

BACD

British Academy of
Childhood Disability

Annual Conference 2006

“Advances in Managing Children and
Young People with Motor Disorders”

Friday 10th March 2006, Assembly Rooms, Derby

Programme Friday 10 March 2006

09.00 *Registration and coffee*

Session 1 Chair Dr Val Harpin

09.30 Electronic Assistive Technology
Dr Donna Cowan and Chailey Heritage Team

10.00 Advances in Augmentative and Alternative Communication
Katie Price, Wolfson Centre Team

10.30 A Review of Spinal Deformity Services for Disabled Children
David Hall, Professor of Community Paediatrics, University of Sheffield

11.00 Discussion

11.20 *Coffee/tea break*

Session 2 Chair Dr Tom Allport

11.40 Botulinum: where are we now?
Dr Charlie Fairhurst, Paediatrician, Chailey and Guys Hospital, Bev Jackson, Physiotherapist, Nottingham, Janet Corderoy, Physiotherapist, Nottingham

12.10 Drug Treatment of Motor Disorders
Professor Robert Surtees, Great Ormond Street Hospital

12.40 Discussion

13.00 *Lunch and AGM*

Session 3 Chair Dr John Gibbs

14.00 Mobility Opportunities Via Education (MOVE)
Christine Shaw, The Disability Partnership

14.30 Working Together to Improve Transition Arrangements to Post 16 Education for Disabled Students
Barbara Waters, Skill

15.00 *Short break*

15.10 Interview with Jess (a 13 year old with cerebral palsy)
Jess and Dr Andrew Lloyd Evans, London

15.30 Children and Young People's Views
Ruth Marchant and Adam Walker, Triangle

16.00 Discussion

16.30 *Conference ends*

Electronic Assistive Technology

Dr Donna Cowan and Chailey Heritage Team

09.30

Abstract

The range of commercially available electronic assistive technology increases and changes annually. This presentation will look at some of the more recent developments in the field and place these in the context of a case study of a typical child seen at Chailey Heritage Clinical Services. Emphasis is placed on access issues for children with complex physical disability and on the increasing range of devices which offer more than one function. The need for bespoke solutions for this client group will also be discussed.

Biography

Donna Cowan is a consultant clinical engineer and head of the Rehabilitation Engineering Service at Chailey Heritage Clinical Services (CHCS). With an electronic engineering background her area of particular interest is electronic assistive technology (EAT). She works as part of the multidisciplinary team at CHCS and is lead clinician for a number of clinics including the switch, communication and mobility potential (SCAMP) clinic which assesses for and recommends a wide range EAT.

Advances in Augmentative and Alternative Communications

Katie Price, Wolfson Centre Team

10.00

Abstract

The Augmentative Communication Service team at the Wolfson Centre conduct assessments for children with complex communication impairments to support families and local teams in their decision-making around selection and provision of communication equipment and strategies. Over recent years, with increase in the availability of communication aid equipment, and in local expertise, referral questions to the team have changed, and service delivery models are being examined to approach these new questions for consultation. This presentation will discuss some "FAQ's", including

- how do we decide how to divide up the speech therapy resources pie between oro-motor/speech work and aided communication?
- how do we assess vision skills for communication in children with multiple disabilities?
- how does the developmental assessment findings relate to the achievements reported in school?

Biography

Katie Price is a Speech and Language Therapist working with the Augmentative Communication Service at the Wolfson Centre at Great Ormond Street Hospital, London. She has a special interest in the assessment process for supporting children with complex communication impairments."

For information about BACD or for membership details, please come to the BACD table situated in the foyer!

A Review of Spinal Deformity Services for Disabled Children

David Hall, Professor of Community Paediatrics, University of Sheffield

10:30

Abstract

A review of services for spinal deformity, with particular reference to children and young people with disabilities

In response to anxieties raised by parents about access to specialist expertise for their children with progressive spinal deformity, the London Specialised Commissioning Group undertook a review of spinal surgery services, with particular reference to children and young people with disability.

A comprehensive study of the available evidence on spinal deformity revealed very few trials that compare alternative interventions for these problems. Only limited data exist on questions like the impact of spinal deformity on morbidity, mortality or quality of life. Nevertheless, there have been several worthwhile outcomes from this work - in particular, the provision of spinal surgery services has been reviewed, resulting in widespread agreement about the resources and staffing needed to provide a modern, safe and comprehensive service.

Two issues are highlighted: first, very few Child Development Centres (CDCs) or Teams have any policy about identifying and monitoring children whose pattern of disability puts them at high risk of spinal deformity (in contrast to the majority who have a policy for monitoring for hip problems); second, a surprising number of CDCs see their responsibility as being mainly for children aged 0 to 5 years, leaving open the question of how monitoring and other services should be coordinated for older children and teenagers.

As the evidence base is weak, this review does not purport to be a formal guideline. It is intended simply to offer an overview of the current position and to suggest how the concerns raised by parents and clinicians could best be addressed by paediatricians, orthopaedic surgeons, therapists and orthotists, managers and commissioners. The review will be published as hard copy and on the Web.

Biography

Emeritus Professor Sir David Hall, Institute of General Practice, Northern General Hospital, Sheffield, S5 7AU. *Previous NHS affiliation:* Children's Hospital and Children's NHS Trust, Sheffield. *E-mail:* d.hall@sheffield.ac.uk

Career: Trained in London and Johannesburg. Consultant St George's Hospital, London 1978-93; Professor of community paediatrics, University of Sheffield, 1993 - 2005. Chaired three Working Parties on child health surveillance ("Health for all children"). President: Royal College of Paediatrics and Child Health, 2000-3. Co-chair: Ill Child modules of Children's NSF.

Interests: Neurological disability, prevention and early identification; service development and NHS research.

Voluntary sector: Contact a Family, AFASIC, Children's Head Injury Trust, Patron of SCOPE, Trustee UNICEF, WellChild and WhizzKidz.

Current activities: Sheffield Master's programme in Neurodisability; paediatric education (child protection); paediatric care in South Africa; National Evaluation of Sure Start; consultancies on scoliosis and on adolescence for Department of Health.

The CDC Directory is now on the BACD website www.bacdis.org.uk

Botulinum: where are we now?

Dr Charlie Fairhurst, Paediatrician, Chailey and Guys Hospital; Bev Jackson, Physiotherapist, Nottingham & Janet Corderoy, Physiotherapist, Nottingham

11.40

Abstract

In 2005 a working party was set up to provide a consensus statement on the management of Cerebral Palsy with Botulinum Toxin. This will be published soon in *Developmental Medicine and Child Neurology*, but it seems sensible to raise it in a meeting such as ours. Its aims are to provide practitioners across Europe with the most up to date Clinical evidence on optimal treatment for children following on from earlier review articles in 1998 and 2000.

Ten key areas are dealt with namely: 1) Definition of Cerebral palsy in line with the Surveillance of Cerebral Palsy in Europe; 2) Medico-legal aspects of Botulinum Toxin therapy, including licensed and unlicensed but accepted uses; 3) Where Botulinum Toxin treatment stands as part of an integrated therapy approach; 4) Therapy goals for treatment; 5) Different Pharmacological aspects of preparations, including dose limits, aliquot size as well as dose per muscle volume and morphology; 6) Procedures for treatment, including analgesia and sedation practices; 7) Assessment and evaluation before and after treatment; 8) When to stop and when to continue Botulinum Toxin therapy; 9) Safety of Botulinum Toxin; 10) Possible future initiatives.

In the time allotted it would be impossible to cover all of these areas, but an overview of the consensus will be provided and greater detail set out in Richard Morton's personal experience and provision of guidelines concerning Botulinum in the light of new developments. Commonly asked questions include:

What muscles can be safely injected?	Is a GA really more humane than sedation alone?
How much do we give to each muscle?	What is the top dose for multilevel treatment?
Does it prevent contractures?	Is it safe in the long term?

The European Consensus on the role of Botulinum Toxin in the treatment of Cerebral Palsy can be found on the BACD website www.bacdis.org.uk

Drug Treatment of Motor Disorders

Professor Robert Surtrees, Great Ormond Street Hospital

12.10

Abstract

Recent advances in the medical and surgical treatment of childhood movement disorders.

Treatment of childhood movement disorders can be specific, but is more likely to be symptomatic. Specific treatments exist for some neurotransmitter disorders causing infantile parkinsonism-dystonia syndrome, Segawa disease and less typical forms of DOPA-responsive dystonia; for some paroxysmal dyskinesias; and for Sandifer syndrome. Otherwise treatment of movement disorders is symptomatic. Whilst symptomatic treatments for chorea, tics, tremor and myoclonus do exist, I concentrate solely on the symptomatic treatment of dystonia. I will review the use of anti-dystonia drugs, Botulinum toxin and deep brain stimulation. I will also emphasize the importance of physical and occupational therapy, and psychology and psychiatry input. Drugs discussed in more detail are Laevodopa/carbidopa, Trihexyphenidyl, Tetrabenazine and the ideas behind the use of triple therapy. Lastly, I will briefly discuss the management of status dystonicus.

Biography

Robert Surtrees is a Professor of Paediatric Neurology, UCL Institute of Child Health, London and currently head of the Neurosciences Unit. His research interests are the biochemical and molecular mechanisms of brain disorders.

Robert Surtrees, UCL Institute of Child Health, The Wolfson Centre, Mecklenburgh Square, London WC1N 2AP

Mobility Opportunities Via Education (MOVE)

Christine Shaw, *The Disability Partnership*

14.00

Abstract

MOVE was designed specifically for children with severe disabilities. It is intended to teach them the functional motor skills needed to sit stand and walk as independently as is possible for them. MOVE is based on the principle that we have to be able to move in order to learn about our environment, the spatial concepts and cause and effect. These are the skills required to make choices, be naughty and interact with peers, but they are also the skills required as an adult to allow as normal as possible interaction with society and to prevent (or limit) the need to be hoisted.

Mobility is not seen as an add on to the child's timetable, but should underpin all areas of the curriculum and be incorporated into the child's whole day. Therapists, as part of the team around the child, support classroom staff to ensure all opportunities are used to learn and practice mobility skills to support the child's access to their curriculum.

We assume that every child can learn new motor skills if the time and energy is applied to teaching them. In order to expand the possibilities for a child to learn, collaboration between teachers, therapists, support staff and families is vital.

The MOVE framework incorporates joint assessment and child and family oriented goal setting. There is then a team led plan to reduce physical support to allow the child to learn a new motor skill. MOVE is wide spread throughout Europe but the Scottish model of developing the programme is unique. Local authorities, health, education and social services throughout Scotland are collaboratively funding and committing to MOVE. Steering groups are set up in these authorities to most effectively train the interagency cluster of staff and carers around the child. A national data base is set up to evaluate the effects of MOVE on each individual child and each authority is developing its own evaluation system.

MOVE supports all education, health and national learning disability strategies towards helping people with disability gain more independence and be more included in their community: Ensuring achievement; Listening to children; Joint assessment and planning; Child and family centred goal setting; Partnership with parents; Equity of opportunities.

Biography

Christine Shaw, MCSP, trained as a physiotherapist in Edinburgh and continues to live there with her partner and two sons. She has worked in paediatrics for most of her career. Christine has worked with children in hospital clinics, schools and in community paediatrics.

For the 15 years prior to taking up the post of Development Manager for MOVE Scotland, she worked for Capability Scotland as superintendent physiotherapist in a school for children with complex needs. She has held the post with MOVE since June 2000.

Since then she has spearheaded the following projects: "Moving Forward Together" and "Partnerships for the Future", both funded by Scottish Executive Education Department. Based in Edinburgh, the Scottish project is an excellent example of MOVE's success and true interagency working.

**BACD will be at RCPCH 10th Spring Meeting 2006 at the University of York on
Tuesday 4 April. Medics and non-medics alike are welcome to join our
multidisciplinary discussions.**

Full programme and details at www.rcpch.ac.uk

Working Together to Improve Transition Arrangements to Post 16 Education for Disabled Children

14.30

Barbara Waters, Skill

Biography

Barbara Waters has been with Skill: National Bureau for Students with Disabilities since 1996 and Chief Executive since 1997 and has responsibility for moving forward Skill's work in all areas of post-16 education, work based learning and employment for disabled students, trainees and jobseekers throughout the UK. She has policy responsibilities in the areas of careers and Connexions and mental health, and development of Skill's work in Scotland and Wales and leads Skill's response to the Disability Discrimination Act.

Skill's policy team, headed by Barbara, have steered the Disability Consortium in bringing amendments to both the Learning and Skills Act 2000 and the SEN and Disability Act 2001, now part 4 of the Disability Discrimination Act, the Higher Education Act 2004 and the Disability Discrimination Act 2005.

Barbara is a Vice Chair of the LSC Equality and Diversity Disability Sub Group .

Interview with Jess (a 13 year old with cerebral palsy)

15.10

Jess and Dr Andrew Lloyd Evans, London

Please see information in the delegate pack

Children and Young People's Views

15.30

Ruth Marchant and Adam Walker, Triangle

Abstract

What do we know about involving disabled children and young people in decisions about their health, their lives and the services that they use? What strategies and approaches facilitate genuine consultation? Triangle is in a privileged position of having consulted directly with more than 1000 disabled children and young people. We will reflect on what we now know, in particular we will consider how 'evidentially careful' approaches developed within the criminal justice system can be adapted to clinical contexts.

Biographies

Ruth Marchant co-directs Triangle, an independent organisation working with disabled children and young people across the UK. Ruth works directly with children, both consulting about general issues and assessing concerns about maltreatment. Ruth has taught and published widely on these issues, including contributing the guidance on interviewing disabled children within Achieving Best Evidence (Home Office), and the Practice Guidance on Assessing Disabled Children within the Framework for the Assessment of Children in Need (Department of Health).

Adam Walker works part-time for Triangle and is also a founder member of Triangle's senior consultative group of disabled young people, which he now co-facilitates. He was involved in the production of the 'Two Way Street' video pack and has worked on a range of projects in Triangle involving communication and consultation with other disabled children and young people. He has a particular interest in the development of consultation resources and the use of IT based consultation with young people. Adam has many years experience of communicating with doctors and other medical staff about his own needs.

BACD would like to thank the following sponsors for their support:

Lilly

Answers That Matter.



JANSSEN-CILAG Ltd



Medtronic

Alleviating Pain · Restoring Health · Extending Life



IPSEN

and thanks to the following exhibitors:

**The Handsel Trust
Harcourt Education
Family Fund**

(Sponsors & Exhibitors are based in the Foyer and Concourse, outside the Great Hall)