qualified in medicine MBBS from UCH, London in 1983. Paediatric training posts were at Stoke Mandeville, Charing Cross Hospital, Great Ormond Street, Northwick Park, and Nottingham. After obtaining an MSc in Community Paediatrics from the Institute of Child Health in London, he moved to Nottingham as Consultant Senior Lecturer in Community Paediatrics 1990-98. He worked in inner city community practice in health centres, schools, day nurseries and specialist outreach to single handed and group practices. He carried out teaching and research into the national child health screening programme and community paediatric outreach to primary care. He returned to London in 1998 and established the River Island Academic Centre for Paediatrics and Child Public Health Teaching and Research at Northwick Park Hospital, Harrow, Imperial College London. His research interests include complementary medicines use in children, international child health indicators, child public health monitoring, and health service evaluation. He co-authored the Manual of Community Paediatrics and the first textbook on Child Public Health. He was recently seconded to the DH to advise on the Healthy Child Programme and is currently Officer for Health Promotion for the Royal College of Paediatrics and Child Health.

Professor Eileen Munro: Improving Outcomes in Safeguarding (The BACCH Annual Lecture)

Professor of Social Policy, School of Economics

The lecture will present an overview of my review on child protection, emphasising the analysis and recommendations that explain how I think the set of reforms can lead to a system more focused on improving outcomes for children than on compliance with an excessive level of bureaucratic demands.

Eileen Munro was a social worker for many years before taking up an academic career. She has studied philosophy, in particular the philosophy of science, and this has fuelled her interest in the reasoning skills needed in social work. Her current research interests include how best to combine intuitive and analytic reasoning in risk assessment and decision making in child protection, and the role of the wider organisational system in promoting or hindering good critical thinking. At the request of the Secretary of State for Education, she undertook a review of child protection in England and published the final report in April 2011.

Dr Philip Watson: Investing in the pre-school years - thinking ahead

Senior Lecturer in Infant Mental Health, University of Glasgow

The arguments for investing in services for children in their preschool years are becoming irrefutable. Changes in NHS policy and patterns of public investment have nevertheless been relatively slow and sometimes misguided. This presentation will focus on early neurodevelopment and the arguments for active early identification and treatment of its disorders. The key (and widely misunderstood) role of universal services in the identification of these problems will be highlighted, and early results from pilot work on the redesign of the child health surveillance programme in Glasgow will be presented.

Phil Wilson is a GP and senior lecturer in infant mental health at the University of Glasgow. He trained in medicine after completing a research doctorate in neurochemistry. He contributed to the Scottish Needs Assessment Programme on Child and Adolescent Mental Health and the HeadsUpScotland Infant Mental Health report, and has published numerous academic papers on early childhood mental health. He was part of a group which petitioned the Scottish Parliament to maintain a universal health visiting services linked to primary care teams. He is currently involved in evaluating the parenting support strategy for Glasgow and in research designed to improve early identification and treatment of psychological and psychiatric problems in infancy.

10.00 Assessing Severity in Autism Spectrum Disorders (ASD) as a Measure of Long-Term Outcome

Lauren Hamilton

Introduction: A question on many parents' lips when faced with a diagnosis of autism, is how severe is it and what does the future hold?

Aims: (i) To identify whether there are any diagnostic tools used in clinical practice that measure severity in autism; (ii) To determine whether there is an association between autism severity and long-term outcome.

Methods: A literature review was conducted using Pubmed from November 2010 to April 2011, to identify publications concerned with severity and long-term outcome in ASD. The Boolean search algorithm was used, examples include: "Autism spectrum disorders AND severity", "Autism AND severity AND outcome". The bibliographies of the articles were then combed for secondary references.

Results: Six ASD rating scales that measured severity, were identified and evaluated: the Childhood Autism Rating Scale, the Gilliam Autism Rating Scale, the Autism Diagnostic Schedule, the Autism Diagnostic Interview-Revised, the Social Responsiveness Scale, the Severity of Autism Scale. The proposed DSM-V revision has tiered autism severity into 3 levels but the effect this will have on future practice is unknown. Whilst poor outcomes e.g. in education and employment were more likely in children with low IQ, or in those not speaking by 5, previous research has failed to show a consistent link between severity score at diagnosis and long-term outcome. Links between outcome and regression, co-morbidities and neuro-imaging were also explored suggesting only a link between the number and severity of co-morbidities and outcome.

Conclusions: As hypothesised there is not a universal tool to measure severity in clinical practice. If a way to measure severity were to be devised it would need to add something to current clinical practice e.g. levels of interventions and clinical services could be implemented according to a child's severity

10.15 Child and family practitioners' understanding of child development: lessons learnt from a small sample of serious case reviews

Catherine Ellis, Marian Brandon, Peter Sidebotham, Sue Bailey and Pippa Belderson

Introduction: This study explores a small number of serious case reviews to consider how the knowledge that practitioners, and especially social workers, have of child development might have had an impact on case management and subsequent outcomes for the children.

Aims: To consider how the knowledge that practitioner's have of child development might have had an impact on case management and subsequent outcomes for the children.

Methods: A qualitative study of six serious case reviews, purposively selected from 33 available, for thematic analysis.

Results: The issues raised by these six cases included, bruising to babies, problems with feeding and growth, disability, complex health needs, self harm, disguised parental compliance, and disputed and differing judgements made by health and social care professionals. The findings highlight professional responses to physical and emotional development in infants and young children in the context of bruising and faltering weight and widen out to consider older children and professional responses to social and behavioural development, including behavioural distress among young people, and children with disabilities. The findings also consider 'what does the child mean to the parent?' and vice versa. The findings summarise what has been learnt from these six cases about acting on maltreatment and development.

Conclusions: Each of the six children's lives and experiences were unique and different. However, there are some recurring themes in agencies' faltering responses to potential warning signs of abuse and neglect that could be seen to link to the child's development, or to an understanding of the child's likely developmental capacity. A central aim in presenting these findings is to highlight the messages from these individual cases for both practitioners and for Local Safeguarding Children Boards.

10.30 Long term impact of a programme to help health professionals' work more effectively with parents of young children to prevent childhood obesity

Rebecca Brown, Mary Rudolf

Introduction: Despite epidemic numbers of obesity in children, health professionals report a lack of confidence in working with parents around lifestyle change. HENRY _ Health Exercise Nutrition for the Really Young _ aims to tackle childhood obesity through training health professionals to work more effectively with parents. The 2-day training was developed and piloted in 2007 and has since been adopted across the country.

Aims: To assess the long-term impact of HENRY on health professional's knowledge, skills and confidence in tackling obesity prevention.

Methods: An online survey comprising both quantitative and qualitative questions was developed using the 'google docs' programme. This was piloted on 25 course leaders and then sent to 1601 health professionals who had undergone training over the last four years. All data collected was anonymous.

Results: 237 (14.8%) emails were undeliverable. 345 (21.5%) participants completed the online survey to date; 64% to 77% reported using knowledge and skills gained on a regular basis in their professional lives. Areas of greatest impact included working in partnership with clients and the value of empathy, with 69% and 77%, respectively, using these aspects on a regular basis. Respondents also reported an impact on their personal lives, 46% to 69% used the knowledge and skills gained on a regular basis at home. A wealth of anecdotal evidence from the free text responses such as alteration of mealtime behaviours to include the whole family and reduced portion sizes captures this. The effect is longstanding with 82% of participants who had undertaken the training more than 12 months ago stating they continued to use the concept of healthy nutrition in their professional lives and 76% continuing to use the solution focused approach.

Conclusions: Brief training can have a long term profound impact on practitioners' professional and personal lives. We have yet to see if this training impacts on levels of childhood obesity.

10.45 A Pilot Study Exploring the Potential of the Wii Fit to Improve Motor Skills in Children with Developmental Coordination Disorder

James Hammond, Victoria Jones

Introduction: Developmental Coordination Disorder (DCD) is a condition characterised by a marked impairment in motor coordination. Despite its high prevalence and harmful secondary effects, there remains little in the way of intervention for DCD.

Aims: To investigate the potential of an innovative new intervention tool, the Wii Fit, used in a school setting, to improve motor proficiency and well-being in children with DCD.

Methods: A cross-over design was used, with 19 children (age 6 to 10 years) recruited from two schools. Children were screened for likelihood of DCD before inclusion. The study was made up of two phases, each lasting 4 weeks.

In Phase 1 children were divided into two groups, group one using the Wii Fit (10 minutes/3 times a week) and the other (group 2) continuing with the school- run programme for children with DCD (1 hour/weekly). During Phase 2 the groups were swapped with one another. Measures of motor proficiency (BOT-2-SF), children's self-perceived ability with motor tasks (CSQ) and a parental assessment of emotions and behaviour (SDQ) were made before and after Phase 1 and after Phase 2.

Results: There was a mean improvement in motor proficiency of 10.1 percentiles after using the Wii Fit ($p=0.01$). Improvements in self-perceived ability in both groups was also made (group one CSQ pre 27.5, post 37 $p=0.01$). There was also an improvement in emotional and behavioural well-being in group one at the end of phase one (from total SDQ score of 16 to 12 vs 8.7 to 10.3 in group two $p=0.06$).

Conclusion: Use of the Wii Fit in children with DCD is likely to be an effective intervention for improving motor proficiency and overall well-being. The fact the Wii Fit is cheap, easy to use, requires no professional resources and has no apparent adverse effects further promotes its potential as a future intervention tool.

11.00 Preparing for the future: how does the participation of adolescents with cerebral palsy compare to the general population?

Catherine Tuffrey, BJ Bateman, K Parkinson, AC Colver

Introduction: Adults with cerebral palsy (CP) have lower rates, as compared to their peers, of employment, independent living, and having a partner. An important aspect of adolescence is the transition to adult roles. In this paper we report the participation of adolescents with CP in preparing for these adult roles.

Aims: To determine the participation rates for young people with CP in preparing for adult roles, and to compare this with the general population.

Methods: The Questionnaire of Young People's Participation (QYPP) was used to obtain data from adolescents with CP in the North of England and from a group of secondary school students.

Results: 68 adolescents with CP and without severe learning disability completed the QYPP as did 540 young people from the general population. The CP group was aged 13.2years to 21.3years, (median 16.1years) and the general population sample, 13years to 17.9years, (median 14.6years). Participation was less frequent in the CP group for having an informal part-time job (9% vs 36% $p<0.001$), formal paid work (4% vs 20%, $p<0.005$), discussing leaving home (52% vs 66%, $p<0.05$), sleeping over at friends' houses (45% vs 91%, $p<0.001$) and spending time alone with a girl or boyfriend (21% vs 52%, $p<0.001$). Participation in work experience was more common in the CP group. Discussing careers was similar for the two groups.

Conclusions: This study shows a striking difference in rates of participation between adolescents with CP and a general population sample in a number of areas which prepare young people for adult roles, particularly in part-time work, romantic relationships, and sleeping away from home. Since the comparator group were slightly younger, this difference may be even larger when compared with an age-matched control sample. Further work is needed to look at the barriers and facilitators for young people with disabilities in participating in these areas of life.

Workshops, Tuesday 11 October

Paediatric Palliative Care - Networks and the West Midlands Paediatric Palliative Care Toolkit (Room 145)

Claire Thomas

Synopsis

Interactive workshop looking at the national picture for Paediatric Palliative Care, the benefit of palliative care networks, resources available to support clinicians in this field and introduction to the West Midlands Paediatric Palliative Care toolkit

Facilitator biography

Consultant Paediatrician working for Wolverhampton City PCT since 2004 and Honorary Senior Lecturer Birmingham University; designated Doctor for Safeguarding Children for Wolverhampton. Her main interests are Paediatric Palliative Care, Child Protection, and Management of children with complex Neurodisability and Aetiological Investigation of Children with hearing loss. As the Chair of the West Midlands Paediatric Palliative Care Network Claire recently coordinated the successful West Midlands regional submission of 55 bids for the Department of Health project “£30m for Paediatric Palliative Care”.

Demonstrating competence and performance: what's available? [First session only] (Room 135/7)

Martyn Clark, Claire Ormandy, Ian O’Donoghue

Synopsis

We will discuss the competency framework, plans for the CSAC’s resource pack, requirements for revalidation and career development incl CESR and ways to record evidence for any of these. The workshop is suitable for trainees, SSASGs wishing to record evidence for appraisal or progression through thresholds, their supervisors or indeed anyone who needs to show they are competent or performing well for revalidation or career development.

Masterclass: making best use of the e-portfolio and ASSET [Second session only] (Room 135/7)

Martyn Clark, Claire Ormandy, Ian O’Donoghue

Synopsis

The practical nuts and bolts of using the e-portfolio and ASSET to record progress and assessments, show progression and provide evidence for ARCP and CESR. The workshop is suitable for trainees using electronic recording, trainers who wish to learn how best to use the new systems and/or SSASGs who might wish to use the e-Portfolio to record evidence of progression.

How can we use e learning effectively? (Room 130)

Mitch Blair

Synopsis

By the end of the workshop, participants will be:

- 1) familiar with the curriculum of the Healthy Child Programme HCP e learning package and be able to map this to relevant paediatric competencies
- 2) introduced to a model “learning path” using a specific clinical topic
- 3) able to share ideas on using e learning sessions as part of a blended learning experience in their workplace
- 4) to design a high quality training experience for themselves and their trainees using these resources

Facilitator Biography

See page four.

Workshops, Tuesday 11 October

The new trinity: Informatics, Quality & Money (Room 131/2)

Fawzia Rahman, Gabriel Whitlingum, Sanjay Thomas

Synopsis

Delegates will learn from experienced colleagues how to obtain and use information to defend & fund services as well as provide evidence of quality outcomes at service and individual levels. A summary of the national picture on the latest available reference costs, suggested quality measures and preferred diagnostic codes will be presented for discussion to inform the final recommendations of the BACCH informatics working group.

Facilitator Biography

Dr Fawzia Rahman has edited the BACCH news informatics column since 2003. She believes that good information is an essential requirement for the delivery of quality services and that it is obtainable by proper clinical involvement. For the last ten years the simple excel spreadsheet and locally designed coding key used by Dr Rahman's colleagues in Derby have provided data which has demonstrated the service's value to managers and commissioners as well as informed service objectives, PBR returns, quality & outcomes frameworks and individual appraisals. Her latest endeavour in refining the system is to develop for BACCH a nationally agreed list of 50 most commonly used diagnostic codes. Dr Whitlingum and Dr Thomas both have recently succeeded in reversing severe budgetary cuts by close working with managers, accountants and informaticians as well as enlisting gp and commissioner support. They will report on their need, search, and use of relevant information

BAPA Workshop: Why does this deaf child not wear hearing aids? (Room 144)

Jane Lyons, Gill Painter

Synopsis

There will be two scenarios for attendees to consider. By exploring the issues around babies and children not wearing their hearing aids, we expect that attendees will have a better understanding of the complex and varying reasons underlying this problem.

With improved understanding we expect clinicians to be in a better position to support the families they encounter in their clinics

Facilitator Biography

Jane Lyons has been practising in paediatric audiological medicine since the 1980s. She started in Community Child Health as a CMO, then SCMO and now consultant. She is a founder member of the British Association of Paediatricians in Audiology, and is the current chair. She works in Bury and Rochdale, which has a high ethnic minority and high incidence of congenital sensorineural hearing loss.

Sleep disordered breathing in children with disability (Conference 3)

Mark Rosenthal

Synopsis

Things to look out for in children with disabilities - with regards to sleep disordered breathing.

Facilitator Biography

Consultant Paediatrician specialising in Paediatric Allergy, Food allergies, Paediatric Respiratory, Sleep disorders.
Clinical Interests: Food Allergy and cough.
Research Interests: Cystic Fibrosis and Respiratory Physiology.
'Not pretty but different.'

Workshops, Tuesday 11 October

Understanding growth and puberty with new charts for 2012 (Room 139)

Penny Gibson, Mary Rudolf, Jin Soo Moon, Eileen Birks

Synopsis

The Workshop will cover:

- Using readily available information about a child's puberty to improve interpretation of growth.
- Estimating a child's adult height
- BMI without a calculator and its significance.

Come to learn and give your opinion about proposed innovative growth charts, due for release in 2012.

Facilitators Biography

Both are Community Paediatricians and members of the RCPCH Growth Charts Working Group. The Group is currently developing new growth charts to take account of puberty

Programme for Wednesday 12 October

- 08.45-09.05** **Registration (day delegates only)**
- 09.10** **KEYNOTE LECTURE**
Size Matters – is it all in the genes?
Dr Trevor Cole
- 09.50** **KEYNOTE LECTURE**
Size Matters in child mental health
Dr Dasha Nicholls
- 10.30* *Morning Coffee, Posters & Exhibition*
- 11.00** **KEYNOTE LECTURE**
Size matters for WHO?: Weight faltering, Height and Obesity
Professor Mary Rudolf
- 11.40** **PERSONAL PRACTICE PRESENTATIONS x 4**
- 12.40* *Lunch, Posters & Exhibition*
- 13.45** **PERSONAL PRACTICE WORKSHOPS**
- 15.50** **THE FUTURE OF CCH**
A Scottish Perspective: Developing CCH Services for the 21st century
Dr Zoe Dunhill
- 16.45** **AWARDING OF PRIZES**
CLOSING COMMENTS

Speakers, Wednesday 12 October

Dr Trevor Cole: Size Matters – is it all in the genes? (Keynote Lecture)

Consultant in Clinical and Cancer genetics, West Midlands Regional Genetics Service

Significant growth excess or growth failure may occur as an isolated phenomenon or as part of a complex syndrome disorder. In both groups of conditions the underlying causes are extremely heterogeneous but achieving a diagnosis may have significant prognostic, management and genetic implications. Molecular investigations are slowly unpicking the underlying mechanisms and pathways. Intriguingly opposite genetic or epigenetic perturbations can result in the mirror opposite phenotypes.

These findings and diagnostic pathways will be illustrated with clinical examples.

After training in adult medicine and paediatrics Dr Cole worked as an Action Research fellow and Specialist Registrar at the Institute of Genetics in Cardiff, as well as a Pathology Society travel fellow at the Research Institute in Toronto before his consultant appointment in Birmingham in 1992. His early research focused on genetic growth and endocrine disorders and this is now a significant component of his specialist work. As lead for cancer genetics services in the 1990s he developed and implemented clinical pathways for the management of inherited cancers and integrated molecular testing to improve the efficacy of management. Upon appointment as clinical lead for clinical genetics this remit expanded to include integration of medical genetics into a wide range of mainstream specialities. This pilot work was supported by a Department of Health grant following the 2003 government white paper on medical genetics. An additional clinical interest lies in the area of translational research and introduction of new genetic technologies into mainstream practice. He is currently chair of the Joint Royal Colleges Committee for Medical Genetics (JCMG) and sits on the UKGTN working group on commissioning laboratory genetics, the National Commissioning Group and the NICE diagnostics assessment committee.

Dr Dasha Nicholls: Size Matters in child mental health (Keynote Lecture)

Consultant Child and Adolescent Psychiatrist and Honorary Senior Lecturer, Great Ormond Street Hospital, London

Dr Dasha Nicholls is Joint Head of the Feeding and Eating Disorders service (FEDS) at Great Ormond Street Hospital and Honorary Senior Lecturer at the Institute of Child Health. Her clinical work is concerned with aspects of feeding and eating disorders in children and adolescents, particularly early onset anorexia nervosa. She is actively engaged in research, writing, lecturing and teaching, is active in national and international eating disorders organisations, and is President Elect of the Academy for Eating Disorders. She chaired the development of the Junior MARSIPAN (Management of Really Sick young Patients with Anorexia Nervosa) guidelines.

Dr Zoe Dunhill: A Scottish Perspective: Developing CCH Services for the 21st century

Retired Consultant Paediatrician and Independent Child Health Consultant Working with Scottish Government and other NHS Bodies

Dr Dunhill was commissioned by the Scottish Government in 2009 to undertake a review of Community Child Health Services with a view to their current status, future issues and sustainability. She outlines that process and its results, and gives an overview of the recommendations made.

Dr Zoë Dunhill MBE DCH FRCPE FRCPCH MBA was a Consultant Paediatrician in Lothian for many years, an Honorary Senior Lecturer at the University of Edinburgh and Director of the School of Community Paediatrics. She had a special interest in neurodisability and child health information systems. She was Clinical Director of the Royal Hospital for Sick Children for 8 years until 2008 and previously CD of Community Child Health and CAMHS. She was a member of the Board of Health Scotland and on the Court of Queen Margaret University. She works now as an independent child health consultant focussing on redesign and early years and being a "critical friend". She recently (2009) completed a review of all children's health services for NHS Highland and a significant case review for the Renfrewshire CPC (2010). She is currently working on a sustainability review of paediatric secondary care for the North of Scotland Planning Group of 5 health boards. She is a director of Action for Sick Children (Scotland). In her spare time she is a fibre artist and the family genealogist.

11.40 Evaluation of a New Approach to Quality of Life Measurement in Children with Life-Limiting Illness

Nicky Harris, Antonia Beringer, Anna Baverstock

Background: Measurement of Quality of Life is difficult in children for a variety of reasons, and many tools exist to enable professionals to attempt to quantify this. Despite these efforts, a recent survey of practice in the UK showed that most paediatric professionals do not routinely evaluate quality of life.

Details: The survey of current practice in QOL assessment, and the development of a new tool (MY QOL-T), were funded by the Department of Health as part of their £30m investment in children's palliative care services in 2010/11. Focus groups of parents of life-limited children, and professionals working within CHSW, were consulted about the development of a new, patient-led, interactive web-based model of evaluating current health or social issues identified and prioritised by patients or their families. Using MY QOL-T (Measure Yourself Quality of Life Tool) patients/families were able to monitor these issues on a daily or weekly basis, and assess the impact of interventions initiated by their professional carers over time. The tool allows for contemporaneous data collection rather than the "snapshot" assessment typical of other QOL measures, and generates a graph of changes over time. It was introduced to patients and professionals for use in clinical settings from March 2011.

Evaluation: Qualitative analysis of feedback from children, parents, and professionals using the tool was sought in July 2011. The feedback was via a structured questionnaire circulated to all individuals invited to use the tool. Suggestions for improving the tool were included within the product development plan.

Conclusion: MYQOL-T is user-friendly and empowering for patients, with potential to improve patient care on an individual basis, and improve the quality of communications between health care professionals and their patients. Ultimately it could contribute to the evidence-base for interventions in the management of chronic disease and palliative care.

11.55 How was your Botox? Will entonox help? Parental questionnaire about parent's perceptions of their child's injection experience and ways to improve this

Jill Yates, Vivienne Campbell

Background: Chailey Heritage Clinical Services (CHCS) is community based outpatient service for children with complex physical disabilities. Services available include IM injection of Botulinum Toxin (Botox). Initially performed under midazolam sedation, practice evolved when a colleague reported older children preferring not to have sedation, midazolam ceased following review of sedation outside of a hospital setting.^{1,2,3} We wanted to explore if Entonox was acceptable for our children or if this service was better moved to an acute hospital setting.

Details: Children and parents are informed about the procedure, and role of Entonox along with distraction and cold spray, when the decision to inject is made. We explore how the child used the mouth piece and encouraged practice before the injections.

Evaluation: A postal questionnaire to parent's of children, who had received Botox over a 12 month period. Thirty of forty six were returned (65%). Parents judged injections a 'less difficult than a blood test' (37%), 'about the same as a blood test' (57%) or 'worse than a blood test' (3%).

40% of the children were able to try Entonox during the injections, half of whom parents felt that it helped their child cope with the procedure. 59% of the parents felt that it would have been helpful to have had an alternative to the mouth piece. Nevertheless, 83% of parents did not see a need to consider another form of sedation.

Conclusion: Given the physical disabilities of our populations, we were surprised how effective Entonox could be and how few parents would now consider midazolam sedation in this sample. We are exploring alternative mouth pieces and will detail which children were able to activate Entonox.

We are aware that we focused on parental thoughts in this survey - children's views are being sought currently.

References:

1. C. Fairhurst, J. Bridgeman, D. Browning; To sedate or not to sedate that is the question – which analgesia is necessary for botulinum toxin injections? BPNA Abstracts 2007
2. Scottish Intercollegiate Guidelines Network (SIGN) . Safe Sedation of Children Undergoing Diagnostic and Therapeutic Procedures. A National Guideline. Revised 2004 (now withdrawn)
3. National Institute of Clinical Evidence (NICE). Sedation in Children and Young People (GC112). December 2010

12.10 Exercise programme for overweight adolescents with severe learning difficulties

Phillip Harniess, Jill Ellis

Background: Obesity is known to be more common in young people with learning difficulties but there is limited research on effective ways to address this. In Hackney young people with learning difficulties faced barriers to participation in leisure activity and this impacted on their ability to lose weight. We ran a pilot of a physiotherapy supported individualised exercise programme to encourage physical activity in this group.

Details: Subjects were recruited from a special school for children with severe learning difficulties. Children were included if they were obese (BMI > 98th centile), and their parents consented. They were excluded if the school considered that they would not be able to engage with the programme. The children were taken weekly to a local gym, for exercise led by the physiotherapist, supported by 2 learning support assistants and gym instructors. The physiotherapist offered to meet the parents/carers for each young person in order to plan for continuing gym visits after completion of the programme. The primary outcome was change in BMI, measured at the start and 6-12 months later. A 6 minute walk test was also used to assess fitness.

Evaluation: 6 young people participated, aged 12-17 years, attending a mean of 10 sessions over two terms. The underlying diagnosis of children varied and included Down syndrome, non specific learning difficulties, Joubert syndrome and Angelman syndrome. At the start all were obese (mean BMI 34.5) and 5 had a BMI over the 99.6th centile. At 6-12 month follow-up the BMI of each individual had fallen; mean difference 1.1 (X-X). 3/6 children continued to attend a gym regularly outside of school after the programme finished

Conclusion: With appropriate support and encouragement young people with severe learning difficulties are able to engage in gym based activity, which if continued will be associated with health benefits

12.25 Clinical Outcomes Following Evaluation of a Remodelled Autism Assessment Service

Janice Bothwell, Christine Hayden, Cliona Cummings, Rachel Gibbs, Sarah Meekin, Dorinda Gregg

Background: In November 2010 Belfast Trust had an autism service unable to meet demand. Two hundred and ninety eight children were waiting in excess of 13 weeks, the longest waiting 15-months for assessment. Difficulties included separate waiting lists, assessment variation across legacy trust sites and insufficient diagnostic capacity within a consultant-led service.

Details: Centralising, redesigning and modernising the service by implementing four full-time SLT-led diagnostic teams, facilitated increased capacity from 18 to 80 diagnostic slots monthly for the duration of an estimated 5-month recovery plan period. Assessment procedures and processes were harmonised in line with regional and national guidelines and experienced multi-professional teams totalling seventeen paediatricians, SLT, OT and child psychology/psychiatry staff were identified to undertake assessment in liaison with education and educational psychology. Appointments were partially booked.

Evaluation: Over a 5-month period 354 appointments were offered. Twenty-one DNA or CNA were recorded (6%). Outcome audit was integral to the recovery plan and to date 225 forms have been returned (63.6%). All children had a multidisciplinary assessment, with educational information available for 197 children (87.6%). All children with a positive diagnosis had a medical completed. 43.5% of children were given a diagnosis of Autism/Asperger's syndrome, 9% triad of impairment, 2.7% social communication difficulties, 31% other diagnoses and 13.8% required review. Diagnostic rates for males and females were 44% and 42% respectively. Children given a positive diagnosis were referred for intervention. Introducing a standard referral form reduced referrals accepted by 30%.

Conclusion: The Autism Co-ordinator focused existing services to consider alternative ways of working. Developing links between the trust, education, voluntary services and parents was essential. A modernised, multi-professional sustainable diagnostic service model has been achieved and validated throughout the recovery plan period. The current diagnostic waiting time is 6 weeks.

Workshops, Wednesday 12 October

Engaging and listening to young people in health discussions – how do you do it?

(Room 135/7)

Emma Fillmore

Synopsis

Aims: to promote discussion and sharing of experience in engaging and listening to young people.

Learning Objectives: to learn a new skill to use during health discussions with young people.

Format : Intro, feedback from young persons survey of health discussions –what works, what doesn't Sharing of experience, practice of successful scenarios, conclusions, questions, feedback.

Facilitator Biography

As a paediatrician with responsibility for the health of children in general paediatric clinics, children in care and in safeguarding situations, I meet young people in many different and difficult situations. In my experience, young people are interested in their health, but the health issues they initially want to discuss often are often different to that of the health professional. Past experience, trauma, mistrust and no one seeming to listen often leads to an initial difficult consultation. This can be overcome by good listening and tuning in to a young person's needs (both verbally and non-verbally expressed).

I am interested in gathering and sharing experience from young people and professionals in how to make these discussions more fruitful and therefore beneficial to the young person.

Training in Safeguarding

(Room 130)

Naomi Jones, Michelle Zalkin

Synopsis

This workshop aims to familiarise delegates with current developments in training paediatric trainees in Safeguarding. Trainee's views on working and training in safeguarding will be outlined and the SPecial INterest module in Safeguarding will be introduced. There will be opportunity to discuss how the module can be promoted and delivered locally and the facilitators will give examples from their own training of how the module competences can be achieved..

Facilitators Biography

Dr Naomi Jones and Dr Michelle Zalkin are final year community SpRs training with an interest in Safeguarding. Naomi works in the Northern Region and developed an interest in safeguarding as a medical student when she wrote her 3rd year dissertation on the history of the criminal justice system and the protection of children. She has worked with the Northern Deanery to develop a plan to train with this interest including forensic paediatrics. She has recently been appointed to a consultant post which includes the Named Doctor role. Michelle works in The London Deanery and is currently in the second year of a pilot special study module in safeguarding. She has developed an extensive safeguarding portfolio since becoming an SpR which included completing her MSc dissertation on paediatric registrars views on child protection training and barriers to safeguarding work. Her particular interests are social paediatrics, complex safeguarding and child sexual abuse. She is involved in undergraduate and post graduate safeguarding teaching to a multidisciplinary audience.

Early diagnosis of brain tumours in children and the HeadSmart campaign

(Room 139)

Sophie Wilne

Synopsis

The aims of the workshop are:

To raise awareness of brain tumours as a cause of significant morbidity and mortality in children and young people.

To raise awareness of the varied symptoms and signs that occur in brain tumours and the link between tumour presentations and tumour location, patient age and the presence or absence of raised intracranial pressure.

To help healthcare professionals identify when a child or young person may have a brain tumour and appropriately investigate these children.

To raise awareness of the HeadSmart – be brain tumour aware campaign.

To demonstrate the HeadSmart website and its use in identifying children and young people who require CNS imaging.

Workshops, Wednesday 12 October

The workshop will include a variety of teaching and learning formats including videos, discussion, a “hands on” neuro-anatomy model and (a few) slides. All participants will be provided with a summary of the key points to support future learning and HeadSmart symptom cards for local use and distribution.

Facilitator Biography

I'm a consultant paediatric oncologist at Nottingham University Hospital's NHS Trust and have worked on strategies to reduce delays in diagnosis in childhood brain tumours since 2004. I was appointed clinical research fellow for the "Pathways project" at the Children's Brain Tumour Research Centre in the University of Nottingham in 2004. My job in this post was to devise, with the help of healthcare professionals throughout the country, a guideline to help healthcare professionals recognise and appropriately investigate children and young people who may have a brain tumour. The

"Diagnosis of Brain Tumours in Children" guideline was appraised and endorsed by the Royal College of Paediatric and Child Health in 2008. Writing a guideline is only the first step in changing practice and I have continued my work in this area with the HeadSmart campaign which aims to increase awareness of the symptoms and signs caused by brain tumours in children and young people and in doing so reduce delays in diagnosis. I currently divide my time between caring for children and young people with cancer in the East Midlands, research related to cancer in children and young people including the HeadSmart campaign and helping further develop the East Midlands Children and Young Person's Cancer Service.

Road Testing ST7 Assessment Questions

(Conference 3)

Melanie Parker, Maria Bredow

Synopsis

The purpose of the Workshop is to 'Road Test' a bank of ST7 Community questions and ensure that they are both fair and do-able in the 8 minutes available for each station in the actual assessment. We also need to know that they can be marked fairly by non-specialist Community Paediatricians

Facilitator Biography

I am in the fairly unusual position of not only having had many years experience as a Staff Grade Community Paediatrician, but also having had to go 'back to the floor' as a junior doctor, to fulfil the requirements of Article 14 for a CESR. For the initial application submitted in 2009, I thoroughly researched the training requirements and I have kept abreast of the changes taking place. I have just taken up a Consultant post in Weston-super-mare, leading for Preschool Disability. I am keen for the ST7 to be a fair means of assessing readiness to become a consultant.

Clinical Challenges in treating ADHD

(Room 131/2)

Somnath Banerjee, Chinnaiah Yemula

Synopsis

Epilepsy: Seizure control is first priority as numbers of seizures are directly related to processing and attention difficulties. Structural abnormality in brain is probably a risk factor for epilepsy with comorbid ADHD. Moreover uncontrolled seizures cause disturbed sleep, which in turn may result in attention difficulties during the day. Side effects of some anti epileptic drugs such as topiramate, vigabatrin, gabapentine are known to increase aggression in Learning Disability (LD) and many children with epilepsy are likely to have LD. ADHD children are more prone for unprovoked seizures than the normal population. The SPC for MPH state it may lower the convulsive threshold in patients with prior history of seizures and in patients with prior EEG abnormalities. DEX has some anticonvulsant activity especially in nocturnal seizures (Taylor E Plenary session: Current controversies in ADHD treatment 14th International Congress of ESCAP; 11-15 June 2011, Helsinki, Finland)

Autism Spectrum Disorder (ASD): ASD presents with difficulties in social communication, social interaction and stereotyped, repetitive behaviour. Clinical symptoms of ASD supersede that of ADHD and should be the primary diagnosis and can co-exist. The current diagnosis criteria in the two major manuals exclude ADHD in presence of ASD. Although clinicians feel that ASD can exist with ADHD. The FDA in USA has recently approved the use of risperidone in controlling aggressive and self-injurious behaviour and irritability.

Sleep: Problems with sleep are a common complaint among ADHD patients of all ages. Any decrease in sleep quality and/or quantity may lead to worsening of behaviour, mood, alertness and level of concentration. It is therefore important to screen for sleep difficulties. The causes of ADHD related sleep problems may include anxiety, Oppositional

Workshops, Wednesday 12 October

Defiant Disorder (ODD), primary sleep disorders, Obstructive Sleep Apnoea (OSA), Restless Leg Syndrome (RLS) and Delayed Sleep Phase Syndrome (DSPS). Also stimulant medications may increase the difficulty of falling asleep. Melatonin is a sleep inducer and helps to fall asleep at night. Certain foods are rich in melatonin such as oats, rice, sweet corn, barley and tomatoes. Melatonin 2-10 mg may be administered 30-60 minutes before the bedtime for children with significant difficulty getting to sleep. There is no available information on the safety and efficacy of melatonin use on long-term.

Learning objectives:

To practice Evidence Based Medicine in ADHD

To address epilepsy, ASD and sleep difficulties co-morbid with ADHD.

Facilitator Biography

Dr Somnath Banerjee is a Community Paediatrician in East Kent Hospitals University NHS Foundation Trust, Kent. His main areas of interests are Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder and Epilepsy in children and young people. Dr Banerjee has a lead role in continuing to develop the services for children with ADHD in Canterbury and Thanet. He Chairs ADHD team meetings in his Trust. Dr Banerjee received the annual Trust Award 2004 for the 'Best Clinical Audit Project'. He has presented various papers/posters & conducted workshops on ADHD in National and International conferences. He has been involved with various Pan-European researches on ADHD drugs. Dr Banerjee has contributed chapters in many medical books. He is the co-founder of Kent ADHD Network and Convenor; George Still Forum (National Paediatric ADHD Network Group), a special interest group of Royal College of Paediatrics and Child Health in UK.

Child Sexual Abuse – the Manchester SARC model

(Room 144)

Catherine White

Synopsis

- Outline current SARC model in Manchester.
- Providing services for Child Sexual Assault - what are the difficulties?

Facilitator Biography

Dr White has been Clinical Director SARC since 2003, and Vice President of the Faculty of Forensic and Legal Medicine since 2010. She has worked in the field of forensic medicine since 1995, specialising in the examination of women, men and children where there has been an allegation of rape or sexual assault. She is a guest lecturer on the Judicial Studies Board, Serious Sexual Offences seminars and the Family Courts.

Dr White is the Deputy Chief Examiner for the Membership of the Faculty of Forensic and Legal Medicine, responsible for Sexual Offences Medicine. She is also on the Committee of Management for the establishing of the Diploma in Forensic and Clinical Aspects of Sexual Assault (DFCASA), Society of Apothecaries of London.

Dr White is on the ACPO (Association of Chief Police Officers) Rape Working Group and on the National SARC Steering Group.

What do mental health competencies bring to complex paediatric cases ?

(Room 145)

Liz Didcock

Synopsis

This workshop will use complex paediatric cases to illustrate the importance of a biopsychosocial formulation, misunderstanding or missing emotional health issues at ones peril!

Facilitator Biography

Dr Liz Didcock is a general Paediatrician working in Community Paediatrics in Nottingham. She is also Designated Doctor in Child Protection, for Nottingham City. During her training and since working as a Consultant, she has developed an interest in mental health issues in Paediatric practice, and is Convenor of the British Paediatric Mental Health Group, a specialty group of the RCPCH.

The following posters are displayed in the refreshment area.

Empowering families to manage sleep difficulties in children with Autism Spectrum Disorder

Elaine Clark, Consultant Paediatrician

An audit of the diagnosis and management of constipation in children by community paediatricians and specialist nurses in Wakefield District as compared to NICE guidelines

Noel Silvester, Associate Specialist

Outcomes of Peripheral Social Communication Clinics in Mid Essex

Pradeep Sahare, Associate Specialist in Community Paediatrics

Development and Evaluation of Visual Symbols for Use in Health Care Settings for Children with Learning Disability (LD) and Autism Spectrum Disorders (ASD)

Irene Vaz, Consultant Paediatrician

An audit of referrals to the Sunshine clinic: a Wakefield community paediatric clinic for infants of mothers with substance misuse

Danielle Ingham, ST5 Paediatrics

ABCD Cymru – a support and advocacy organisation to improve services, and promote well being in Black and Minority Ethnic (BME) children with disabling conditions

Elsbeth Webb, Reader in Child Health

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