Contents

Foreword 2

Invited Speakers 3

Oral Presentations 13

Posters 24

Index 46
Foreword

The present issue contains abstracts for the scientific presentations taking place at the 16th Annual Meeting of the European Academy of Childhood Disability (EACD) in Edinburgh, Scotland, October 7–9th, 2004. The theme of the meeting is ‘From Evidence to Empowerment’. There is an emphasis on what the barriers might be to learning which are encountered by children with disability. The presentations cover a wide range of issues from the science of language and cognition through to how to optimize children’s environment by protecting them against emotional abuse.

The lectures, tables, and posters to be presented represent a great variety of topics. These include: molecular mechanisms, underlying speech and language disorders, verbal dyspraxia and other childhood speech–sound disorders and their diagnostic boundaries, the role of the brain in language and functional aspects, such as pragmatics, along with the evidence base for the treatment of specific language impairment. The presentations cover updates on genetic syndromes in neurodisability, cognition in epilepsy and ADHD, antenatal glucocorticoid programming of the brain, functional vision, management of regulatory difficulties and motor disturbance in infants with cerebral palsy, the different approaches to the management of spasticity in cerebral palsy, hand function, empowering children, and the evidence base for interventions in developmental disabilities, such as autism and developmental coordination disorder. Thus the topics take us from basic science right through to the delivery of services.

The 16th Annual Meeting of the EACD is particularly honoured to have been chosen to host two memorial lectures: the Malgorzata Borzyskowski Memorial Lecture will address Management of the Neurological Bladder and the Tom Ingram Memorial Lecture will take the topic of Consensus in the Management of Cerebral Palsy. These give a lasting tribute to colleagues who were clinicians of academic excellence.

The authors of the abstracts represent most of the countries in Europe as well as many other parts of the world and bring together all the major groups of professionals working in childhood disability. The local organizing committee and the scientific committee of the EACD would like to thank the keynote speakers, authors, and delegates for their support of the Meeting. Through their participation the EACD can achieve its aim of promoting understanding for professionals working with children with disabilities throughout Europe so that they can develop an international perspective, make new professional contacts, learn of current research and best working practice, and support the development of habilitation for children with disabilities.

Dr Anne O’Hare
Chair of the Local Organizing Committee and President of the EACD

Mac Keith Press is pleased to publish the Abstracts for the 2004 meeting of the EACD – they will be seen by all our subscribers around the world. The Editors would be glad to consider any papers deriving from the meeting for publication in Developmental Medicine & Child Neurology.

Though Abstracts are often regarded as the most up-to-date record of research in any field, they are not peer-reviewed and should be judged accordingly.

Peter Baxter
Editor, Developmental Medicine & Child Neurology

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Cerebral palsy: modern imaging, developmental neurology, and management of motor disorder in cerebral palsy

M BAX
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Tom Ingram would have approved of the title of our Conference, ‘From Evidence to Empowerment’.

Today we have new ways of collecting evidence about cerebral palsy (CP) with the use of MRI. We find that the imaging links very much with the clinical findings so that the degree of abnormal topographical features of the image distinguishes between spastic diplegia and the spastic quadriplegias. Most of these cases are associated with periventricular leukomalacia. We can also observe the extent of the damage in hemiplegia which may be caused by a ‘stroke’ or by asymmetrical periventricular leukomalacia. We can note the often extensive damage to motor cortex in the latter cases, and to motor tracts in the former cases and wonder why it is that children with hemiplegia and spastic diplegia walk.

I shall, then, review the earlier literature on the development of human walking, including the work of Peiper and Andre-Thomas. This suggests that the basic mechanism of walking is not a cortical function. A clearer understanding of these mechanisms has significance for the way we organize therapy.

A combination of imaging data and clinical data means that there are predictions, as shown from gross motor function studies, of the outcome in terms of walking and they are now rather good. Our physical therapy should be thought out accordingly. This will lead me to suggest that we can make rather specific suggestions about what therapists can and cannot do with particular children with CP.

I shall end by hoping that Ingram would have approved of my proposals.

Molecular basis of Rett syndrome

A BIRD
Edinburgh University, Edinburgh, UK

Rett syndrome (RS) is an inherited neurological disorder characterized by stereotypic hand wringing, irregular breathing, microcephaly, seizures, and motor impairment. About 80% of patients have a mutation in the X-linked MECP2 gene, which encodes a methyl-CpG binding transcriptional repressor. To understand the molecular basis of RS, it is necessary to identify MECP2-regulated genes. MECP2-null mice mimic certain features of the Rett phenotype and previous studies of this model revealed minor alterations in brain gene expression. A candidate approach, however, established the gene for a brain-derived neurotropic factor, a neuronal growth factor, as an MeCP2 target. We have used differential display and microarray technologies to seek additional deregulated genes in the MECP2-null mouse brain. We found that mice displaying neurological symptoms showed apparent mis-expression of several genes and this has been confirmed by quantitative ‘realtime’ PCR analysis. Several of the affected genes have subsequently been shown to bind MECP2 in the brain. Physiological measurements raise the possibility that these transcriptional changes underlie some aspects of Rett syndrome.

Pragmatics in communication

D BISHOP
University of Oxford, Oxford, UK

Most assessments of children’s language focus on mastery of structural aspects of language (grammar and phonology), verbal knowledge and reasoning, or verbal memory. However, many children have communicative difficulties that may not be tapped by such tests. Communication may break down if the child does not construct messages to take into account the listener’s knowledge, or fails to take context into account when interpreting what other people say, leading to an over-literal interpretation. In this talk I shall discuss the range of pragmatic difficulties that we have observed in our studies of children with communication problems, and consider issues surrounding the assessment of pragmatic skills. Pragmatic impairment is an important and often overlooked component of many developmental disorders, and may arise for a range of different underlying reasons.

Neuroepileptic correlates of autistic symptomatology in tuberous sclerosis

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Tuberous sclerosis (TS) is a genetic disorder resulting from mutation in the tumour suppressor genes TSC1/TSC2. Mutations in these genes give rise to variable numbers of relatively circumscribed tumorous growths (hamartomas) that can be located in a variety of different organ systems. The classic brain lesions include subependymal nodules and cortical tubers. TS is strongly associated with autistic spectrum disorder, with around half of those affected developing the behavioural syndrome. Individuals with TSC2 mutations seem to be more prone to develop autism, but the disorder is reported in individuals with TSC1 mutations. Moreover, monozygotic twins with TS who are discordant for autism spectrum disorder have been reported, suggesting that non-genetic factors influence developmental outcome. Several neurological features index the risk for autism spectrum disorder in TS and these include: the presence of early-onset, treatment resistant, infantile spasm-like seizures, temporal lobe epileptiform discharges, and cortical and subcortical metabolic changes on PET imaging in the temporal lobes, cerebellum, and caudate. On the basis of these findings and neuropsychological theories of autism, it has been proposed that secondary generalized, focal epileptiform discharges within the temporal lobes may perturb the proper establishment of key social–cognitive representations.
concerned with gaze and face processing during an early critical period of development. In turn, this leads onto the development of an autism spectrum disorder. The evidence for and against this hypothesis will be reviewed.

**Spasticity: mechanisms of deformity and management**

**JK Brown, PD Eunson**

*Royal Hospital for Sick Children, Edinburgh, UK*

The current practice for management of spasticity and secondary deformity is not strongly supported by good quality evidence. Controlled studies in this population are not easy as the final outcome is delayed by many years and there are many confounding factors. Yet clinicians and therapists are expected to manage spasticity and prevent contractions. The choice of physical therapy philosophy, orthotic devices, drug therapy, and orthopaedic interventions increases each year.

This personal practice session will review the mechanisms of deformity in children with spasticity; and review the evidence for use of orthoses, botulinum toxin therapy, and intrathecal baclofen therapy. The speakers will use their own clinical experience to illustrate the session and will welcome discussion with the audience.

**Acquired cognitive impairment as a consequence of epilepsy**

**T Deonna**

*Neuropediatric Unit, University Children’s Hospital, CHU, Lausanne, Switzerland*

Most children who develop epilepsy maintain their cognitive potential. However, several factors, directly or indirectly related to the disease can interfere, temporarily or during a more prolonged period of childhood, with learning abilities, school progress, and behaviour. Some epileptic syndromes present with language, cognitive, and/or behavioural regression as the main, and sometimes only, epileptic manifestation, but with intense paroxysmal epileptic EEG activity, mainly during sleep (CSWS). The existence, severity, duration, and nature of these symptoms is extremely variable but has been unraveled by longitudinal correlative clinical-EEG studies. Language, cognition, and/or behavioural regression can be seen in children with a variety of focal brain pathologies, but also in children within the spectrum of otherwise benign epilepsies (idiopathic partial epilepsies with focal sharp waves). The dynamics of onset and recovery of the cognitive and behavioural ‘epileptic’ symptoms may be insidious and protracted unless the clear paroxysmal manifestations are considered the hallmark of epilepsy. The functional role of the epileptic zone(s) involved is one of the crucial determinants of the clinical symptoms, as can be observed in some frontal epilepsies, and can long go unrecognized. The direct role of epilepsy in causing cognitive and behavioural symptoms can be seen and studied in very different situations, such as prolonged ictal-post-ictal ‘cognitive’ states, as an immediate correlate of EEG discharges, in special cognitive epileptic syndromes, in cases of newly diagnosed epilepsy, and in some surgical cases. These situations have helped us to understand and isolate the direct effect of epilepsy from all other variables (drugs, brain damage, psychological problems, etc.), often confounded in cross-sectional group studies.

**Redesign of services for children with disabilities**

**E Dhouib, J Mackenzie, Z Dunhill**

*Royal Hospital for Sick Children, Hospitals Division, Lothian University, Edinburgh, UK*

Following on from the redesign of Acute services within the Royal Hospital for Sick Children, a redesign of Community and Therapy services took place.

The purpose of this project was to provide an integrated responsive service for children with complex needs and their families which was needs, rather than service, led.

The redesign was done from a ‘bottom up’ approach involving views of all stakeholders, but supported the Scottish Executive Child Health Support Group Child Health Template (2001) and the action plan from the Scottish Executive ‘For Scotland’s Children’ (2001) report.

Several workshops were held involving parents, voluntary groups, Primary Care, three local authority social work and education personnel, and our own staff to identify the issues and plan the work. A parent focus group was held, and several of the action teams had parent or parent groups represented. Two voluntary agencies representing parents, the Special Needs Information Point (SNIP), and Contact a Family also sat on the project’s Strategy Group. The project was divided into four main areas: Integrated Practice, Information Management, Infrastructure, and Training.

All work supported better integration of services across agencies and involving the child and family in decision-making.

The project set up local multi-agency care coordination teams to plan services and goals with families. This was supported by a single assessment process, parent held records, integration with mainstream schools, clear transition process into adult services, improved interface between acute services, Primary Care, community services, parent and professional information, sharing of information, equipment management, and streamlined management structures.

**Functional vision in children with visual impairment: identifying the limitations and working within and around them**

**GN Dutton**

*Royal Hospital for Sick Children, Glasgow, UK*

One’s own brain is the frame of reference for one’s own normality. Children with poor vision from an early age know their vision to be ‘normal’ just as we do, but we cannot use our vision as the frame of reference for what the child with poor vision sees.

We need to be able to characterize the vision of the child and identify the limitations. The basic thresholds of visual function comprise: binocular visual acuity; contrast sensitivity; colour discrimination; stereopsis; the binocular visual fields; and the perception of movement.
Usefulness of the hemiplegic hand: aspects of treatment in children with cerebral palsy
AC ELIASSON
Karolinska Institute, Stockholm, Sweden

An individual’s ability to perform hand skills efficiently is to a great extent influenced by sensorimotor capacity, but also by the context in which the hand would be used. When investigating adolescents’ experience of living with hemiplegia, it was apparent that they made conscious choices about what would be the most effective strategies to use for carrying out certain activities in certain environments. The choice involved weighing the ability of different options to find the least negative alternative. Treatment for children with cerebral palsy (CP) requires careful analysis of tasks as well as behaviour, taking into consideration the complex issue of using the hands. An additional important aspect for treatment is the expected typical development after early brain lesions. Almost nothing is known about the development of hand function in children with CP. However, preliminary results of a study investigating basic coordination during grasping (mean age at assessment 13 years in between investigations), demonstrated small changes of the temporal pattern and force regulation while functional improvements of hand skills were more consistently improved. This different course of development needs to influence the development of theories for treatment. This presentation will justify different treatment programmes based on principles of motor control and motor learning. Motor learning models emphasize that self-generated, voluntary actions – at the right level of task difficulty, utilized and repeated in playful and motivational settings, are most successful. Based on these assertions, treatment can be guided by certain key words: motivation, goal setting, activities of an appropriate difficulty level, repetition, and supervision. The aim of this talk is to use knowledge of children’s experience and wishes, clinical practice, and studies of intervention to highlight the possibility of improving the usefulness of the hands in daily life. Examples of treatment will be provided with the assistance of the World Health Organization International Classification of Functioning, Disability and Health on the levels of Body Function and Activity and Participation.

Dissection of molecular mechanisms underlying speech and language disorders
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A significant proportion of children have developmental learning disorders of unexplained origin, such as autism, speech/language impairment, and dyslexia. In combination, these problems may affect 10 to 15% of the population, making a major impact on education, mental health, and social well-being. Impairment tends to run in families and studies of twins suggest that genetic risk factors are important. However, many genes are probably involved. Innovations in molecular genetics have raised the possibility of identifying specific genetic variants that confer susceptibility. Success in this area will have substantial ramifications. These include early identification of those at elevated risk, use of genetic information in developing novel environmental interventions, and increased understanding of how and why these disorders occur. We recently found the first case of a gene that is mutated in a speech and language disorder. This gene has the technical name of ‘FOXP2’. People who have FOXP2 mutations develop major problems with controlling the complicated mouth movements needed for speech, along with deficits in many aspects of language and grammar. Alteration of FOXP2 itself explains only a small proportion of cases of developmental disorder. However, studies of the function of this gene give a novel route for exploring the relevant neuronal mechanisms.

Molecular investigations of the central nervous system indicate that the gene may be involved in establishing and maintaining connectivity of neural circuits in mammals, by switching on or off other genes in early development. Notably, it has been shown that FOXP2 was subject to positive selection during primate evolution. Finding genes that confer susceptibility. Success in this area will have substantial ramifications. These include early identification of those at elevated risk, use of genetic information in developing novel environmental interventions, and increased understanding of how and why these disorders occur. We recently found the first case of a gene that is mutated in a speech and language disorder. This gene has the technical name of ‘FOXP2’. People who have FOXP2 mutations develop major problems with controlling the complicated mouth movements needed for speech, along with deficits in many aspects of language and grammar. Alteration of FOXP2 itself explains only a small proportion of cases of developmental disorder. However, studies of the function of this gene give a novel route for exploring the relevant neuronal mechanisms.

Insight on hand function from functional brain imaging
H FORSSBERG
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Impaired dexterity in children with cerebral palsy (CP) has a multifactorial background. In addition to spasticity, musculoskeletal malformations, and muscle weakness, the sensorimotor mechanisms generating and adapting the movements are disturbed. The dexterity of the human hand is based on the ability to control movement and force of the fingertips precisely in relation to a given task. When we lift an object, grasp stability is provided by an automatized generation of grip forces preceding the initiation of lift forces. If the object is familiar, the fingertip forces are targeted to the weight of the object and to the friction of the contact surfaces, in order to perform a smooth and well coordinated lift movement. The programming of fingertip forces is based on internal neural representations of the object, which are updated after each lift of the object. If the force output is too large the movement will be jerky and there will be a rapid termination.
In several studies, the sensorimotor mechanisms for providing grasp stability and for anticipating the fingertip forces have been shown to be deficient in children with CP. In order to understand which brain functions are disturbed in these conditions, we first performed a series of functional MRI experiments in which we explored the bilateral fronto-parietal cortical areas that are involved in the control of the fingertip forces during object manipulation. We could identify areas with specific functions for providing grasp stability and for controlling small delicate forces during a grip. Recent studies indicate that Brodman area 44 and the anterior part of the inferior parietal gyrus are involved in the process of updating the internal representation of the object, and that the cerebellum is involved in correcting an erroneously high programmed movement. The contralateral sensorimotor cortex induces increased force pulses after an erroneously low programmed force output.

The National CLEFTNET Project for children with cleft palate
FE GIBBON
Queen Margaret University College, Edinburgh, UK

Electropalatography (EPG) is a technique that measures the tongue’s contact with the hard palate. In order to record these articulatory contact patterns, a special artificial palate is constructed that fits against the roof of the speaker’s mouth. Embedded in the palate are electrodes that can detect when the tongue is touching them. EPG also gives visual feedback of tongue patterns and, under the guidance of a speech therapist, people with speech disorders can use this feedback to improve their articulation. Although research has shown that EPG is an effective therapy, it was not available in Scotland until CLEFTNET was established.

CLEFTNET, funded in 1996 by the Scottish Executive Department of Health, provided cleft palate centres in Scotland with EPG and established electronic links between the centres and Queen Margaret University College (QMUC), Edinburgh. Articulatory data gathered at the centres are sent to QMUC, where experts carry out a detailed analysis leading to a precise diagnosis of the speech difficulty and to a set of therapy guidelines. Results are returned to the clinicians for use in therapy sessions. The project has widened access to EPG so that it is now available to everyone in Scotland with cleft palate.

CLEFTNET is also a unique research resource. EPG data is entered into a database, allowing researchers to study articulation disorders in a larger group than has been possible in the past. The research team have recently secured major funding to extend CLEFTNET to include England, Wales, and Northern Ireland. The new project, CLEFTNET UK, began in July 2004.

Feeding problems: another look at the functional background of oral transport difficulties. Oral autotherapy with the Innsbruck Sensorimotor Activator and Regulator
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Oro-pharyngeal transport problems based on postural and movement dysfunctions of oral and extraoral structures can produce the same dysfunctional stereotypes in very different diseases and pathological conditions. A habitually open mouth, mandibular instability, poor facial, lip, and tongue movements which result in drooling, and feeding and speech problems are the most irritating consequences. They are partly based on developmental changes of bony structures and soft tissues between the skull base and shoulder girdle and also on multiple functional interrelations between them. Multifunctional use of these structures and the fact that they are interlinked makes them prone to interlinked dysfunction. However, these same properties also makes them accessible to therapeutically induced beneficial cycles.

Therapists who work on facial and oro-pharyngeal dysfunctions have to take into account postural influences from the whole body on the mouth, especially the shoulder girdle and neck, for therapy to be successful. Insufficient work on such pre-conditions and the immediate demand during therapeutic sessions can substantially reduce therapeutic success.

The autotherapeutic capacities of the Innsbruck Sensorimotor Activator and Regulators (ISMARs), used in the relaxed setting of rest or sleep, can make these devices valuable instruments to complement oral-therapeutic efforts, especially in times of limited finances and time for therapy.

Used nocturnally after a period of adaptation, just as the classical orthodontic devices of Andresen-Haeupl and Fraenkel, a combination of which ISMARs are based on, they can teach oral key functions such as ‘mobile stability’ of the lower jaw and, hence, the hyoid bone. This makes improvements in lip and tongue posture and movements more likely and will have an impact on velar and pharyngeal functions. Free nasal airways are the essential prerequisite. ISMARs are used from age 5 years upwards with no upper age limit.

Handwriting difficulties in children: some theoretical and practical issues
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Handwriting is a complex skill involving a wide range of cognitive, linguistic, and perceptual-motor skills. It is the recording on paper of thoughts expressed through language, and writing systems vary according to the language used. Children do not simply learn the conventions of their writing system automatically as if they were learning to run or hop; the required movements have to be taught in a well-structured way, from the beginning. Even with expert tuition, however, handwriting is a skill which takes time and effort to perfect. Among children who find this skill exceptionally difficult to
acquire, there are some with labels, e.g. developmental coordination disorder (or dyspraxia), attention-deficit–hyperactivity disorder, dyslexia, specific language impairment, autistic spectrum disorders, and others besides. Whatever their origins, however, such difficulties not only affect academic attainment but may also affect self-esteem and emotional well-being.

Children with handwriting difficulties are seen by professionals from many different disciplines – each with their own perspective on the problem. In this paper, I will discuss some of the theoretical and practical problems to be solved if we are to provide adequate services for such children. To achieve this, I will draw on data from four projects: a survey of handwriting teaching in schools in the UK; an evaluation of parent satisfaction with a physiotherapy service-provider; the development of a standardized handwriting speed test for children aged 11 to 16 years; and a study designed to examine interactions between motor and attentional difficulties in the production of written language.

Management of regulatory difficulties and motor disturbance in infants with neurological dysfunction

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Early intervention in infants with neurological dysfunction aims at: (1) promotion of social, emotional, intellectual, motor, and physical development; (2) prevention of secondary problems; and (3) support of the family. However, no consensus exists on the best way to achieve these goals. This holds true for young infants being cared for in the hospital, for instance in the neonatal intensive care unit (NICU), but also for older infants cared for at home.

In the NICU environment, intervention varies between stress-reducing programmes, such as Kangaroo Care and Newborn Individualized Developmental Care and Intervention Program (NIDCAP), stimulation, and developmental programmes, including Neurodevelopmental Treatment (NDT), and programmes consisting of a mix of stimulation and stress reduction. The effect of these programmes is heterogeneous, with NIDCAP intervention having the best documented results. Evidence suggests that NIDCAP has a positive effect on the infant’s cognitive development, but not on motor development.

Research shows that infants with moderate to severe regulatory disorder are at a high risk for later perceptual difficulties, language problems, sensory integration dysfunction, and behavioural difficulties in the preschool years. In addition, there is a growing body of literature suggesting that sensitivity to infant behavioural cues is beneficial at a very early age, perhaps implying that there are early intervention benefits to be had. However, most screening and evaluation instruments are limited in their ability to describe the complex behavioural repertoire that newborn infants bring to the world. We know that self-regulation mechanisms are complex and develop as a result of physiological maturation, caregiver responsibility, and the infant’s adaptation to environmental demands. For the parents this requires the ability to read and understand the infant’s needs, and the knowledge, energy, and resources to respond in ways that are helpful.

The neurobehavioural model proposed by Brazelton provides a framework for the understanding of neurobehavioural functioning in young infants. The Neonatal Behavioral Assessment Scale (NBAS) is the most comprehensive examination of neonatal behaviour available and is used in both research and clinical settings throughout the world. In this model, infants’ behavioural manifestations of disorganization or loss of self-regulation are indicators of developmental vulnerabilities and sensory thresholds. When the NBAS is administered by a clinician sensitive to the subtleties of a behaviourally disorganized high-risk infant, it cannot only help identify the areas of deficit and guide the clinician in planning intervention, but it can also provide a unique opportunity to support the infant and family and help the parents to read the behavioural cues as meaningful communication.

Intervention is aimed at facilitating prolonged periods of organization, thus decreasing the manifestation of disorganized behaviours while recognizing and reinforcing the infant’s individual self-regulatory style. At the Royal Free Hospital we have a neurodevelopmental follow-up clinic for babies from NICU for up to three years. The purpose is to monitor and evaluate behaviour and development, to support families, to offer anticipatory guidance, and to make appropriate referrals. The presentation will aim to describe the use of the NBAS in our early intervention programme, particularly in the identification and management of irritable infants, and demonstrate through a case study how early intervention may prevent later problems.

Programmes for management of infants with neurological dysfunction in the home environment vary between infant stimulation programmes such as the Portage Program and physiotherapeutical programmes, such as neurodevelopment NDT or Vojta. The principle of infant stimulation programmes is that a trained paraprofessional home visitor uses an individual assessment of the infant to develop short- and long-term objectives for developmentally sequenced behaviours in six areas: infant stimulation, cognition, language, self-help, motor behaviour, and socialization. Various studies indicated that infant stimulation programmes have a beneficial effect on infant development. However, until now it could not be demonstrated that NDT or Vojta have a positive effect on infant motor development. The absence of effect is remarkable as animal research suggests that intervention in early life can have a positive developmental effect. Possibly the absence of beneficial effect of early NDT and Vojta are due to the contents of these therapies, which aims at normalization of motor behaviour and reflex inhibition. Novel concepts on normal and abnormal motor development, such as the neuronal group selection theory, suggest that keywords in early intervention in motor disorders might be variation and stimulation, whilst disregarding the aspect of normality of motor behaviour. Current research aims at testing the efficacy of this approach.
Seizure diagnosis in children with disabilities: experience from the evidence-based Scottish Intercollegiate Guidelines Network

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The objective of the Scottish Intercollegiate Guidelines Network (SIGN) is to improve the quality of health care for patients in Scotland through the use of clinical guidelines that contain recommendations for effective practice based on current evidence.

A multidisciplinary working group is developing a clinical guideline addressing the ‘Diagnosis and Management of Epilepsies in Children and Young People’, and this is to be published later this year.

It is of considerable long-term importance that an accurate diagnosis of epilepsy is made in a child and misdiagnosis of epilepsy appears to be a major problem. Children with disabilities are at a higher risk of epileptic seizures but equally may also present with non-epileptic seizures. Electroencephalography plays an important role in refining a clinical diagnosis of epilepsy. However, using this investigation to confirm or refute a diagnosis of epilepsy, particularly in children with a disability, is fraught with difficulty.

Using the SIGN literature appraisal methodology, this presentation will review the evidence available for making a clinical diagnosis of epilepsy and undertaking appropriate investigations to arrive, where possible, at a syndromic diagnosis. Children and their parents deserve information and management appropriate to that individual’s particular type of epilepsy rather than to the huge spectrum of epilepsies that exist across childhood.

Evidence base for the treatment of children with primary speech and language impairment

J LAW, J QUINLAN
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This presentation will summarize the findings of a recent systematic review and meta-analysis of intervention for children with primary speech and language impairments completed for the Cochrane Collaboration and funded by the Nuffield Foundation. Primary speech and language impairments are those which occur in the absence of any other developmental conditions.

Results will be reported in terms of expressive and receptive phonology, syntax, and vocabulary. In all, 33 trials were identified from the past 30 years’ research, but of these only 13 were sufficiently similar to be combined in a meta-analysis. Results show that there is good evidence for the effectiveness for treatments of phonology and expressive vocabulary; but results are more mixed for interventions for expressive syntax. There is little that can be said at this stage for intervention directed towards improving verbal comprehension.

Results of the studies will be summarized and the research and policy implications of the findings identified.

Computerized training of working memory in children with ADHD

T KLINGBERG
Karolinska Institute, Stockholm, Sweden

Deficits in working memory (WM) are associated with disturbances of frontal lobe function and affect many other cognitive functions, such as control of attention and reasoning ability. Deficits in WM are also thought to underlie many of the symptoms in attention-deficit–hyperactivity disorder (ADHD). We have, therefore, developed and tested a computerized method for training WM. Children aged between 7 and 12 years with ADHD participated in two studies (Klingberg et al. 2002, Klingberg et al. forthcoming). Participants were randomly assigned to use either the treatment computer program for training WM or a comparison program. The main outcome measure was the span-board task: a visuo-spatial WM task which was not part of the training programme. For the span-board task there was a significant treatment effect, both post-intervention and at follow-up, three months after training. In addition, there were significant effects for secondary outcome tasks measuring verbal WM, response inhibition, and complex reasoning. Parent ratings showed a significant reduction in symptoms of inattention. In a separate study (Olsen et al. 2004) we investigated how WM training affects brain activity. We measured brain activity with functional MRI in 11 healthy adults while they performed a WM task, before and after training. We found that task-related activity increased in frontal and parietal regions as an effect of training. This possibly indicates training-induced plasticity in the neural systems underlying WM.

These studies show the effectiveness of intensive training in improving WM. In addition, training resulted in improved responses inhibition and reasoning and a reduction in inattention symptoms of ADHD.

Autism and autistic spectrum disorders

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Much progress has been made in the recognition and understanding of autism and autistic spectrum disorders (ASD). This greater awareness has led to pressure for early detection and access to early interventions (NAPC 2003). There is evidence of the effectiveness of a range of intervention approaches (in particular, educational and behavioural) but no good evidence for the use of one particular intervention or therapy over another. Further, recent systematic reviews have concluded that the standard of experimental research is poor and many unanswered questions remain. It would be unrealistic to assume that any one approach would be appropriate for all affected individuals. Research needs to focus on which treatments work best for which individuals at which stages of development and within which family and social context. Appropriate strategies are needed to evaluate both general and specific interventions for ASD and comorbid disorders. In this presentation I will review some recent intervention studies, concentrating particularly on studies of young children.
with suspected/definite autism undertaken as part of the UK intervention consortium (Charman et al. 2003). I will consider specific child-focused strategies and early intervention approaches which involve parents, using our own research findings to illustrate the importance of randomized group comparison designs. I will then describe some largely anecdotal reports of clinical improvement in children with ASD using untested treatments and emphasize the importance of systematic scientifically rigorous independent research. There is an urgent need to expand the evidence available to parents and service providers in choosing interventions.

Neurocognitive problems following very preterm birth: are they preventable?
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Preterm birth is frequently followed by a range of adverse neurological and cognitive outcomes, which become more frequent as gestation falls. Recent evidence suggests that these poor outcomes have not diminished over the past 10 years despite advances in perinatal–neonatal intensive care. The origin of these disabilities is unclear and their relationship to quantifiable perinatal factors is difficult to show.

A range of interventions have been proposed based around the style of nursing and parenting in an attempt to reduce the impact of these disabilities, some of which have now been subjected to randomized trials. Results of these trials will be critically assessed and discussed, in particular the long-term outcomes from the Avon Preterm Infant Project and the Infant Health and Development Programme, in the context of early interventions research.

Effective interventions are still required in order to minimize the neurocognitive burden of very preterm birth but, equally, understanding the pathways by which disability develops is required in order to provide theoretical underpinning for future trial methodology.

Outcome and prognosis of non-accidental head injury in infants
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The average mortality rate for non-accidental head injury (NAHI) in children less than 2 years of age is 20%. The morbidity is considered under the following categories. (1) Developmental and global outcome: 34% with severe disabilities, 25% with moderate disabilities, and a normal neurodevelopmental outcome following NAHI can be expected in approximately 11% of infants. An absence of ‘catch up’ and a ‘sign free interval’ may be evident in about half of any cohort which apparently recovers completely after a shaking injury but are later, after an interval of 6 months to 5 years, found to have some form of disability. (2) Neurological abnormalities include motor deficits, such as quadriplegia (35%) and hemiplegia (18%), which are the most commonly acquired motor disorders. Cranial nerve deficits have been reported in some 20% of infants at follow-up and the incidence of epilepsy in survivors of NAHI is 30%. (3) Evolution of long-term brain damage results in neuroimaging patterns which include: chronic subdural haematoma; subdural hygroma; ventricular abnormalities; specific cerebral infarction patterns; cerebral atrophy and microcephaly; global slowing of brain growth; malacic and cystic encephalomalacia; and secondary subdural haemorrhage. (4) Visual disability with blindness occurs in 15% of survivors after non-accidental head injury; and there is some visual impairment in 45%. (5) Cognitive deficits occur in 54% of infants. (6) Incidence of emotional and behavioural sequelae is at least 38%. The re-injury rate may be up to 27% and 7% may have evidence of progressive brain damage.

In summary, 20% of NAHIs are fatal and 59% of infants with NAHI have severe motor deficits, epilepsy, microcephaly, and visual, learning, behavioural, and emotional sequelae.

Emotional abuse and child disability
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Emotional abuse refers to a relationship between the carer and child which is characterized by patterns of non-physical harmful interactions. The interactions may be viewed as abusive even when the carer does not intend to harm the child. Three tiers of concern may alert the observer to the presence of emotional abuse: (1) adult’s difficulties (2) harmful carer–child interactions (ill-treatment); and (3) impairments in the child’s health and development.

A model for assessing emotional abuse and neglect will be presented. A classification of harmful carer–child interactions will be discussed. This classification attempts to group together conceptually the many different parental interactions and behaviours which may be viewed as emotionally abusive. It will be argued that such a classification is not only helpful in the identification of emotional abuse and in the efficacy of intervention, but that it may provide some insight into the meaning of the abuse to the carer and the child, and that, in turn, has important implications for treatment.

Given that emotional abuse is defined in terms of harmful carer–child interactions, identification does not depend on child characteristics. Thus, children with a disability need not be disadvantaged in the process of recognizing emotional abuse. It may be, however, that children with a disability are particularly vulnerable to certain categories of harmful carer–child interactions, such as inappropriate developmental expectations. This other harmful carer–child interactions will be examined with regard to the particular needs and vulnerabilities of children with a disability.
Families affected by childhood visual impairment: promoting participation through the web

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Childhood visual impairment has far-reaching effects throughout life. However, in the UK the actual number of children with visual impairment is not known. One thing we do know is that the true number of children with visual impairment in Scotland is significantly more than the number on the official blind and partially sighted register. Yet, it is important to know the real number of children with visual impairment in order to plan services appropriately. The official register was developed to meet the needs of adults of working age who had fallen out of employment because of sight loss. Aspects of the current registration system do not, therefore, meet the needs of children and their education. Based on the needs of parents of visually impaired children, Visual Impairment Scotland (VIS) was set up to meet two complementary aims: (1) To pilot a comprehensive notification system for children with visual impairment and (2) to develop a tailored information and support service. This paper will focus on the second aim of VIS. The development of a support service is aimed to fulfill unmet needs and to encourage and motivate parents and children to become involved in the VIS project. Elements of the support and information service which VIS shall focus on are:

- A virtual web-based club for children with visual impairment called VISKIDS
- A safe and secure internet chat room for VISKIDS members
- The success of the on-line understandable medical information documents
- A web-based parents’ discussion forum
- The development of a website (http://www.viscotland.org.uk) to access all these services and to help achieve these aims

The internet has become a powerful tool in that it not only empowers parents with children with visual impairment, and the children themselves, but also promotes ownership of an organization that has developed to meet the needs of the client group it serves.

Role of the cerebellum in language

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Recent studies have confirmed the role of the cerebellum in processing higher cognitive functions. Congenital cerebellar alterations are frequently observed in children with neurodevelopmental disorders. These anatomical alterations (global or partial vermis hypoplasia or hemispheric hypoplasia) are associated with neuropsychological or developmental disorders that often give rise to various degrees of learning disability with behavioural changes that may even lead to autism.

Studies of normally developing children with acquired cerebellar lesions (tumors or stroke) have made it possible to reveal different neuropsychological profiles depending on the lesion site: vermis lesions are related to behavioural and verbal production alterations, whereas those affecting the cerebellar hemispheres are associated with patterns of side-specific cognitive dysfunctions.

The children with right cerebellar tumours presented with disturbances of auditory sequential memory and language processing whereas those with left cerebellar tumours showed deficits on tests of spatial and visual sequential memory.

The vermal lesions led to two profiles: (1) post-surgical mutism, which could be subdivided into speech disorders (even to the extent of anarthria) and language disturbances similar to agrammatism; and (2) behavioural disturbances ranging from irritability to behaviours reminiscent of autism.

Antenatal glucocorticoid programming of the brain

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Epidemiological evidence suggests that adverse events in foetal life permanently alter the structure and physiology in adult life, a phenomenon called ‘foetal programming’. Low weight or thinness at birth is associated with an increased risk of cardiovascular, metabolic, and neuroendocrine disorders in adult life. Glucocorticoid (GC) administration during pregnancy is well-documented to reduce birthweight and alter the maturation of organs. A decade ago we hypothesized that prenatal exposure to excess GCs or stress might represent a mechanism linking foetal growth with adult pathophysiology. In addressing this we found that in rats birthweight is reduced following prenatal exposure to the synthetic GC dexamethasone, which readily crosses the placenta, or to carbamoxolone which inhibits 11ß-hydroxysteroid dehydrogenase type 2 (11ß-HSD2) which is the physiological foeto-placental ‘barrier’ to the higher levels of GCs in the maternal circulation. Whilst the infants regain the weight deficit by weaning, as adults they exhibit permanent hypertension, hyperglycaemia, increased hypothalamic-pituitary-adrenal (HPA) axis activity, and anxious behaviour. Physiological variations in placental 11ß-HSD2 activity near term correlate directly with foetal weight. The critical ‘window’ for GC programming appears to be the last trimester of gestation. In humans, 11ß-HSD2 gene mutations cause low birthweight and several studies show reduced placental 11ß-HSD2 activity in association with intrauterine growth retardation. Interestingly, stress or psychiatric disorders in pregnancy reduce foetal growth and gestation length. Moreover, low birthweight infants have higher plasma cortisol levels throughout adult life, indicating HPA axis programming. Data are also emerging that suggest low birthweight correlates with affective disorders in later life. Molecular mechanisms may reflect permanent changes in the expression of specific transcription factors, key amongst which is the glucocorticoid receptor (GR) itself. The differential programming of GR in different tissues reflects effects upon one or more of the multiple tissue-specific alternate first exons/promoters of the GR gene. Overall, data suggest that both pharmacological and physiological exposure prenatally to excess GCs programmes cardiovascular, metabolic, and neuroendocrine pathologies in adult life.
Verbal dyspraxia and other speech production disorders: where are the diagnostic boundaries?

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Converging evidence supports the likelihood of etiological subtypes within childhood speech–sound disorders (SSD) of currently unknown origin. This presentation will review selected research issues that are central to an eventual explanatory account for one proposed etiological subtype of SSD: verbal dyspraxia.

Verbal dyspraxia (also termed childhood apraxia of speech) is a putative clinical entity of notable recent interest to both clinicians and researchers. From a clinical perspective, verbal dyspraxia appears to be overdiagnosed in young children who have delayed onset of speech, atypical speech, and prosody–voice characteristics, and/or severe and persistent speech disorder. From a research perspective, the array of genetic, neuroanatomical, and other findings from studies of the KE family (a family in whom half the members have a speech–language disorder associated with a mutation of the FOXP2 gene) has infused research in a number of sciences and applied disciplines, including speech–language pathology.

A complex disorder framework will be presented that posits seven etiological subtypes of SSD associated primarily with (1) genetic transmission, (2) early recurrent otitis media with effusion, (3) verbal dyspraxia, (4) dysarthria, (5) psychosocial involvement, and (6) phonological attunement (two subtypes). We will briefly consider some epidemiologic and diagnostic marker findings supporting the hypothesis of alternative distal and proximal origins of selected subtypes. Preliminary findings from two members of a family who have a balanced de novo translocation and suspected verbal dyspraxia will be compared with the speech–prosody phenotype reported for affected members of the KE family. Summative comments will address diagnostic assessment and phenotype marker issues, including findings from a preliminary study using automatic speech recognition.

Eco-developmental approaches to intervention in children with developmental coordination disorder

DA SUGDEN
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This presentation emphasizes that effective intervention is multifaceted and multilayered; it is not confined to a single principle or method within one experimental or clinical framework. It draws together knowledge of the developing child and how movements are controlled and learned from a dynamical systems perspective, and is firmly set within the everyday life of the child and the family context.

Data are presented from a longitudinal study which involved 51 children with developmental coordination disorder who were being followed for a period of four years. For part of the time the children had intervention from both teachers and their parents who, in turn, had advice and guidance from professionals. Each child was monitored and assessed for progress in motor and other educational achievements over the period. Profiles of individual children are presented and the results are encouraging. Many children improved following intervention and this improvement stayed with them after the intervention period and throughout the four year period. Others improved but only during the intervention phase, while a very small number showed little improvement. Associated difficulties and overlap for clinical work involving schools and parents are discussed alongside the role of health professionals. The study also raises methodological and analysis issues which, with other data, can generate a debate on the nature of the disorder.

Nutrition and gastrointestinal dysmotility in children with neurodevelopmental disabilities

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Correction of malnutrition (undernutrition and obesity) is vital in children with neurodevelopmental disabilities. Our approach is based in the setting of a multidisciplinary nutritional support team (NST), and includes nutritional assessment and provision of appropriate nutritional support. Nutritional support can range from energy boosting in the diet through oral calorie supplements to enteral tube feeding. Of the 220 children in south-east Scotland currently managed by our regional paediatric NST due to their need for home enteral tube feeding (HETF), over 60% are children with neurodevelopmental disabilities. The majority are fed by nasogastric tube in the short term and gastrostomy tube in the longer term. Although we frequently assess and encourage oral feeding, many remain dependent on HETF (daytime bolus and/or overnight continuous feeding regimens) in the long term. There is a very limited evidence base on nutrition support in these circumstances. Obesity is emerging as a difficult, and sometimes intractable, problem for ambulatory children with neurodevelopmental disabilities.

Gastrointestinal dysmotility is common in children with neurodevelopmental disabilities. It is commonly recognized as gastro-oesophageal reflux and constipation, but may also include gastroparesis (causing early satiety and limitation of intake), and duodeno-gastric reflux (causing bilious vomiting). The cause is damage to the enteric nervous system, and this may become a progressive problem with time and complications and a poor outcome. Our practice is to use transgastric jejunal feeding tubes, with gastric ports for aspiration and drug administration in these circumstances.
Working with children and young people with disabilities to meet their information needs

SA YOUNG
Royal Hospital for Sick Children, Edinburg, UK

Each year, Quentin Blake, the children’s book illustrator and former Children’s Laureate, makes a financial donation to an organization funded by the Roald Dahl Foundation. In 2000 the Special Needs Information Point (SNIP) won this award to take forward two pieces of work with children and young people: (1) A quarterly comic for children and (2) a leaflet about SNIP for young people.

We were clear that we wanted to involve children and young people in both of these developments and today I want to explain the processes we went through, the outcomes, and the subsequent developments.

The Comic. We sent out a questionnaire with our monthly newsletter to parents of children with disabilities, asking their children to let us know what they would like the comic to contain, what sort of layout they would prefer, and ran competitions to name the comic and the logo, which Quentin Blake kindly designed for us. We launched the comic at a party attended by over 50 children and their parents. A magician gave his services free of charge and our Patron, TV presenter Kaye Adams came along too to present the winners with their prizes. The comic is named Kids Zone and the logo is ‘Bird Brain’.

The Leaflet. We worked with a group of young people with disabilities from the local Fabb Club to produce a leaflet. This involved brainstorming to find out what sort of information they felt they would like to get from our service and then using their ideas and designs for the leaflet. They told us they would like to contact us by texting, so we bought a mobile phone.

The comic is now produced by a young person with a disability. The National Information Forum recognized the leaflet as an example of excellence last year at a ceremony in London.
Oral Presentations
(In alphabetical order)

Survey of clinical practice in rehabilitation of children with cerebral palsy through video case presentations: part II
I. Autti-Rämö, H Anttila, M Mäkelä
FinOH TA, Helsinki, Finland

Objective: The objective of this study was to gather data on areas of concern when making rehabilitation plans for children with cerebral palsy (CP) in Finland.

Method: Structured interviews were sent to the rehabilitation teams of five university hospitals, 15 central hospitals, and one rehabilitation centre. The teams were asked to identify the three most important rehabilitation goals or areas for three children with varying severity of diplegia and present this on video and in written summary. The goals/areas were later specified as being strategic (structural level), intervention (functional level), programme (participation level) or focused on technical aids, environment, welfare of the family, or on the child’s quality of life (HQL).

Results: For patient 1 (GMFCS level II, no additional problems) 61 goals were set: 29 structural, 10 interventional, 17 programmes, four family welfare, and one HQL goal. For patient 2 (GMFCS level III, additional visuomotor disorder indicating specific learning disorder) 66 goals were set: 24 structural, 14 interventional, 16 programmes, four on technical aids, two environmental, four on family welfare, and two HQL. For patient 3 (GMFCS level IV, additional problems in visuomotor, perception, and oral motor control) 66 goals were set: 19 structural, 22 interventional, 15 programmes, six on technical aids, one environmental, and three on family welfare.

Conclusions: A variety of areas of concern and goals for rehabilitation were identified. The goals were skewed towards structural and functional level and the welfare of the family and the child’s quality of life were seldom identified as being major areas of rehabilitation.

Early multidisciplinary nutritional intervention improves functional outcomes in children with neurodisability: a prospective study
Z Bassi, W Blumenow, G Lancaster, A Dalzell, K Mohammed, L Rosenbloom

Objective: To assess the impact of early nutritional intervention on health status, functional abilities, and neurodevelopment in children with neurodisability.

Methods: All newly referred children under 7 years of age attending a multidisciplinary feeding clinic were recruited over 12 months. Developmental abilities (Griffiths Developmental scales [GQ]), functional abilities and scores (GMFCS levels and GMFM scores), communication skills (Pre-verbal Communication Schedule [PVCS]), feeding abilities (Schedule of Oral-Motor Assessment [SOMA]), and caloric intake (3-day diet diary) were assessed at recruitment and six months following intervention.

Results: Fifty children were recruited (mean age 30 months, SD 18; 28 males). Feeding routes were oral (n = 26), gastrostomy (n = 8), and combination of both (n = 16). Baseline versus follow-up z-scores (SD) for height and weight were: −2.5 (1.2) vs −0.8 (1.4) and −1.4 (1.4) vs −1.0 (2.1) respectively. Mean percentage estimated average requirement for energy increased from 83% to 95%. Median GMFCS levels at baseline and follow-up were IV and III respectively. On baseline assessments, 65% of the children showed oro-motor dysfunction and this improved in 80% of the children and the improvement was irrespective of the route of feeding. PVCS and GMFM scores improved from 26% to 39% and from 18% to 31%. This improvement in GMFM (p = 0.03, 95% CI 1 to 25) and PVCS (p = 0.03, 95% CI 1 to 56) scores was more marked in...
Risk factors associated with intellectual and executive functioning at 5\frac{1}{2} years of age in children born preterm

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Objective: The aim of this study was to evaluate intellectual and executive functioning in preschool children born preterm and to identify early medical risk factors, as well as protective factors.

Methods: In a population-based follow-up study (the Stockholm Neonatal Project), 182 children with a birthweight of 1500g or less (VLBW) and a control group of 125 children born at term without disabilities were examined with the Wechsler Preschool and Primary Scale of Intelligence – Revised (WPPSI-R) and a neuropsychological test battery (Nepsy 1990) at 5\frac{1}{2} years of age.

Results: The WPPSI-R results of the VLBW children fell well within the normal range: Full-scale IQ 95.7, Verbal IQ 99.9, and Performance IQ 91.6. A larger proportion of the VLBW children, compared with controls, were in the lower area of the IQ distribution, especially on the Performance IQ. There was a significant correlation between parental education and IQ. The need for glasses and lenses was inversely associated with all IQ measures and severe retinopathy of prematurity (ROP) had the most negative impact on Full-scale and Performance IQ. The controls surpassed the VLBW children on tests of executive functions (EF), even after controlling for IQ. EF was associated with ROP and with problems of vision.

Conclusion: We conclude that ROP and the need for glasses or lenses risk lowering the intellectual level and executive functioning of preschool children born preterm.

Cerebral language lateralization and early linguistic development in children with focal brain lesions

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The relationship between brain lesion characteristics at structural MRI, early linguistic development, and hemisphere lateralization for language was studied by the longitudinal assessment of 24 children, 12 with left hemisphere focal brain damage (LHD), and 12 with right hemisphere focal brain damage (RHD). Cerebral lateralization for language was measured by means of the Fused Dichotic Words Test and confirmed, in selected cases, by fMRI at school age. Comprehensive longitudinal linguistic assessment was performed with two evaluations at 2 and 4 years of age. An early left side-specificity for language was revealed by the presence of lexical and grammatical delay in the majority of LHD children. Plasticity and the potential for re-organization were documented by a shift of lateralization for language to the right hemisphere in 90% of LHD children. There was an association, irrespective of side, between the largest lesions and the most atypical functional hemispheric asymmetries. The atypical lambda values,
indicating an abnormal language lateralization at the Dichotic test, were also significantly associated with a delay in grammatical development. The type and timing of brain lesion significantly correlated with hemispheric lateralization, as shown by the Dichotic test and FMRI, and language short term outcome. Cortical-subcortical-periventricular lesions, generally occurring at term age, showed a greater degree of or atypical lambda and language delay in comparison with lesions confined to periventricular white matter, mostly occurring during the preterm period. The presence of EEG abnormalities and/or seizures negatively affected language outcome.

Impact of early-onset seizures on cognitive development in children with intractable temporal lobe epilepsy

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Pathology of the temporal lobes has long been associated with specific deficits in declarative memory. There is, however, evidence that focal epilepsy can have a profound effect on cognition, particularly with onset in infancy, and if seizures are uncontrolled. The extent to which this picture is present in children with temporal lobe epilepsy (TLE) is largely unknown. This study sought to examine the full range of cognitive functioning in children with intractable TLE, and to relate this to clinical and seizure variables.

Seventy-nine children who went on to have temporal lobe resection were studied (mean age at assessment 11.5y; 48% male). All children underwent a multidisciplinary evaluation: MRI, EEG, psychiatric and neuropsychological investigations, which included assessment with the Wechsler Intelligence Scale. Data on age at onset of epilepsy, acquisition of developmental milestones, and number of medications were obtained from parental interview and review of clinical records. The majority of children in this sample were found to have clinically significant cognitive dysfunction: 14% of children could not be formally assessed, mostly due to communication and behavioural difficulties, and 57% of those who could be assessed had IQs below 70. Three variables predicted the level of cognitive function: age at onset of epilepsy, number of medications, and duration of epilepsy, with the largest and most consistent contribution coming from age at onset of epilepsy. The developmental, rather than progressive, nature of the impairment is evident in the high incidence (71%) of delayed or regressed milestones in children with onset before the age of 2 years.

Thus, intractable epilepsy during early childhood, even when arising from focal pathology of the temporal lobes, can have a devastating global effect on the acquisition of cognition.

Additional nutrition significantly increases brain growth in infants with perinatal brain damage

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Objectives: To determine whether augmented nutrition during the first year of life in infants with perinatal brain damage will significantly increase brain growth.

Participants: Infants with severe hypoxic-ischaemic encephalopathy, cystic periventricular leukomalacia, or intraventricular haemorrhage with parenchymal extensions, born in the northern region of the UK.

Methods: At term, participants were randomly allocated to intervention and control groups, controlling for gestation, sex, postcode, and brain lesion. A specialist dietician visited regularly to ensure dietary intake of 120% and 100% of estimated energy requirements for intervention and control groups respectively. Anthropometric measurements and transcranial magnetic stimulation to estimate maximum corticospinal axonal diameter (CSAD) were performed three monthly. Parents and researchers (LD and JAE) were blind to group allocation.

Results: Sixteen infants were recruited: 11 males and 10 preterm infants. There was no significant difference in gestational age and sex nor weight and height centile differences and CSAD at birth and/or term. The intervention group had faster rates of weight gain in the first 6 months (p<0.05), by 12 months were longer (p<0.05), had larger OFCs (p<0.05) and CSADs (p<0.01) than the control group.

Conclusion: This randomized, double blind, prospective study demonstrates that increased nutrition in the first year significantly increased brain growth. It also suggests that babies with significant perinatal brain damage have increased nutritional requirements to maintain normal rates of growth in the first 12 postnatal months.

Acknowledgement: Newcastle Healthcare Charity, Wellcome Trust.

Children’s perceptions of the impact of developmental coordination disorder on everyday activities

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Background: Children with developmental coordination disorder (DCD) have a motor impairment that affects their ability to perform everyday tasks. Although severity of motor impairment can be measured, methods for assessing the impact of DCD on daily activities have not been established. The purpose of this study was to understand the children’s views of the impact of DCD on their lives, and to compare these with concerns identified by parents and teachers.

Methods: Children aged 5–10 years, referred to occupational therapists with coordination difficulties, were assessed using the Movement Assessment Battery for Children: children who received scores below the 15th centile were included. The
Reliability of the Gross Motor Function Classification System for children under 2 years of age

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Background: The Gross Motor Function Classification System (GMFCS) is now widely used to classify gross motor function of children with cerebral palsy (CP). For children under 2 years of age, however, modest intrarater reliability (k=0.55) has been reported compared with reliability with older children (k=0.75). Also, the stability over time (from <2 years to over 12 years) is good (k=0.79) but varies inversely with age of first classification.

Method: By combining adjacent GMFCS levels we created a two level classification system for children aged 12–18 months (GMFCS levels I, II, and III; GMFCS levels IV and V) and a three-level classification system for children aged 18–24 months (GMFCS levels I and II; GMFCS level III; GMFCS levels IV and V). Motor performance of 20 infants with probable CP was classified independently by three observers. Interrater reliability was analyzed using the kappa statistic for each pair of observers separately.

Results: Interrater agreement in 13 children with a corrected age of 12–18 months (mean age 13.6mo, range 12 to 17.5mo) was excellent (k=0.83, 0.84, and 1.00). Seven children aged 18–24 months (mean age 20.6mo, range 18.5 to 23mo) were classified in three categories; interrater agreement was 0.73, 1, and 1.

Conclusion: For children aged 12–18 months and for children aged 18–24 months, combining GMFCS levels improves the reliability of the GMFCS. Further research is needed to examine the trade-off between reliability and predictive validity of the GMFCS for infants as young as 12 months of age.

Early progression from dynamic equinus to multilevel deformity in spastic diplegia: can we really prevent deformity?

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Introduction: Botulinum toxin (BTX) is used in the management of children with spastic diplegic cerebral palsy (CP) but there is little evidence about its long-term effect or about the natural history of the deformity. This study describes 15 children with CP who presented with dynamic equinus and were subsequently referred for an orthopaedic review.

Patients and Methods: Fifteen children (mean age 4.2y, range 2.7 to 5.6y; mean GMFCS level 2.4) with CP who presented initially with dynamic equinus to an experienced multidisciplinary team and were managed with BTX (mean number of courses of injection 2.5), serial casting, and orthoses were later referred for an orthopaedic review. Six children were independent ambulators at presentation, and the other nine used posterior walking frames. Thirteen of 15 children were referred for three-dimensional gait analysis following orthopaedic review.

Results: At orthopaedic review (mean age 7y, mean interval from first presentation 2.8y), all of the children had developed multilevel fixed deformity. Four children had decreased by 1 GMFCS level, and 2 had decreased by 2 levels. Gait analysis showed an increased mean minimum knee flexion in stance (24°, SD 10.7°). Fourteen of the children had surgical intervention at a mean age of 7.5 years, a mean of 3.5 years from their initial presentation.

Conclusion: The study group is selective but suggests that some children with spastic diplegic CP may progress rapidly to multilevel fixed deformity despite initial appropriate non-operative management. This has adverse implications for their response to subsequent surgical intervention and for their long-term mobility.

An investigation of emotional and behavioural problems in developmental coordination disorder

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Social and emotional problems have been cited frequently as secondary characteristics for children with coordination difficulties that may have a significant and persistent impact into adolescence and adulthood. This paper will explore the incidence and extent of emotional and behavioural disorders in children referred to a Community Paediatric Occupational Therapy service who have been identified as having developmental coordination disorder (DCD; n=47). Results of parental report of both pro-social behaviours and psychopathology using the Strengths and Difficulties Questionnaire will be discussed and contrasted to age and motor ability of the children. Significant emotional and behavioural problems were identified in 85% of these children in at least one domain – results of which were independent of age or degree of motor impairment. The proportion of children with DCD reported to have emotional and behavioural problems was found to be compa-
Perceiving the opposite direction of motion in children with perinatal brain lesions

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Perception of coherent motion is mediated by area MT+ in monkeys and humans. For example, local stimulation of a small portion of the MT/MSt neurons produces a bias of the direction of perceived flow. In this study we report a specific deficit in motion perception in two children affected by spastic diplegia, with perinatal bilateral lesions mainly involving periventricular white matter. These children perceive coherent motion of a random dot display in the opposite direction to the direction of movement. The deficit is specific to translation motion: rotation, expansion, and biological motion are perceived normally. Both children had major difficulties with crossing roads or riding a vehicle.

The psychophysical discrimination of direction (2AFC) sensitivity to translation dots (limited life time and 500ms exposure) was below minimum. However, when the operator inverted the response normal sensitivity was reached, implying that the children perceived the motion in the opposite direction. Increasing the exposure to 3 seconds decreased the level of chance at all coherence values. Discrimination of expansion/contraction and clockwise/counter-clockwise directions were within the normal range. Contrast sensitivity for static stimuli was normal, but a consistent deficit was assessed at high spatial frequencies for direction discrimination. Visual evoked potentials to coherent/random motion alternations were atypical, indicating a preference for a particular direction of motion. Alternation between flow motion and random noise produced a strong BOLD response (fMRI) in MT+. Interestingly, no response was measured in the same session to stimuli alternating between translation and random noise, implicating an anomaly of the MT+ circuitry.

These data suggest that these children constantly perceive coherent translation motion in random dot patterns, and indicate a high specificity in the MT+ circuitry to analyze motion.

Infant Motor Profile: a standardized and qualitative method to assess motor behaviour in infancy

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Objective: Assessment of motor dysfunction in young children is still in its infancy. This is regrettable because a sensitive, reliable, and valid instrument is a prerequisite for early detection of infants with developmental motor disorders. We developed a video-based assessment of motor behaviour of infants aged 3 to 18 months (the Infant Motor Profile; IMP), which is based on ideas from neuronal group selection theory. The IMP not only addresses motor abilities, but also movement variation, symmetry, and fluency. The present study aims at testing intra- and interobserver agreement. In addition, pilot data on concurrent validity with the Alberta Infant Motor Scale (AIMS) and neurological condition are presented.

Methods: Nine healthy term and four preterm infants were assessed once or multiple times between the corrected ages of 3–12 months (total 40 assessments). Each assessment consisted of a video-recording of spontaneous motor behaviour and a neurological examination according to Touwen. On the basis of the video, IMP and AIMS were determined.

Results: For the majority of IMP items intra- and interobserver reliability were good (kappa > 0.6). The IMP total score and subscores on performance and variability correlated well with the AIMS score. The IMP total score and subscores on variability, symmetry, and fluency of infants with a complex form of minor neurological dysfunction (MND) were significantly worse than those of infants with simple MND or a neurologically normal condition.

Conclusion: The pilot study suggests that the IMP might be a useful tool to evaluate neurological integrity during infancy.

Development and validation of an instrument to measure the impact of childhood disabilities on the lives of children and their families

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Health districts in the UK maintain registers of children with disabilities in order to monitor epidemiology, improve service planning, and contribute to research.

Information on such registers is more useful if a validated measure of severity and impact of a child’s disability is included. The development of a parent-completed questionnaire (Generic Lifestyle Assessment Questionnaire; LAQ-G) which measures such impact is described.

Data were collected on 95 children, with various disabilities, and 65 control children without disability living in the district of Northumberland, UK. Case-control, test-retest, and interreporter reliability was analyzed.

Multidimensional scaling techniques were used to derive six domains, representing impact of disability in a structure analogous to the participation domains of the World Health Organization International Classification of Functioning, Disability and Health.

Construct validity was assessed by looking at association of LAQ-G scores with a measure of functional limitation, and by comparing children with different diagnoses.

Results show that the LAQ-G discriminates between children with or without disability, is stable over time, and has acceptable levels of interreporter reliability. There is a high
Early confirmation of hearing impairment improves speech and language at 7 to 9 years

**Conclusion:**
Confirmation and management of PHI before age 10 months leads to significant improvements in speech and language outcomes. After adjustment in a regression analysis using Rasch analysis in an intervention study involving 41 children with spastic hemiplegia.

**Results:**
Rasch analysis suggested that the test rationale, the usefulness of the assisting hand, forms a uni-dimensional construct and that the 22 items represent the tested phenomenon well. The analysis provides a hierarchy of items that range from easy to difficult and a hierarchy within participants reflecting their ability – from low to high assisting hand function. Results from an intervention study indicate responsiveness to change and the test was found useful for intervention programme planning. The AHA exhibits potential to become a useful tool for clinical practice and research.

One-year change in repetitive behaviours in young children with communication disorders including autism

**Introduction:**
Repetitive behaviours are one of the triad of impairments for a diagnosis of autism. However, they have been studied much less than social and communication impairments, and recent research suggests that repetitive behaviours have a potentially different heritability and developmental course. Therefore, the degree, type, and pattern of change of repetitive behaviours are potentially important markers for the further understanding of autism.

**Methods:**
We report a follow-up of a cohort of 104 children with autism, autism spectrum disorder (ASD), or specific language impairment (SLI), from mean age 37 months to mean age 50 months. We predicted that repetitive behaviours would increase, in line with three previous USA and UK studies using similar methodology (Autism Diagnostic Interview – ADI-R).

**Results:**
Cluster analysis was used at Time 1 to characterize different patterning of repetitive behaviours. The largest cluster had a low rate of repetitive behaviours, and included all the children with SLI but also 15 children with autism or ASD. Unsurprisingly, children with a lower ability level had more repetitive behaviours, but one cluster of relatively able children with autism or ASD also had a high level of repetitive behaviours, particularly unusual sensory interests, repetitive use of objects, and resistance to change. All clusters of children showed a decrease in ADI-R ratings of repetitive behaviours over time, except that the able children showed increased...
unusual preoccupations and attachment to objects.

Conclusions: The observed decrease in ratings of repetitive behaviours was unexpected. It may arise from families developing coping strategies to lessen the impact of the behaviours upon children and upon family life. A planned longer follow-up study will include use of qualitative methods to enable professionals and other parents to learn from shared experience.

Popliteal angle in children with spastic cerebral palsy: the effect of anaesthesia

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Background: The decision to lengthen a muscle surgically in a child with spastic cerebral palsy (CP) is based, in part, on passive range of motion (ROM) measurements made in the clinic. These measurements are often repeated with the child under anaesthesia before surgery. Measurements of ROM in the clinic are unreliable. The effect of anaesthesia on the measurement of reliability has not been reported.

Methods: We assessed the popliteal angle (PA) of 15 children (30 limbs) with spastic CP admitted for lower limb surgery (age range: 6 to 14y, mean age: 8.8y). CP type was: diplegia (n=9), quadriplegia (n=5), and hemiplegia (n=1). The PA was assessed twice on each limb, firstly when the child was conscious and again under anaesthesia before intervention.

Results: There was no significant difference between the means of the PA measured under the two conditions (p=0.17). The within-patient variance (measurement error) was less under anaesthesia (5° vs 15°). A two-way ANOVA demonstrated that the variance due to the state of consciousness of the patient was significantly greater than the within-patient variance. The 95% limits of agreement of measurements taken under the two conditions were 19° and 25°.

Conclusion: Measurement of the PA is more reliable when the patient is under anaesthesia, and measurements made preoperatively poorly predict those made under anaesthesia. Evaluation of ROM in the conscious child with CP should be considered as a coarse measure, and re-evaluation of hamstring length before intervention under anaesthesia is appropriate.

References

Acknowledgement: This work was funded by the One Small Step Charitable Foundation.

Prolonged ‘dystonic’ toe-walking: a transient disorder mistaken for cerebral palsy

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Some children with persistent toe-walking are difficult to fit into the usual categories of either ‘habitual’ toe-walking, or congenital short tendo calcaneus and have neither the clinical signs of spastic diplegia nor those of a peripheral neuro-muscular disease. They have a foot posture in constant plantar flexion, maximal when standing and walking, and increased passive resistance to ankle dorsiflexion which is not purely mechanical and is best described as dystonic. We report seven children with normal medical histories (born at term, referred at a mean age of 18 months) with marked, often asymmetrical, toe-walking and also feet posture in lesser plantar flexion when lying. ‘Stiff’ ankles (increased passive and active tone with normal reflexes); unusual pre-walking locomotion; and slightly late independent walking but otherwise normal neurological examination. None had used a baby walker. Normalization with progressively normal heel contact, passive tone, and range of motion at the ankles occurred in the 2nd or 3rd year of life. The children were re-examined several years later (1–11y) and had normal gait. The persistent marked, often asymmetrical, toe-walking, the abnormal foot posture and tone at the ankles in the absence of pyramidal signs, and the spontaneous normalization corresponds to a variant of “transient dystonia of infancy” (Willemse, Deonna). Knowledge of its existence may justify a period of observation without special investigations, surgery or casting.

Adaptation of reaching movements in children and young adults with myelomeningocele

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Objective: The aim was to investigate the adaptation of reaching movements to new visuomotor conditions in participants with myelomeningocele (MMC) and participants without disabilities. Thirty participants with MMC (age range 9 to 19 years) and 30 matched controls were included in the study. Data were collected with a digitizing tablet linked to a computer. Participants made reaching movements toward three targets at different distances displayed on the computer screen. Movements were carried out under two different gain conditions: a base condition and an altered condition. Adaptation was quantified from the extent of error and expressed as a percentage of the target distances. For statistical analysis ANOVA and t-tests were used.

Under the base condition, no significant difference between the groups was found (p=0.346). After the first gain change, the MMC group evinced a larger error compared with the control group (p=0.005). Analysis showed that movements were rapidly adapted to the new gain in the control group, but participants in the MMC group did not fully adapt their movements under the altered condition after several trials of practice (p=0.001). Participants with early and severe symptoms of brainstem dysfunction showed a dramatic increase in error variability under the altered condition, while participants who had shunt treated hydrocephalus did not have a larger error compared with the others.

In conclusion, adaptation of reaching movements was impaired in the MMC group, but short-term motor learning also occurred in this group.
Use and benefits of modifications of the environment on everyday activities and care in young children with cerebral palsy

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Objective: The study describes use of assistive devices and other modifications in everyday life and their impact on functional independence and caregiving in young children with cerebral palsy (CP).

Method: Ninety-five children (55 males, 40 females; mean age 58mo, SD 18mo) and their parents were studied using a cross-sectional design. The Pediatric Evaluation of Disability Inventory (PEDI) was applied to assess mobility, self-care, and social function using the three measurement scales: Functional Skills, Caregiver Assistance, and Modification of the Environment. Use of modifications was described related to the five severity levels of the Gross Motor Function Classifications System (GMFCS). Benefits were rated on the Caregiver Assistance scale of the PEDI and on a 5-point Likert scale.

Results: A total of 1077 modifications were used to support mobility, self-care, and social function among 84 children. The number increased with GMFCS levels; children at level IV and V applied 80% of the modifications, however the variations between children were large. Adaptations of the home environments facilitated effective use of devices. From 16–27% of the parents experienced some reduction in need of caregiver assistance with use of modification. Half of the parents rated the modifications to have moderate to very large effect on the child’s mobility, 25% on self-care skills, and 20% on social function. Sixty-five percent reported that the modifications lightened the caregiving for mobility, 25% on self-care skills, and 20% on social function. Functional independence and caregiving demands benefited from different types of modifications.

Health-related quality of life one month after diagnosis in children with brain tumours and its relationship to cognitive outcome and maternal emotional health

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Objective: To present preliminary findings on UK patients from the attention-deficit–hyperactivity disorder (ADHD) observational research in Europe (ADORE). Methods: ADORE is a 2-year, prospective, observational study of ADHD. To date, 174 patients from the UK have been assessed.

Results: The dataset consisted primarily of males 147 (86%) and the mean age for all patients was 9.2 years (SD 2.6y). The first awareness of ADHD problems was at a mean age of 5.1 years (SD 3y). Treatment was first sought at a mean age of 7.7 years (SD 3.1y). Reported birth/maternal problems included maternal smoking (36%) and preterm birth (12%). In school, 41% of patients were considered manageable in the classroom, whereas 37% experienced some exclusion from school lessons, and 26% were in special education programmes.

Mean ADHD Rating Scale score was 42.1 (SD 7.9), with a mean inattentiveness score of 21.6 (SD 4), and a mean hyperactivity/impulsivity score of 20.5 (SD 5.2). The mean Clinical Global Impression-Severity score was 4.2 (SD 0.8). Comorbid symptoms included oppositional defiant disorder (60%), learning disorders (42%), coordination problems (35%), anxiety (39%), and conduct disorder (27%). Of other patient health problems, difficulty with sleep was reported as a significant problem in 22% cases. At baseline, patients received some form matched for age, sex, and socioeconomic status. The Pediatric Quality of Life Scale (PedsQL) was used to measure HRQL. Cognitive outcome was assessed by the Wechsler Intelligence Scales for Children – 3rd edition (WISC-III). The Beck Depression Inventory II (BDI-II) was used to assess maternal emotional health.

Conclusion: Children newly diagnosed with brain tumours have significantly reduced HRQL, particularly with respect to the physical and emotional domains. Surprisingly, the determinants of HRQL do not appear to include cognitive state or maternal emotional health. Further research in this patient population is required to define the determinants of HRQL, the changes in HRQL over time, and therapeutic approaches to ameliorating the reduction in HRQL.

Preliminary findings from ADORE UK: symptom severity, treatment, and burden of illness

S. PRASAD, S. RALSTON, D. CCOHILL, V. HARPIN, M. LORENZO

Objective: To present preliminary findings on UK patients from the attention-deficit–hyperactivity disorder (ADHD) observational research in Europe (ADORE).

Methods: ADORE is a 2-year, prospective, observational study of ADHD. To date, 174 patients from the UK have been assessed.

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Parents of children with disabilities: how useful is the internet in meeting their information and support needs?

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The information needs of parents of disabled children are widely recognized, as are the difficulties of providing such information at a time when they need it, in a form that they find useful (Sloper and Turner 1992, Beresford 1995, Chamba et al. 1999). The British Government’s National Strategy for Carers (1999) proposed that information systems to carers should be improved by the use of information and communication technologies (ICTs). If ICTs are to meet the needs of a socially diverse population, it is acknowledged that research needs to engage more with the experience of those who are users or potential users (Hellawell 2001). Currently, little is known about parents’ experience of ICTs. This paper reports on a study which aimed to identify patterns of ICT use among a sample of parents of children with disabilities across the UK and to explore their experience of using it. The study included a postal survey of 789 parents across the UK and interviews with 22 who were given training and free access to the internet in their own homes. The paper reports on patterns of internet use together with the factors associated with it. Barriers to internet use are also discussed, as are the positive opportunities and limitations as identified by the parents. It draws on parental experience to indicate the implications for service provision.

Reaching and grasping in children with hemiplegic cerebral palsy: uni- and bimanual performance

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Knowledge on how reaching and grasping movements are spatially and temporally organized and executed in children with hemiplegic cerebral palsy (CP) is limited. One aim of the present study, therefore, was to investigate these movements kinematically and describe them. A second aim was to explore how a task that requires decoupling between the arm and hand movements on each side may influence reach and grasp quality. These movements were studied during both uni- and bimanual tasks in children with hemiplegic CP who were aged between 5 and 12 years and in age-matched controls. The children with hemiplegia were classified as having either a mild or a moderate degree of impairment. We found that the children with moderate hemiplegia exhibited reaching movements with prolonged duration and that they did not show any anticipatory shaping of their fingers when grasping with their affected hand. They also showed a higher degree of movement-to-movement variability, for both reaching and grasping, than the children with mild hemiplegia. These children, on the other hand, showed ability for anticipatory hand closure and performed reaching movements with similar duration and peak velocity trajectory as the control children. The quality of the grasping movements performed by the children with mild hemiplegia was, however, reduced as indicated by a wider opening of the hand, both at maximum grip aperture and at object contact in comparison with the controls. Movement quality was not affected by the demands of the bimanual task in this group of children. Further, the children with moderate hemiplegia showed a higher degree of coupling between the arms and hands.

Dislocation of the hips in children with bilateral cerebral palsy in southern Derbyshire, 1985–2000

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Aims: To assess the rate of hip dislocation at different ages in children with bilateral cerebral palsy (CP) attending special schools in southern Derbyshire between 1985 and 2000.

Methods: Medical notes were obtained for 110 participants who were divided into groups according to the Gross Motor Function Classification System (GMFCS). It was determined whether their hips were dislocated or not at the ages of 5, 10, and 15 years, and the surgery performed.

Results: The percentage of participants with one or both hips dislocated increased with age and with severity of disease. In GMFCS level II none were dislocated; in level III none were dislocated at ages 5 and 10, but 11% by age 15; in level IV 8% were dislocated by age 5, 19% by age 10, and 25% by age 15; in level V 22% were dislocated by age 5, 48% by age 10, and 48% by age 15. Forty-two per cent of participants with hip dislocation had not had previous preventive surgery; 21% of hips operated on still proceeded to dislocation.

Conclusion: There was a high rate of hip dislocation in this study, especially in GMFCS levels IV and V, and this often occurred very early in the child’s life. Preventive surgery avoided dislocation in a large number of children. However, orthopaedic referral was often not made before dislocation was discovered, or too late for soft tissue surgery to be successful. These results may be compared with those from current hip management programmes, involving radiological surveillance and early use of conservative and surgical interventions.

Social communication and behavioural profiles of visually impaired children with optic nerve hypoplasia and septo-optic-dysplasia

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Introduction: Optic nerve hypoplasia (ONH) may occur as an isolated defect of development of the optic nerves with associated visual impairment (VI) of varying degrees, or with
Neurobehavioural effects of oxcarbazepine and carbamazepine in long-term monotherapy: a randomized, controlled study in children

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Introduction: Patients with epilepsy are more prone to cognitive and behavioural deficits and a variety of factors contribute to such deficits: underlying neuropathology, seizure type, age of onset, psychosocial problems, and treatment side effects. Objective: This randomized parallel study was conducted to evaluate the impact of long-term therapy with oxcarbazepine (OXC) and carbamazepine (CPZ) on cognitive function of patients with simple focal and benign childhood epilepsy with centrotemporal spikes, tested by psychometric tests. Oxcarbazepine is a homolog of carbamazepine with fewer drug interactions.

Participants and Methods: During the period 1999 to 2003, 43 patients who were prescribed OXC, 28 who were prescribed CPZ with new-onset epilepsy, and 45 healthy controls participated in the study. They all fulfilled the inclusion criteria of: (1) age range 6 to 14 years; (2) no behavioural problems; (3) no evidence of either progressive brain or systematic disease; and (4) treated with monotherapy. All participants underwent a complete neurological examination, EEG, brain MRI, and psychometric tests (Wechsler Intelligence Scales for Children – 3rd edition, Bender-Santucci, Athina test) before treatment. Re-examination took place after 12 and 24 months of therapy. The EEGs showed focal abnormalities, which depended upon the type of the epilepsy. The controls' EEGs were normal.

Results: The psychometric test did not show statistically significant differences in IQ among the patients before the administration of the drug nor the controls, which demonstrates the important similarity of the samples. In 7/71 patients and 3/45 controls, learning disabilities were observed. The difficulties were localized in the ability for mathematical thought, logical abstractive thinking, and long-term and visual short-term memory; IQ was normal. Twelve to 14 months after the administration of the therapy an improvement on logical abstractive thinking and verbal comprehension was observed in 43% of the OXC group and in 47% of the CPZ group. Twenty-four months after administration of both drugs, improvements in long-term memory and visuomotor coordination were observed. This shows that the drug did not influence the ability for long-term acquisition.

Conclusion: Both carbamazepine and oxcarbazepine improved performance on a focused attention task and on manual writing speed. They had a slight stimulant effect on some aspects of psychomotor functioning. Additionally, the study showed no statistically significant cognitive differences between oxcarbazepine and carbamazepine. Children with epilepsy had the same IQ distribution as the general pediatric population but had a higher risk of learning disabilities and academic weakness. Therefore, the confirmation of learning disabilities in the pre-treated patients was of great importance in early intervention.

Motor function, activities of daily living, and functional independence in children before and after epilepsy surgery

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Objective: To evaluate motor function, activities of daily life (ADL), and functional independence in children before and after epilepsy surgery. Participants: Thirty-nine children (age range 0.1–17.4y) with pharmacologically uncontrollable epilepsy, of whom 17 were also diagnosed with cerebral palsy (CP). Methods: Motor function was measured using the Gross Motor Function Measure (GMFM-88) in children with CP, the Movement Assessment Battery for Children, and the Motor component of the Bayley Scales of Infant Development in children and infants without CP. ADL-function and functional independence were measured in all children using the Pediatric Evaluation of Disability Inventory. Assessments were done before surgery (T0), and at six (T1), twelve (T2), and 24 months (T3) after surgery.

Results: Over the two years, motor function improved signifi-
Severe handwriting problems (dysgraphia) are commonly observed in children at primary schools. Handwriting legibility of these children is poor and speed often slow. The underlying mechanisms for dysgraphia are not yet very well known. There is evidence in the literature that dysgraphia is related to a lack of control in the fine motor coordination system and/or to a deficit in visual-motor integration. Although there are studies that report comorbidity of dysgraphia and language disorders (e.g. dyslexia), the influence of language processes on severe handwriting problems have not been examined so far.

Objective: The present study investigated the role of fine motor coordination, visual-motor integration, and specific language ability (i.e. word identification) in children with dysgraphia.

Method: Forty primary school children (grade 4, 5, and 6) who were receiving special care because of handwriting problems, and 40 matched controls participated in the study. The Concise Assessment Scale for Children’s Handwriting (BHK) was used to determine the quality and speed of handwriting. Fine motor coordination was assessed with part A of the Movement-ABC, and visual-motor integration with the Beery Visual Motor Integration test. The One-Minute Test (OMT) was used to determine word identification ability. In addition, school teachers filled in an ADHD questionnaire.

Preliminary results: The group with dysgraphia (n=22) scored significantly worse on BHK-quality, part A of the Movement-ABC, on the VMI (all, p<0.001), and on the ADHD-questionnaire (p<0.05) compared with controls. No significant group difference was found for BHK-speed and OMT. In the group with dysgraphia, poor quality handwriting was significantly correlated with slow speed of handwriting (r=0.54, p<0.05). Further, a significant correlation was found between BHK-quality and OMT score (r=0.49, p<0.05), and between BHK-speed and OMT score (r=0.68, p=0.001). No significant correlation was found in the control group.

Conclusions: Results indicate that children with dysgraphia have deficits in fine motor coordination and visual-motor integration in comparison with controls. Correlations, however, show that individual differences in the group with dysgraphia for quality and, in particular, speed of handwriting are better accounted for by word identification ability than by fine motor coordination or visual-motor integration ability.

Botulinum toxin with and without occupational therapy and the upper limb in cerebral palsy: a randomized controlled trial

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Objective: To evaluate Botulinum toxin (BTX) injections to the upper limb and the influence of occupational therapy on impairment, functional limitation, and disability-related outcomes in children with cerebral palsy (CP).

Design: Randomized controlled trial with allocation concealment in four groups: (1) BTX and occupational therapy (OT) (BTX/OT), (2) BTX only, (3) OT only, and (4) no intervention.

Method: Eighty children with CP (mean age 5y 10mo; range 2 to 14y) were randomly assigned to treatment groups; 90% completed follow-up. Follow-up was at 2 weeks, 3 months, and 6 months posttreatment. BTX injections were single session injections using electrical stimulation localization. OT consisted of one hour per week for 12 weeks in addition to existing interventions. Assessments included the Canadian Occupational Performance Measure (COPM), Goal Attainment Scaling (GAS), Melbourne Assessment of Unilateral Upper Limb Function, Quality of Upper Extremity Skills Test (QUEST), Pediatric Evaluation of Disability Inventory (PEDI), Modified Ashworth scale (MAS), Tardieu Scale, active and passive ROM, and a parent questionnaire.

Results: A single arm was selected as the study limb and mean total dose of BTX was 170.9U (50–410) and 8.5 (2–17)U/kg. The BTX/OT group had significantly more change in performance and satisfaction scores on the COPM than the control group at three months (mean change:95%CI: BTX/OT=2.9/2.1–3.8; control=1.1/0.4–1.8). The BTX/OT group was the only group to reach a T-score of 50 on GAS at three months, which indicates that, on average, goals were met. There was no difference between groups on the PEDI, Melbourne Assessment, or QUEST. The angle of first catch of the elbow flexors changed significantly in all groups receiving BTX compared with the control and OT groups at 2 weeks but there was no difference between groups by 6 months. MAS scores in the BTX groups were significantly different from control and OT groups at 2 weeks and 3 months but no different at 6 months.

Conclusion: There is promising evidence that the outcomes of BTX are enhanced by the addition of occupational therapy. Further results will be included in the presentation of this paper.
**Problems encountered by children displaying normal development related to their siblings with learning disability**

E. Ahmetoğlu, N Aral

*Trakya University, Edirne, Turkey; Ankara University, Ankara, Turkey*

The study aimed to identify problems encountered by children displaying normal development related to their siblings with mental retardation, and whether certain factors cause a difference in the problems. The study involved siblings, between the ages of eight and eighteen, who lived with a brother, sister, mother or father with mental retardation and were registered at Trakya University Training and Research Centre of Mentally and Physically Handicapped Children in Edirne, Turkey. The Sibling Problems Questionnaire, developed by Taylor (1974) and McHale et al. (1986), adapted to Turkish children by Ahmetoğlu (2004) was applied to children participating in the study on a voluntary basis. Independent samples t-test and one-way ANOVA analysis were used to determine whether the points obtained by the siblings from the Sibling Problems Questionnaire differed with regard to certain factors. A Scheffe test was applied to determine the group causing the difference. In the Sibling Problems Questionnaire, father’s profession was the only factor associated with significant differences in points obtained by siblings with normal development. Children whose fathers were civil servants experienced less problems related to their siblings with mental retardation compared with those whose fathers worked freelance.

**Anxiety levels of mothers of children with learning disability**

E. Ahmetoğlu, N Aral

*Trakya University, Edirne, Turkey; Ankara University, Ankara, Turkey*

The study aimed to determine the anxiety level of 100 mothers of children with mental retardation and to examine whether certain factors cause a difference in mothers’ level of anxiety. Participants were mothers of children attending Trakya University Training and Research Centre of Mentally and Physically Handicapped Children in Edirne, Turkey. One hundred mothers of children with mental retardation were included in the study on a voluntary basis. In order to obtain certain general information on children with mental retardation and other family members, the following were used: Questionnaire on Resources and Stress, developed by Holroyd (1976) for determination of anxiety levels of mothers and translated into Turkish and verified in terms of reliability by Akkök (1989); and the General Information Form. The data obtained have been evaluated with statistical methods and the findings are discussed.

**Evaluation of multidisciplinary community based gastrostomy feeding service for children with neurodisability in Wales UK**

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Introduction: A community-based gastrostomy feeding service was developed in February 1999 in Caerphilly to support children with neurodisability and complex feeding problems. The service provided a comprehensive diagnostic and management support package, which was developed and delivered by the team within the community setting, and will be discussed in detail.

Objectives: (1) To describe this unique community based gastrostomy service. (2) Evaluate parental satisfaction with gastrostomy feeding and service provision.

Methods & Results: We identified 23 gastrostomy-fed children attending the feeding clinic between January 2000 and January 2003. The underlying diagnoses included: cerebral palsy; severe developmental delay of unknown aetiology; velocardiofacial syndrome; Moebius syndrome; Treacher Collins syndrome; nemaline myopathy; and Sanfilippo syndrome. Twenty children, who were non-ambulatory and well below 0.4th centile for weight and height before gastrostomy, showed improved general health and fewer hospital admissions for feeding related problems. The study involved siblings, between the ages of eight and eighteen, who lived with a brother, sister, mother or father with mental retardation and were registered at Trakya University Training and Research Centre of Mentally and Physically Handicapped Children in Edirne, Turkey. The Sibling Problems Questionnaire, developed by Taylor (1974) and McHale et al. (1986), adapted to Turkish children by Ahmetoğlu (2004) was applied to children participating in the study on a voluntary basis. Independent samples t-test and one-way ANOVA analysis were used to determine whether the points obtained by the siblings from the Sibling Problems Questionnaire differed with regard to certain factors. A Scheffe test was applied to determine the group causing the difference. In the Sibling Problems Questionnaire, father’s profession was the only factor associated with significant differences in points obtained by siblings with normal development. Children whose fathers were civil servants experienced less problems related to their siblings with mental retardation compared with those whose fathers worked freelance.

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**Survey of clinical practice in rehabilitation of children with cerebral palsy in Finland through video case presentations: part I**

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FinOHTA, Helsinki, Finland

Objective: The objective of this study was to gather data on current clinical practice in rehabilitation of children with cerebral palsy (CP) in Finland.

Method: Structured interviews were sent to the rehabilitation teams of five university hospitals, 15 central hospitals, and one rehabilitation centre. The teams were asked to make rehabilitation plans, presented on video and in a short written summary, for three children with varying severity of diplegia.
**Results:** For patient 1 (GMFCS II, no additional problems) the total number of therapy sessions ranged from 60 to 112; BTX-A treatment was recommended by 15/21 teams, electrical stimulation by 9/21, and surgical intervention by 3/21 rehabilitation teams. For patient 2 (GMFCS III, additional visuomotor disorder indicating specific learning disorder) the total number of therapy sessions ranged from 100 to 200; BTX-A treatment was recommended by 12/21 teams, electrical stimulation by 4/21, and surgical intervention by 7/21. For patient 3 (GMFCS IV, additional problems in visuomotor, perception, and oromotor control) the amount of therapy sessions ranged from 116 to 225; BTX-A treatment was recommended by 16/21 hospitals, electrical stimulation by 6/21 hospitals, and surgical intervention by 4/21 teams.

**Conclusions:** Video case presentations can be used to evaluate the current practice within a country. The differences in current practice call for a consensus based on the existing evidence. This could then provide equal opportunities of rehabilitation within the country which do not underestimate or overestimate the possibilities of various intervention methods.

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**Anxiety levels of mothers of children with attention-deficit–hyperactivity disorder**

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Attention-deficit–hyperactivity disorder (ADHD) is characterized by difficulty in sustaining attention, inhibiting activity levels, and maintaining impulse control. Parents’ consideration of continuous game play and excessive activity during game play as normal are among the reasons why ADHD is often left undiagnosed until the preschool education period. Thus, ADHD is generally noticed in school where the child is introduced to rules and expected to obtain certain skills. Diagnosis of ADHD in this period renders acceptance of the child’s disorder by the family difficult. The parents’ level of anxiety increases with the diagnosis. For this reason the study aims to determine anxiety level of mothers and effect of various factors in terms of anxiety levels. Eighty-three mothers of children diagnosed with ADHD between the ages of 4–18 were included in the study. Questionnaire on Resources and Stress (Holroyd 1976) for determination of the anxiety level of mothers and the General Information Form were used to obtain certain general information on children with ADHD and other family members. Independent samples t-test and one-way ANOVA analysis have been used to determine whether various factors affected the level of anxiety of mothers. The study revealed significant differences in anxiety levels of mothers of children with ADHD on the basis of aspects of the Questionnaire on Resources and Stress. The differences seen were shown to depend on age of child at diagnosis, level of information given to families at time of diagnosis, and age at which child began to receive special education.

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**Effect of physiotherapy after internal rotator contracture surgery in obstetric brachial plexus palsy**

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**Aim:** Late recovery of the external rotators and predominance of the internal rotators cause internal rotation contractures. The aim of this study was to evaluate the effect of physiotherapy on functional ability level after subscapularis tendon release and latissimus dorsi (LD) and teres major (TM) transfer to act as external rotators of the shoulder.

**Methods:** Thirteen children participated in the study. Six had subscapularis release and LD \( (n=5) \) or TM \( (n=1) \) transfer. Seven had subscapularis tendon release. An aeroplane cast was worn by children for five weeks after surgery. Assessments were made before surgery and after the physiotherapy programme, and included the Toronto and Grossman Systems to evaluate the functional activity level. After removing aeroplane casts, high voltage pulsed galvanic stimulation for transferred muscles and infraspinatus were applied three times a week for a total of 15 sessions, in addition active range of motion and stretching exercises were done.

**Results:** Functional activity level was improved because of increased range of motion of external rotation.

**Conclusion:** Following surgery to improve external rotation range, physiotherapy is essential to maintain the increased range of motion and prevent internal rotation contracture.

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**Family environment of families who have children with cerebral palsy**

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This study aimed to evaluate the family environment of families of children with cerebral palsy and to determine whether certain characteristics of their child caused a difference in the family environment. The study looked at 120 children aged 3–10 years, diagnosed with cerebral palsy, and hospitalized at Ankara Physical Treatment Rehabilitation Training and Research Hospital of the Ministry of Health, and their families. The General Information Form, which inquires about the child and their family, and the Family Environment Questionnaire have been applied on the children and their mothers. The General Information Form was developed by the author, and the Family Environment Questionnaire was developed by Fowler (its reliability and validation was tested by Usluer [1989]). The family environment has been evaluated in terms of unity-solidarity and supervision. Data were assessed with one-way ANOVA. Findings of the study were discussed and supported by the literature.
Dyslexia and motor problems in children
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Motor difficulties seem often to appear in parallel with dyslexia in children. The intention of this study was to examine what type of motor difficulties a group of children with dyslexia had, and how many of these children exhibited these difficulties. Twenty children with dyslexia, 10–12 years of age, were tested with the Movement Assessment Battery for Children (MABC-test) and nine other separate tests. A comparison group, consisting of 28 children, aged 9 to 11 years, were assessed only on the nine separate tests. Results are discussed in relation to motor control and learning theories.

Results: MABC-test: Sixty percent of the children with dyslexia had clear motor difficulties. The difficulties showed up primarily in the Manual Dexterity subtests, especially the subtest concerned with hand-eye coordination. This subtest required continuous and stable finger coordination movements and stable tracking ability of the eyes.

The nine separate tests: Total score showed significantly greater motor problems in the group with dyslexia than in the comparison group. The group with dyslexia did not score significantly differently from the comparison group in each of the nine separately judged tests. The biggest differences between the groups were in tests requiring dynamic balance with anticipation mechanisms. The children’s difficulties can be related to a possible deficit in underlying fast motor timing. The study does not give an answer to whether the observed motor difficulties assessed, can be observed in the children’s everyday situations.

Apolipoprotein E genotype and outcome after traumatic brain injury in children
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Background: Apolipoprotein E (APO E) is a lipid transport protein expressed in the brain. The gene for APO E has three alleles (epsilon 2, 3, and 4). APO E epsilon 4 is a risk factor for the development of Alzheimer’s disease and for adverse outcome in adults after traumatic brain injury (TBI) and other neurological insults.

Objective: To test the hypothesis that APO E genotypes are related to short-term outcome in children with TBI.

Methods: A convenience sample of 71 participants with TBI, severe enough to require in-patient rehabilitation, were recruited. Thirty-six (51%) were female and 56 (84%) white. Mean age was 13.2 years (SD 5.6). Tissue was obtained by buccal swab for APO E genotype determination. Function on admission and at discharge were assessed by the WeeFIM Quotient.

Results: Fourteen participants (20%) had the 2/3 genotype, 53 (75%) the 3/3 genotype, and 4 (6%) the 3/4 genotype. Other genotypes were not represented. Mean WeeFIM quotients on admission to rehabilitation of 2/3, 3/3, and 3/4 participants were not significantly different. Unexpectedly, 3/4 participants had better mean discharge WeeFIM scores, even when adjusted for age, than did participants with the other genotypes (p=0.01). The epsilon 4 frequency found in our population (4%) was significantly lower than was found in nine studies relating APO E genotype to outcome of TBI in adult participants (p<0.01). It is lower also than the frequency found in a sample of children with autism studied previously at Duke University (13%, p<0.01).

Conclusion: The lower APO E epsilon 4 frequency and better epsilon 4 outcome in children with TBI are different to what was expected based on studies of adults with TBI. The neurogenetics of TBI severity and recovery cannot be presumed to be the same for children as for adults.

Gastrostomy feeding does not adversely affect feeding skills in children with neurodisability: a six-month observational cohort
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Background: Up to 84% of children with neurological problems have feeding difficulties. Gastrostomy feeding is sometimes used as an adjunct route of feeding. Concerns have been raised by caregivers and health professionals that initiation of such assisted feeding methods may have a detrimental effect on the child’s feeding skills.

Participants: All children, under 7 years, with non-progressive neurological disability who were newly referred to a multidisciplinary feeding clinic in a tertiary hospital.

Methods: Functional abilities (GMFCS; Gross Motor Function Classification System) and feeding assessments; Schedule of Oro-Motor Assessment (SOMA), which evaluates oromotor skills with four solid textures and three methods of fluid delivery; were performed at baseline and 6 months.

Results: Twenty-one children were assessed (mean age 34 months, SD18 months). The most common underlying diagnosis was cerebral palsy. Eight children were fed orally and the rest had a combination of oral and gastrostomy feeds. Median GMFCS levels at baseline and at six months were IV and III. At baseline, 61% of children had Oromotor Dysfunction (OMD; with 28% in more than one category). However, at six months only 28% had OMD, with 11% in more than one category. At the time of follow-up assessments, 66% had attempted new textures and 34% had tried more than one new texture/method of feeding. Fifty percent of patients who had abnormal oral motor skills in a particular category had improved their skills to within the normal range. Three children with OMD showed some worsening of scores within a single category (one orally fed and two combination fed).

Conclusion: In our experience there was no difference in acquisition of feeding skills in children fed via the gastrostomy route. A multidisciplinary approach to treating these children can have a significant impact on their feeding ability, and the gastrostomy route should be considered where indicated.
Review of services for children with spinal deformity throughout England
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Objectives: Firstly, to determine scope of services, policies to cover services, and ease of access to information for child development centres and teams; and, secondly, to assess referral, monitoring, and treatment practices in 10 community paediatric physiotherapy services.

Methods: (1) Postal questionnaire sent to 244 persons on the directory for the Child Development and Disability Group (CDDG). (2) Questionnaires sent to 98 community paediatric physiotherapists who had children with spinal deformity on their caseloads.

Results: (1) Response rate from CDDG was 69%; 50% cared primarily for preschool children; 90% cared for children with neurodevelopmental disorders. Monitoring for risk: 90% did not have a written policy. Identified as at risk: 33.3% monitored in a multidisciplinary clinic, orthopaedic clinic in own hospital, and orthopaedic clinic in another hospital. Ten percent were able to access information on those at risk of spinal deformity, those routinely monitored, and those requiring intervention. (2) Ninety-seven physiotherapists responded. No formally agreed referral policies from local services to orthopaedic services, and communication between services was often poor.

Of the 522 children identified as having spinal deformity: 82% were 5 years old or more; 52% had cerebral palsy; 23% had dysmorphic syndromes; 15% had muscle disease; 7% had neural tube defect; 3% had idiopathic scoliosis; 62% were cared for by general orthopaedic surgeons; 38% were cared for by specialist orthopaedic surgeons; 56% were known to have had spinal X-ray; 87% were receiving physiotherapy; 22% had spinal orthoses; and 11% had undergone spinal surgery.

Points for future consideration: Who should be responsible for monitoring spinal deformity in children? What protocols should be in place? Where should the children be seen? What can be done to improve communication?

Functional therapy in preschool children with cerebral palsy – an ecological approach
Part I: the children
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Objective: To evaluate the effect of functional goal-directed training for children with cerebral palsy (CP) on goal-achievement, gross motor function, performance of daily activities, and caregiver assistance. The training was carried out during a five-month period in an ecological setting, i.e. the context of daily life. The setting provided ample opportunities for learning, as the children could actively seek efficient solutions to problems they desired to master.

Participants: Fourteen preschool children with CP (Gross Motor Function Classification System level II–V), without severe learning disabilities participated.

Methods: Seven specific measurable goals, predominantly belonging to the Activity domain of the International Classification of Functioning, Disability and Health, were set for each child in close collaboration with the parents. Goal attainment was evaluated three times: after three months, at five months, and at a follow-up. The Gross Motor Function Measure–66 (GMFM–66) was used to evaluate change in gross motor function. To assess performance of everyday activities in the domains of mobility, self-care, and social function, and caregiver assistance. In addition, the Pediatric Evaluation of Disability Inventory (PEDI) was used.

Results: After three months, 47% of the goals were fully fulfilled and increased to 77% at the end of the training period and at follow-up. GMFM–66 scores improved predominantly during the first two months of training ($p<0.01$) but continued to improve during the whole intervention period. A stable pre- and post-training baseline was found. The children increased their performance in self-care ($p<0.001$), and mobility and social function ($p<0.01$). The need for caregiver assistance was significantly decreased within the mobility domain ($p<0.001$).

Conclusion: Intense goal-directed training, in the setting of daily life, proved to be a successful method of intervention for children with CP.

Acknowledgements: We are grateful to all the children and parents who participated. We also acknowledge the contribution from colleagues in the habilitation team in Uppsala.

Educational outcome after an early intervention project for children with an autistic spectrum disorder
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Introduction: The national recommendations for children diagnosed with an autistic spectrum disorder are that the preschool group have the benefit of an early intervention from a multidisciplinary, multiagency team. In Nottinghamshire, UK, since September 2001, the Early Communication and Autism Partnership (ECAP) has been providing such a service.

Aims: To describe the educational placement attained by the children supported by this team. (Parental satisfaction criteria have been assessed independently.)

Method: Review of initial nursery or school placement (mainstream or specialist) and support needed to maintain this placement.

Results: The team received 57 referrals (11 females, 46 males) between September 2001 and December 2003. A total of 44 children (mean age 2 years 11 months) have been accepted into the programme, 28 (64%) have received the full programme, 11 (25%) home visits only, and five (11%) parental workshops only. Details of educational placement are available for 42 of the children, longitudinal follow-up ranging from 3 to 27 months. To date, two (4.5%) children have entered specialist educational provision, 38 are in a mainstream or private (non-specialist) nursery or school, with varying levels of support, and two are pre-nursery age.

Conclusion: This study suggests that these children are coping
well, so far, with the demands of mainstream education. Further long term follow-up is required.

Reference

Use of the Gross Motor Function Measure in a special school setting
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Background: The Percy Hedley School is a non-maintained Special School in Newcastle upon Tyne for children aged 3–18 years with either cerebral palsy and/or speech and language disorders. The school has integrated education for children with cerebral palsy, where therapists and teachers work collaboratively within the classroom using an approach based on conductive education.

Use of Data: Since 1997, physiotherapists have been using both the Gross Motor Function Measure (GMFM) and, more recently, the Gross Motor Function Classification System (GMFCS). A database of over 30 children aged 3–12 years, with a range of severity of motor impairments, has been established and used in the following ways: (1) A baseline of motor skills is established during initial assessments; (2) Targets within the classroom can be clearly described and set in discussion with teachers; (3) Progress is monitored with observation and repeat measurement, and described at an annual educational review; (4) Problems with increased tone and contractures can be monitored before orthopaedic surgery; (5) Rehabilitation following surgery can be targeted to regain the optimal function indicated by prior GMFM; (6) The GMFM is used to monitor children in a botulinum toxin treatment programme.

Conclusions: The GMFM and GMFCS are being used to allow effective goal setting and monitoring of physical skills within an educational environment. Continued use of the GMFM will allow therapists to quantify changes in children’s function, to monitor interventions, and to relate changes to GMFCS level.

Comparison between visual observation and 3-D gait analysis in children with spastic diplegia
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Background: Three-dimensional gait analysis (3-DGA) is considered the criterion standard for evaluation of walking disorders in patients with cerebral palsy (CP). However, this technology is not always suitable for young children and demands high costs, specialized personnel, and considerable patient preparation time. In everyday practice, clinical observation of the gait, possibly supported by video-recordings, is commonly used for assessing the gait of children with CP.

Objectives: To develop a clinical scale for the evaluation of gait in children with CP and to verify its validity in comparison to quantitative results obtained from 3D-GA.

Methods: The gait of 15 children with spastic diplegia was assessed from videotape recordings of the children’s performance in the frontal and sagittal planes. Simultaneously, quantitative gait data were recorded using the motion analysis system ELITE (BTS, Milan) according to a modified Davis protocol. A new observational scale of gait (OGA) was developed for the qualitative assessment and validated in a pilot study. The scale is based on various items which are related to the behaviour of upper and inferior limbs, trunk, and pelvis during the different phases of gait.

Results: Results of expert observers were compared with the scores obtained for the same items through the data of the corresponding gait analysis. The comparison between 3D-GA and OGA data indicated a total agreement of 68.8%. The percentage of agreement was higher at knee and pelvic level (80.6 and 80% respectively). A larger number of discrepancies was found at ankle level (agreement 53.3%), mainly on the angular variation during the transition from loading response to mid stance. At the hip level, observers’ errors were mainly a result of discriminating the attitude of the hip during mid stance (agreement 73.3%). The inter-observers agreement for the various items of OGA indicated a good level of accordance (Cohen’s K = 0.8).

Conclusion: Results of our study indicate a good level of agreement on clinically relevant items of gait between 3D-GA and OGA, provided that the clinical scale includes an appropriate selection of items and that it is performed by expert observers.

Effect of specific postural support on motor behaviour of young infants in supine position
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Objective: In paediatric physiotherapy it is often claimed that specific postural support can improve infant motor behaviour in supine position. However, this issue has never been studied systematically. The aim of this study was to evaluate the effect of various types of postural support on the motor repertoire of young infants in supine position. Specifically addressed questions were: Does the presence of a supporting pillow in the shoulder region affect the repertoire of arm movements? Does the presence of a supporting pillow in the pelvic region affect the repertoire of leg movements? Does the presence of supporting pillows in both the shoulder and pelvic region affect the repertoire of arm and leg movements? Methods: Spontaneous motor behaviour of 49 healthy term infants (age range 1–5 months) in supine position was video-recorded for 180 seconds in four conditions applied in random order. The conditions were: support by pillow in shoulder region; support by pillow in pelvic region; support by pillows in shoulder and pelvic region; or no additional support. Motor behaviour was analyzed off-line with help of the computer program Observer, allowing analysis of specific forms of motor behaviour with an accuracy of 20ms.

Results: Preliminary data analysis suggests that the presence of supporting pillows facilitates the occurrence of exploratory
movements, e.g. hands playing with each other or hands touching knees, but the effect seemed restricted to infants aged 4–5 months.

Conclusion: Specific postural support may have a positive effect on spontaneous motor behaviour of healthy young infants in supine position.

Parent-held child health record insert for infants born with Down syndrome: a web-based service providing medical information about Down syndrome

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A fourteen-page insert for the Personal Child Health Record for infants born with Down syndrome has been developed by the Down Syndrome Medical Interest Group (DSMIG) in the UK. It contains the following: general information; expected developmental progress; possible health problems; suggested schedule of health checks; advice about immunization, feeding, and growth; Down syndrome specific growth charts; and sources of additional help and advice. The insert was launched in March 1999, and was publicized widely in health related publications and the lay press. DSMIG was established to handle distribution and enquiries, monitor how inserts reached children, and evaluate the families perceptions of the insert. Monitoring was carried out for the first 6 months.

In total, 1630 inserts were sent directly to children aged 5 or under who were members of Down Syndrome Associations in England, Wales, Northern Ireland, or Scotland. Inserts were also made available, free of charge, to any other child with Down syndrome aged 5 or under in the UK on application to DSMIG, and 620 were thus distributed. Nine hundred and sixty were sold to individual health professionals or in bulk to Health Authorities or Trusts. Some will also have reached children with Down syndrome. Overall, at least 2250 have reached children with Down syndrome in the first 6 months of the project: approximately 50% of the target population. All children reached by inserts were sent with a parent questionnaire. Nine hundred and ninety inserts were sent with a parent questionnaire. Nine hundred and ninety were returned, and 275 were not returned. Of the 900 returns, 329 (36.6%) were filled in. A total of 182 questionnaires were received from children with Down syndrome. A total of 182 questionnaires were received from children with Down syndrome.

Determinants of participation in the social life of adolescents and young adults with cerebral palsy

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Objective: The transition phase from childhood to young adulthood is considered as one of the critical phases in the development of participation in social life. Research in young adults with cerebral palsy (CP) shows that they are confronted with restrictions in participation in social activities. The present project aims at a detailed description, and better understanding, of problems encountered by adolescents and young adults with CP and detection of potential determinants of these problems, in order to formulate implications for the treatment of this group.

Methods: As part of the CP Transition Study, in the South-West Netherlands, adolescents and young adults aged 16–20 years, and diagnosed with CP (n=105) were assessed with respect to their participation in social life and patient characteristics (e.g. sex, age, CP type, CP limb distribution, Gross Motor Function Classification System level (GMFCS), level of education, and socioeconomic status). The outcome measures are oral and written questionnaires on social functioning (Vineland Adaptive Behavior Scale and Life Habits and Short Form-36 questionnaires).

Results: About 30% of the participants encountered difficulties in participation regarding mobility, nutrition, employment, responsibility, community, and recreation. CP limb distribution, GMFCS level, and level of education were found to be correlated with participation (r=0.21 to 0.76), suggesting these variables to be potential determinants of participation.

Conclusions: The study confirmed that a significant number of adolescents and young adults with CP encounter problems in participation. These problems are related to characteristics of CP, functional level, and educational level.

Functional therapy in preschool children with cerebral palsy – an ecological approach

Part II: the parents and the network
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Objective: To evaluate the parents’ perception of family-centredness and preschool assistants’ (PAs) perception of competence after a five-month period of functional goal-directed training for children with cerebral palsy (CP). The intervention was carried out with an ecological approach, stressing the importance of the sociocultural context in which the child is an active learner. Emphasis was put on generous guidance in the training approach of important persons in the child’s network: predominantly parents and PAs. The guidance contained educational courses and continuous consultations.

Participants: Fourteen preschool children with CP (GMFCS level II–V, without severe learning disabilities), their parents, and their PAs participated in the study.

Methods: Before and after the intervention, parents and PAs filled in the Measure of Processes of Care (MPOC) questionnaire. The MPOC contains 56 questions, covering five domains, reflecting the perception of services from the habilitation team. The domains are: Enabling and Partnership; Providing General Information; Providing Specific Information about the child; Coordinated and Comprehensive Care; and Respectful and Supportive Care. The parents graded the statements on a 7-point scale which ranged from ‘never’ (1) to ‘to a great extent’ (7). Simultaneously, a questionnaire on perceived competence was administered.

Procedure: The intervention started with a structured four day live-in course for all participants. Furthermore, practical
guidance was initiated and was continued during the following five months.

Results: The parents’ perception of family-centredness had significantly improved in all domains of the MPOC (p<0.001). Analysis of the MPOC results from the PAs showed that this measure, intended for parents, was to a large extent not valid. The additional questionnaire showed that the PAs perceived that they had acquired more knowledge on how to train the child (p<0.01).

Conclusion: Functional goal-directed training paved the way for successful collaboration with parents. Further research is needed to elucidate important aspects of care in relation to others in the child’s network.

Effect of a sensory integration therapy programme on sensory problems in children with autism

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This study aimed to investigate the effect of a sensory integration therapy programme on sensory problems seen in children with autism. The study was conducted at Trakya University Training and Research Centre for Mentally and Physically Handicapped Children in Turkey. The children were divided into two groups (study and control), and each group consisted of 15 children (age range 7–11 years) with autism according to DSM-IV criteria. The children in the each group were assessed with a check-list, Sensory Evaluation Form for Children with Autism (SEFCA), developed by researchers to evaluate sensory features of children with autism.

Children in the study group attended the sensory integration therapy programme for one 45 minute session twice a week for a total of three months. During this period the control group did not participate.

At the end of the study, the two groups were assessed using the SEFCA. It was seen that there were statistically significant differences between the two groups concerning sensory problems. The sensory integration therapy programme had a positive effect on children with autism.

Autonomic dysfunction syndrome in three children with severe traumatic brain injury

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Objective: To present three cases of autonomic dysfunction syndrome (ADS) in children with severe traumatic brain injury (TBI), reviewing both their clinical management and ADS in general.

Patients: Three children who suffered severe TBI were admitted to a Physical Medicine and Rehabilitation Department. All presented with acute phase ADS.

Results: There were two male patients and one female. At time of TBI, the males were 6 and 17 years old and the female was 12 years old. In the males, the cause of TBI was a traffic accident and in the female it resulted from a fall in an amusement park. All three presented a severe TBI with a Glasgow Coma Scale below 8 in the first 24 hours. In the youngest male, hypoxia resulted from a difficult emergency intubation. The period of coma was 51, 20, and 31 days respectively. MRI showed diffuse axonal injury in two patients. All three patients exhibited clinical features of hypertension, sweating, spasticity, fever, and accelerated heart rate and were treated with midazolam, propanolol, chlorpromazine, benzodiazepines, and baclofen. The functional outcome at discharge from the Physical Medicine and Rehabilitation Department was severe disability in two patients and moderate disability in the third, according to the Disability Rating Scale and Glasgow Outcome Scale. All three presented significant neurobehavioural sequelae.

Discussion: ADS is a serious condition often presenting in cases of severe TBI. ADS tends to prolong the period of coma and results in a poor functional outcome. Early diagnosis and treatment of the most serious symptoms help to decrease the possibility of secondary brain injury.

Developing evidence-based partnerships within paediatric occupational therapy to develop the Child Occupational Self-Assessment

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National agendas have called for evidence-based practice.1,2 The benefits of adopting evidence-based practice have been well documented in international literature.3,4 There have also been calls for Paediatric Occupational Therapy to re-focus on the fundamental premise of the field: child centred practice to support engagement in everyday living.5 However, occupational therapy within the UK is yet to establish itself as a child centred, evidence-based profession.6 Therefore, a strategic vision has been adopted to develop research, practice, and education partnerships specifically to focus on child centred, evidence-based practice internationally.

This paper outlines the aims of innovative partnerships between the UK Centre for Outcomes Research and Education (UKCORE) and pediatric practitioners within the USA and UK. In addition, development of a new child focused outcome measure called the Child Occupational Self-Assessment (COSA) within these partnerships will be described.

An account of the UKCORE strategic five-phased plan will be outlined. Specifically it will focus on development of: practice R&D strategic documents; organizational research infrastructure to support the creation of a community of ‘practice scholars’ in a network of working groups; and the COSA within these partnerships. The benefits of creating UKCORE partnerships for developing child centred, evidence-based practice internationally will be explored.

References
Determinants of functional independence and quality of life in children with myelomeningocele: a physical therapy perspective

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Objectives: To investigate determinants of functional independence and to study which functional abilities were determinants for ‘health related quality of life’ in children with myelomeningocele.

Design: Cross-sectional study by means of clinical assessment, disability measurement, and questionnaires.

Setting: Outpatient spina bifida clinic at a university hospital.

Participants: One hundred and twenty children with myelomeningocele, mean age 7.9 years (age range 1–18 years).

Main Outcome Measures: Functional independence as measured by the Pediatric Evaluation of Disability Inventory (PEDI), and Health Related Quality of Life Questionnaire (HRQL). Uni- and multivariate logistic regression models were used to investigate factors that were determinants for these outcomes. Results were expressed as odds ratios and 95% confidence intervals (CI).

Results: Lesion level below L3 (odds ratio [OR] 0.4; confidence interval [CI] 0.1–1.0), cognitive status of IQ ≥ 80 (OR 4.2; CI 1.2–14.9), having no contractures in lower extremities (OR 3.4; CI 1.3–8.8), and having normal strength of knee extensor muscles (OR 4.1; CI 1.4–11.5) were most strongly associated with independence in self-care. Cognitive status (OR 16.1; CI 2.8–93.9), having no contractures in lower extremities (OR 1.5; CI 1.4–5.3), and normal strength in knee extensors (OR 11.0; CI 1.3–97.0), were the most important determinants for independence in mobility. Concerning functional abilities, being independent with regard to mobility was the most important determinant for HRQL (OR 5.3; CI 1.6–17.4).

Conclusions: In children with myelomeningocele, good muscle strength, cognitive ability, and being independent in mobility appeared to be much more important for daily life function and quality of life than other medical indicators of the disorder. This information is of clinical significance in planning a comprehensive and realistic rehabilitation programme.

Posters 31

Spinal fusion in children with myelomeningocele: influence on ambulation level and functional abilities

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Objectives: To determine the effects of spinal fusion on ambulation level and functional abilities in children with spina bifida.

Methods: Ten children (three males, seven females) with myelomeningocele were prospectively followed. Mean age at operation was 9.3 years (SD 2.4 years). Spinal curvature was measured according to Cobb. Pelvic obliquity and trunk decompensation were measured as well. Ambulation level was scored according to Hoffer, and functional abilities, including amount of caregiver assistance, were documented using the Pediatric Evaluation of Disability Inventory. All patients were assessed before and three times after surgery, with a total follow-up duration of 18 months after surgery.

Results: After spinal fusion the magnitude of primary curvature decreased significantly (p = 0.002). Pelvic obliquity and trunk decompensation did not change. The ambulation level showed a significant regression (p = 0.04). Functional abilities and amount of caregiver assistance, with regard to child’s self-care and mobility, showed a non-significant trend of deterioration during the first six months after surgery which was followed by recovery. From pre-surgery to 18 months after surgery, functional skills on self-care showed borderline improvement (p = 0.07), whereas mobility did not (p = 0.2). Mean scores on caregiver assistance improved significantly on self-care (p = 0.03), and borderline on mobility (p = 0.06).

Conclusions: Within the first six months after spinal fusion, more caregiver assistance in self-care and mobility is needed. It takes about 12 months to recover to pre-surgery level, and a further, small, improvement is seen afterwards. After spinal fusion, ambulation often becomes difficult. These findings are important for health-care professionals, as they will allow patients and their parents to be properly informed and prepared for a planned spinal fusion.

Cerebral palsy register for Scotland

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Although cerebral palsy (CP) is one of the most common childhood disabilities, very little is actually known about it in terms of its epidemiology and prevalence. In order to expand our knowledge in these areas, CP registers have been established across the UK.

The CP register for Scotland (CPRS) has been recording information on children with CP from across Scotland since April 2003. The CPRS will bring together information from routine clinical systems, such as the Special Needs System,
and information directly from parents and caregivers. The register is to be used as a research tool to investigate issues of CP, such as its epidemiology, prevalence, and effects on daily living. In conjunction with investigating these issues, the CPRS will work with a network of registers across the UK and Europe to look into CP.

Daily living information will be collected directly from the family via the lifestyle assessment questionnaire for children (LAQC) which was designed to measure the impact of the impairment and disability on the life of a child with CP and their family. The LAQC produces an overall severity rating as well as individual scores on the following six dimensions: clinical burden; social integration; economic burden; mobility; schooling; and physical independence.

It was found that the aspects of physical independence and mobility are having the greatest effect on the child’s life, and that following recent changes in educational policy, most children are attending mainstream school.

Animal models of shaken baby syndrome: revisiting the pathophysiology of this devastating injury

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In order to better understand outcomes after early brain injuries, studies must address multiple variables including age at injury, mechanism and severity of injury, environmental factors (before and after injury), and developmental factors. Animal models are helpful for elucidating these different aspects. Firstly, we describe a new model of shaken baby syndrome (SBS) in mice, without impact or hypoxia. Mortality was 27%; 75% of survivors had focal brain lesions consisting of haemorrhagic or cystic lesions of the white matter, corpus callosum, and cerebellum. All shaken animals, with and without focal lesions, showed delayed white matter atrophy. White matter damage and atrophy were reduced by pre-treatment with an NMDA receptor antagonist, indicating that excess glutamate release contributed to the pathophysiology of the lesions. Secondly, we discuss data on neuroprotection after early brain injuries. Drugs targeting the NMDA receptors cannot be used in clinical practice but indirect neuroprotection strategies, including anti-NO, anti-free radical, and trophic factors, hold promise for limiting the excitotoxic white matter damage induced by early injury, in particular caused by shaking, during brain development. Thirdly, we describe two experimental models in which SBS outcomes are determined when the trauma is combined with environmental influences, i.e. medication during the acute phase (most notably antiepileptic drugs), and rearing conditions.

Insomnia in children with neurological impairments

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Childhood insomnia is defined as significant and persistent difficulty in initiating and/or maintaining sleep. Twenty to 30% of children in the general population have a significant degree of sleeping difficulties. Children with neurological impairments have these problems more frequently.

Objective: The aim of the study was to investigate frequency of sleep disorders and insomnia in children with neurological impairments, and to compare results with those of a healthy control group.

Methods: Relevant data concerning sleeping habits were collected through a sleep questionnaire. Sixty children with various neurological impairments and 60 sex and age matched healthy controls were investigated.

Results: The total number of neurologically impaired children with significant sleep problems seen in the last 6-month period was 46.6%. Sleeping in parent’s bed was the most frequent disorder (26.7%). Insomnia, as a serious sleep disorder was identified in 20% of cases. The group of 12 children with insomnia had: delayed sleep onset (n = 5), severely disturbed circadian sleep-wake rhythm (n = 4), and significantly reduced average duration of sleep (n = 3).

Conclusion: Sleep disorders among children with neurological impairments are much more frequent than in the general paediatric population. It is important to treat insomnia in order to manage proper day-time functioning of the child and their family.

Early development of postural adjustments in standing with and without support

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Studies on postural adjustments in sitting have shown that development during early ontogeny includes great variability in response patterns and a non-linear development of muscle response activity. This study investigated whether these principles are also present during development of postural adjustments in standing.

A longitudinal study of 13 children was conducted to assess postural adjustments evoked by external perturbations with and without support in standing. Children were assessed at 8, 10, 12, and 14 months of age. We used the moving surface of support paradigm. In the ‘standing with support’ condition, the children held on to a horizontal bar in front of them that was attached to the platform. During the ‘standing independently’ condition, children not yet able to stand independently were given postural support by a researcher until shortly before perturbation onset. Support was then released, so that the child stood independently during the perturbation. Muscle activity from neck, trunk, and upper and lower leg of the right side of the body was recorded.

Variable direction-specific postural adjustments were
present well before the achievement of independent standing. While the child was standing with support the rate of direction-specific adjustments increased linearly with age during forward translations from 63% at 8 months to 91% at 14 months. During backward translations, development was non-linear with a peak in activation rates of 88% at 12 months. During standing without support the rates of direction-specific adjustments were high throughout the age period tested (forward translations: 81–91%, backward translations: 87–93%). With age, more muscles participated in the direction-specific responses; this was particularly true when the child was standing without support.

Conclusion: Variable direction-specific and task dependent postural adjustments are present before independent standing is achieved.

**ABSTRACT WITHDRAWN**

**Psychosocial adjustment in Swedish children with upper limb reduction deficiency and a myoelectric prosthetic hand**

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Children with upper limb reduction deficiency are often fitted with myoelectric prosthetic hands to compensate for functional and cosmetic discrepancies. While it is clear that an artificial arm can compensate for parts of the function of the arm, less is known about how children with these devices adjust psychosocially and how their mental health is perceived by others.

**Aim:** To study psychosocial adjustment and mental health in children with upper limb reduction deficiency who had been fitted with a myoelectric prosthetic hand at the age of 3 years.

**Methods:** Sixty-two parents with children aged eight to 18 years with a myoelectric prosthetic hand answered a questionnaire concerning competence and behaviour/emotional problems in their children. Of the 62 children, 37 adolescents who were 11 to 18 years old answered questionnaires concerning their competence, problems, and mood state. The results were compared with Swedish normative data. The children were divided into five groups according to degree of myoelectric prosthetic hand use.

**Results:** Children with upper limb reduction deficiency and a myoelectric prosthetic hand showed social competence and behaviour/emotional problems similar to Swedish standardized norms. However, withdrawal behaviour was significantly higher in all children, social competence was significantly lower in females, and social activities were significantly lower in older children with upper limb reduction deficiency. There was a significant difference between the five prosthetic-use groups: non-users had significantly more delinquent behaviour problems than full-time users, and there was an interaction between sex and prosthetic use in their affect on competence and behaviour/emotional problems, yielding two contrasting patterns. The results from this study are in contrast to earlier studies of psychosocial adjustment in children with limb reduction deficiencies, i.e. in this study, children have, overall, more competence and less emotional/behaviour problems, and less depressive symptoms than earlier studies have suggested.

**Conclusion:** Children with upper limb reduction deficiency and a myoelectric prosthetic hand are as well adjusted psychosocially as their peers without disability. However, there are indications of social stigma related to this disability which need to be considered differently for males and females.

**With me... not to me: therapy for children with multiple and complex disabilities**

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A three day course was designed to provide therapists with an insight into the complexities of therapy needs of children with multiple and complex disabilities.

This group of children are often treated in a very passive way, and it is rare that all the issues they face are looked at holistically with an understanding of how one aspect of the child’s disability may impact on another. Seating, postural management, vision, play, function, and education are all often dealt with by different agencies. In addition, people are frequently unsure of what they are aiming to achieve with this caseload of children and the same general aims remain in situ for many years. This course was developed with these issues in mind.

**Aims:** (1) To review some of the practical issues facing therapists working with children who have profound and multiple disabilities and how these issues impact on each other; (2) To demonstrate through observed therapy sessions how these issues can be addressed in therapy in an integrated way; (3) To demonstrate how a positive change can be achieved with this group of children; (4) To show how clearly set SMART goals can help focus therapy and measure outcome; and (5) To change the perspective of therapists attending the course.

**Methods:** Simple mechanisms were put in place to measure learning outcomes from the course. A short precourse questionnaire was used to measure baseline knowledge. This knowledge was retested immediately post course. A third questionnaire was also sent out 6 months after completion of the course to evaluate retained knowledge and to ask therapists if the course had changed their practice.

**Results:** One hundred percent of therapists had increased their knowledge following the course and found the treatment observations helpful in showing how this knowledge could be integrated into practise. The third questionnaire was completed by 25% of the therapists; all stated that the course had altered their practise, resulting in positive changes in their ability to set goals for their patients.
Effect of early intervention on motor development – a review
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Objective: To review the effects of early intervention on motor development in infants from birth to 18 months.

Methods: Review of the literature on early intervention in infants aged less than 18 months based on a literature search of the online resources Medline, PsycINFO, AMED, CINAHL, and PEDro. Papers were included when the study was designed for infants at high biological risk for developmental disabilities whose intervention, aimed at improving motor development, had started between birth and 18 months. Twenty-nine studies fulfilled the selection-criteria.

Results: Sixteen studies were applied within the neonatal intensive care unit (NICU) environment. Eight had a high methodological quality (highest level of evidence and at least fair internal and external validity); of which, three demonstrated a positive effect of intervention on motor development. The focus of the intervention in these studies differed, and included stress reduction (Newborn Individualized Developmental Care and Assessment Program; NIDCAP), infant stimulation, or normalization of infant motor behaviour. Of the 13 post-NICU studies, 11 had a high methodological quality. Eight of these studies addressed the effect of neurodevelopmental therapy (NDT). Only one reported a significantly positive effect of NDT on motor development. Two studies evaluated the effect of infant stimulation. Both found significantly positive effects on motor development. One study demonstrated a significantly better motor outcome after early intervention (consisting of infant stimulation) than after NDT.

Conclusion: Current methods of early intervention are heterogeneous. Little support was found for the effectiveness of NDT on infant motor development. Possibly the best way to promote motor development in infants at risk for developmental disorders is by means of a developmental infant stimulation programme.

Consequences of comorbidity of developmental coordination disorders and learning disabilities for severity and pattern of perceptual-motor dysfunction
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Background: Children with Developmental Coordination Disorders (DCD) have difficulty learning and performing age-appropriate perceptual-motor skills but have no diagnosable neurological disorder. Descriptive studies have shown that comorbidity exists for DCD with attention-deficit–hyperactivity disorder (ADHD) and/or learning disabilities (LD).

Aim: The present study examined severity and pattern of perceptual-motor dysfunction resulting from comorbidity of DCD and LD.

Method: Four groups of children participated: (1) DCD without LD (n=57; mean age 93.3mo, SD22.07; 77% males, 33% females); (2) LD without DCD (n=94; mean age 100.7mo, SD27.65; 70% males, 30% females); (3) DCD and LD (n=53; mean age 103.8mo, SD21.04; 81% males, 19% females); and (4) without DCD or LD (n=545; mean age 95.6mo, SD26.65; 52% males, 48% females). Children were tested on a standardized assessment of perceptual-motor ability, the Movement Assessment Battery for Children Test (Movement ABC-Test).

Results: Children with DCD and LD (group 3) performed worse than children with DCD without LD (group 1) on the Movement-ABC Test. Furthermore, it appeared that children with DCD and LD have particular difficulty performing manual dexterity and balance tasks but not ball skills.

Conclusion: We conclude that comorbidity of DCD and LD not only affects severity of perceptual-motor dysfunction but also is associated with a distinctive pattern of perceptual-motor dysfunction. Implications for understanding the relationship between perceptual-motor problems and learning disabilities are discussed.

Comparison of gross motor function between children with visual impairment and healthy peers
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Objective: Running ability and balance is poor in visually impaired children according to their level of visual loss. The aim of this study was to examine the gross motor function of children with visual impairment and healthy peers and to compare the results.

Method: Ten children with visual impairment, aged 81.2 months (SD2.14), and 10 healthy children, aged 81.7 (SD2), were included in the study. The running speed, agility subtest, and balance subtest of Bruininks-Oseretsky Test of Motor Proficiency-Standard Form were used.

Results: Running and balance functions were poorer for visually impaired children than for peers (p<0.05).

Conclusion: The motor ability problems are not unexpected for visually impaired children. However, the results show variability in motor ability according to level of visual loss. This detailed assessments has, perhaps, effectively demonstrated this problem. Thus, assessment of gross motor function is appropriate for use in rehabilitation programmes for children with visual impairment.
Reorganization of the somatosensory cortex in children with hemiplegic cerebral palsy: a functional MRI study

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Introduction: We have used functional MRI to study the cortical mechanisms underlying preserved somatosensory capacity in two children with early brain injury.

Patients and Methods: Patient 1 was a 7-year-old male, who had sustained a traumatic brain injury and right hemiplegia at the age of 2 years. He could grasp and release objects with clumsiness and compensatory movements and although he could recognize a tactile sense in the palm of his affected hand, it had decreased sensitivity compared to the non-affected hand.

Patient 2 was a 5-year-old female who had sustained left hemiplegia of unknown origin. She showed limitations of performing fine motor activities of left hand, and showed decreased tactile sense of affected hand.

The BOLD functional magnetic resonance imaging (BOLD fMRI) measurement, which employs the echo-planar imaging technique, was performed using a 1.5T MR scanner.

For the somatosensory task paradigm, tactile stimulation by brushing of the palm was performed at a frequency of 1Hz for stimulation over a repeated cycle of 15 seconds of rest and 15 seconds of stimulus; fMRI data were analyzed using SPM-99 software.

Results: In patient 1, the contralateral primary somatosensory cortex was activated by affected hand stimulation. However, the amount of cortical activation was reduced compared with that of the non-affected hand. In patient 2, the fMRI showed activation of the perilesional contralateral cortex following stimulation of the affected hand.

Conclusions: We believe that reorganization of the sensorimotor cortex after early brain lesion can be induced by recruitment of redundancies within primary somatosensory area or by the activation of undamaged cortical areas adjacent to the lesion site.

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Teenage outcome of being born at term with moderate neonatal or hypoxic ischaemic encephalopathy

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Background: Population-based long-term follow-up studies of individuals born at term with moderate neonatal encephalopathy (NE) or hypoxic ischaemic encephalopathy (HIE) are very rare. About 50% of all such cases are expected to develop unequivocal signs of cerebral palsy (CP). The outcome for those without CP is not well understood.

Aims: To assess cognitive functions and behaviour problems in children with moderate NE/HIE but without CP.

Material and methods: The study population comprised all 97 468 children born in Sweden in 1985. Of these, 684 were born at term with an Appgar score of <7 at 5 minutes. These children’s obstetric and neonatal records were examined and children were classified according to degree of NE/HIE. Teenagers with moderate NE/HIE without CP underwent a clinical assessment, which included interviews, neuropsychological tests, and assessment of data from medical and psychological records. Age at assessment was 16–19 years.

Preliminary results: Fifty-eight children had at least moderate...
NE/HIE and survived the neonatal period. In this group, 20 had developed CP. Nine of the remaining 38 participants had parents who declined to participate in the study. Of 29 teenagers without CP who were examined, 21 had definite cognitive dysfunction and five had hearing impairments.

Conclusion: Of the total NE/HIE group of 58 teenagers, follow-up data was available for 49 participants, and only eight of these were without dysfunction. Of those who were considered to be free from impairments, such as CP, our study revealed that 72% had problems that interfered with their daily life situation.

Clinical follow-up, including assessments of cognitive functions before school start, should be considered for all individuals in this high risk group.

Asperger syndrome: a revision of neurological and cognitive profiles of 20 children

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Introduction: Asperger syndrome was described by Hans Asperger seventy years ago. It is characterized by impairment in social interaction, peculiarities in language and in non-verbal communication, and having a restricted set of interests.

Objectives: To investigate if there are neurological data which could help in the diagnosis, and to analyze the neuropsychological profile.

Patients and methods: Criteria derived from Gillberg and Gillberg1 (1989) were used to identify 20 children with Asperger syndrome who had been diagnosed in our neurological department between January 2000 and April 2004. A retrospective study of the medical report and neuropsychological assessment was performed.

Results: Familiar antecedents, motor coordination deficits, good verbal ability, social relation problems, and restricted interests are findings which suggest a diagnosis of Asperger syndrome.

The neuropsychological assessment showed good verbal performance, except pedantic and literal use of language, and better mechanical reading than comprehension, as well as good constructional praxis. On the other hand, they had troughs during attentional tasks and understanding of social behaviour, and showed graphomotor dyspraxia.

Conclusion: This study underlines characteristic alarm signs for the paediatric neurologist to look out for which may support a diagnosis of Asperger syndrome. We emphasize the importance of analyzing cognitive and neurological data to achieve a correct differential diagnosis with other similar entities.

Reference


A web-based service providing medical information about Down syndrome

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The Down Syndrome Medical Interest Group (DSMIG) is a network of doctors, primarily paediatricians, whose aim is to ensure equitable provision of medical care for all people with Down syndrome in the UK and Ireland. The website (www.dsmig.org.uk) was launched in 2000. It provides essential information for health-care professionals on best practice medical care for people with Down syndrome.

The site provides a wide range of information, including a Medical Library of resources developed by DSMIG as well as selected information from other sources. Information is up to date, and fully referenced.

DSMIG resources include: Down syndrome insert for the UK Parent Held Child Health Record (PCHR); UK Down syndrome growth charts; evidence-based guidelines for essential clinical surveillance for key disorders (cardiac, thyroid, cervical spine instability, hearing, vision, and growth); and clinical awareness notes on other common concerns.

The Medical Library can be accessed through Medline subject categories. Information is categorized by level of complexity. Information considered particularly parent-friendly is indicated throughout by a special icon. The site subscribes to the HON code of conduct (HONcode). All information is available free of charge. Around 25 000 pages are accessed every month.

DSMIG also responds to individual queries. This service has been widely used by health professionals and others. Data describing the people using the service and the nature of their queries will be presented together with data about website usage. This will be used to demonstrate how the two arms of the information service complement rather than duplicate each other.

Domiciliary support for families of children with exceptional health-care needs

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Here the setting-up of the Lothian Paediatric Outreach Service is described.

Most families of children with exceptional health-care needs prefer to care for their children at home, despite seemingly insurmountable difficulties. However, for some families, caring for 24 hours a day simply becomes physically and psychologically stressful.

The Scottish Executive funded a pilot project in Lothian from September 2001 to March 2003. Its aim was to set up and evaluate an outreach service for these families.

Desired outcomes of the project included adopting a high standard of care based on: evidence, quality, consistency, and cost effectiveness.

Following the success of the project, we have now established a permanent outreach service in Lothian. A team of registered and unregistered staff work in partnership with
parents at home and other care giving agencies to provide up
to 24 hour, 7 day-a-week respite for these families.

We would like to see improvements in the service for these
families, and more effective respite coordination from the
first point of referral to patients’ transfer into adult services.

The Outreach Service for these families is an increasingly
important area of children’s services. Increasing survival
rates of these children places greater emphasis on respite
care at home. Outreach services should not take over caring
for these children, but give the parents the support to enable
them to continue caring for their children. The ethos is to
help improve each family’s quality of life by empowering
them to live as normal a life as possible with the least amount
of health-care related disruptions.

Severe episodic memory disorder after
bacterial meningitis in early infancy

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Memory deficits in children are increasingly recognized
and have been described after cerebral injury, or as a specific
developmental disability without visible lesion. Reports
are nevertheless rare and further descriptions of the nature
(encoding, recall, recognition) and type (e.g. short/long-
term, episodic/semantic) of deficits are needed, as well as
analysis of the disorder’s consequences on developing cog-
nitive functions.

We report the case of a male who presented with bacterial
meningitis at 6 weeks of life and whose parents complained
of abnormal forgetfulness (e.g. personal souvenirs, getting
lost) and learning difficulties. Neuropsychological assess-
ment at 14 years of age showed low-average intelligence and
preserved language, executive function, and attention. Short-
term memory, semantic knowledge, and procedural memory
were normal. Anterograde verbal and visual memory was
characterized by complete failure of recall, whereas encoding
curve and recognition skills were partially preserved. Memory
impairment was significant compared with deficits in other
cognitive skills. Lexical-retrieval deficit and dyspraxia were
also observed. Brain MRI showed two very small and hyperin-
tense hippocampi and cortico-subcortical lesions in the left
frontal and both parieto-occipital areas.

This pattern of memory deficit, although more severe, is sim-
ilar to the one described by Vargha-Khadem in children with a
history of hypoxic-ischaemic bilateral hippocampal damage.

This case is particularly interesting because it demonstrates
that despite a very early and severe memory deficit a wide
range of cognitive abilities, semantic knowledge, and academ-
ic achievement (literacy and arithmetic skills) can be acquired
following bacterial meningitis in infancy.

Residual skills in recognition together with preservation
of semantic and procedural memory could play an important
role in cognitive development and learning in such children.
This has implications for rehabilitation programmes.

Psychological outcome and its determinants
one and six months after injury in children
with traumatic brain injury

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Introduction: Traumatic brain injury (TBI) is a major cause of
hospital admission in childhood. It is recognized that TBI
results in cognitive sequelae, but few data exist concerning
psychological outcome.

Aims: (1) To define psychological outcome in children with
TBI admitted to hospital at 1 and 6 months after injury com-
pared with normal uninjured controls. (2) To explore the
factors related to poor psychological outcome.

Methods: This was a prospective cohort study and TBI was
classified by Glasgow Coma Score. Psychological response
was assessed using the Birleson Depression Scale (BDS),
Impact of Events Scale (IES), the Revised Children’s Manifest
Anxiety Scale (RCMAS), and the Child Behaviour Checklist
(CBCL). Maternal depression was assessed using the Beck
Depression Inventory-II (BDI-II).

Results: Eighty-eight patients with TBI (51 severe/moderate, 37
mild) and 47 controls were recruited. There was no significant
difference in age between TBI (mean 13.1 years) and controls
(mean 13.2 years; p=0.877). Children with TBI had significant-
ly higher scores on BDS and CBCL than controls at 1 month
(BDS p=0.003; CBCL p=0.015) and 6 months (BDS p=0.04;
CBCL p=0.001). Sixteen out of 55 (29%) children with TBI who
completed the IES scored ≥ 17 at 1 month, indicating acute
stress disorder; at 6 months 14/47 (30%) scored IES ≥ 17, indi-
cating post-traumatic stress disorder. There was no difference
between TBI and controls on RCMAS at 1 or 6 months (p=0.92;
p=0.83). There was a significant relationship between injury
severity and BDS at 1 month (p=0.001), CBCL at 1 month
(p=0.03), and CBCL at 6 months (p<0.001) but no correlation
between injury severity and IES at 1 month (p=0.77), BDS at 6
months (p=0.25), and IES at 6 months (p=0.81). There was a
significant correlation between maternal BDI and BDS at 1
month (p=0.002), CBCL at 1 month (p<0.001), and CBCL at 6
months (p<0.001) but no correlation between maternal BDI
and BDS at 6 months (p=0.38) or IES at 6 months (p=0.39).
There was significant correlation between IES and CBCL exter-
nalizing score at 6 months (p=0.005).

Attentional status and its determinants
one month after paediatric traumatic brain injury

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Introduction: Traumatic brain injury (TBI) is a major cause of
hospital admission in childhood. TBI is recognized to result in
attentional problems, yet surprisingly few data exist concern-
ing their nature and determinants, especially shortly after TBI.
Aims: (1) To define attentional status in children with TBI admitted to hospital at one month after injury compared with normal uninjured controls. (2) To explore the factors related to attentional status.

Methods: This was a prospective cohort study and TBI was classified by Glasgow Coma Score (GCS) as severe (GCS 3–8), moderate (GCS 9–12), or mild (GCS 13–15). Attentional status was assessed using the Test of Everyday Attention for Children (TEA-Ch). Psychological response was assessed by the Birleson Depression Scale (BDS), Impact of Events Scale (IES), Revised Children’s Manifest Anxiety Scale (RCMAS), and Child Behaviour Checklist (CBCL). Maternal depressive symptomatology was assessed by the Beck Depression Inventory-II (BDI-II).

Results: Eighty-eight participants with TBI (51 severe/moderate, 37 mild) and 47 controls were recruited. There was no significant difference in age between children with TBI and controls (mean 13.1 years and 13.2 years respectively; \( p = 0.877 \)). There was a significant difference between children with severe/moderate TBI and controls, but not between those with mild TBI and controls, for the following assessments: selective attention (Map Mission, \( p < 0.001 \)); attentional switching (Opposite Opposite Worlds, \( p < 0.001 \)); and divided attention (Sky Search DT, \( p < 0.05 \)). There was a significant relationship between children’s attentional status and problematic behaviour (CBCL externalizing score, \( p = 0.005 \); CBCL total problem score, \( p = 0.004 \)) but not between attentional status and symptoms of depression or anxiety (BDS \( p = 0.36 \), IES \( p = 0.74 \), RCMAS \( p = 0.55 \)). There was a significant correlation between the child’s attentional status and maternal depressive symptomatology (\( p = 0.008 \)).

Conclusion: TBI produces significant problems across a range of attentional domains. Attentional difficulties correlate with injury severity and problematic behaviour in the child but not with depression or anxiety, which is in contrast to the pattern seen in adults. The positive correlation between attentional status and depressive symptomatology in the mother suggests that further research should explore the impact of improved maternal support on the child’s cognitive outcome.

Cognitive and psychological outcome following surgically treated traumatic extradural haematoma in children
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Introduction: Traumatic extradural haematoma (EDH) in children without significant underlying parenchymal injury is generally regarded as being associated with good outcome, but few data exist concerning cognitive and psychological outcome following EDH.

Aim: To define cognitive and psychological outcome in children with EDH one month after injury in comparison with matched uninjured controls.

Methods: This was a prospective study and TBI severity was classified by admission Glasgow Coma Score (GCS) as mild (GCS 13–15), moderate (GCS 9–12), and severe (GCS 3–8). Controls were matched for age, sex, socioeconomic status, and premorbid academic achievement. Cognitive outcome was assessed by the Wechsler Intelligence Scale for Children–III (WISC–III), Test of Everyday Attention in Children (TEA-Ch), and the Children’s Memory Scales (CMS). Psychological outcome was assessed using the Birleson Depression Scale (BDS), Impact of Events Scale (IES) and the Achenbach Child Behaviour Checklist (CBCL).

Results: All children with EDH underwent surgical evacuation and all had good neurological outcome postoperatively, with no focal deficits. At follow-up, children with EDH scored significantly lower than controls on Performance IQ (\( p = 0.016 \)) and the TEA-Ch Map Mission (\( p = 0.01 \)). There was no significant difference between children with EDH and controls for Verbal IQ (\( p = 0.50 \)), TEA-Ch Dual Task (\( p = 0.11 \)), and Opposite Worlds (\( p = 0.21 \)). There was no significant difference in the CMS between the 9/12 who completed this test and controls (\( p = 0.43 \)); however, 3/12 were unable to complete the CMS. There was no significant difference between children with EDH and controls on the BDS (\( p = 0.16 \)) but there was a highly significant difference between children with EDH and controls with respect to the CBCL Total Problem Score (\( p < 0.001 \)), CBCL Externalizing Score (\( p = 0.003 \)), and CBCL Internalizing Score (\( p = 0.009 \)). Three out of 11 children who completed the IES scored \( > 17 \), indicating possible Acute Stress Disorder; 1/12 was too psychologically disturbed to complete the IES.

Conclusion: Results indicate that children with EDH are at risk of cognitive and psychological problems. We suggest that follow-up of these children is required to identify problems at an early stage so that remedial action can be undertaken.

Barriers to timely multidisciplinary assessment in neurodisability
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The National Service Framework for children is likely to recommend national standards for the assessment of children with neurodisabilities and speech and language disorders. Nationally there is great variation in the services available to assess the needs of children with disabilities. The National Autism Plan for Children (NAPC) recommends that to combat these difficulties, the time taken from first concern to full multidisciplinary assessment should take no longer than 30 weeks. Although these guidelines relate only to autistic spectrum disorders, these issues apply to other disabilities, and this model should be equally applicable to these groups.

To see if these guidelines are workable we looked at the timescale for multidisciplinary assessments in our centre.

Method: We looked at all assessments carried out between April 2001 and March 2002 (\( n = 76 \)). A retrospective audit of these children’s notes was carried out. Fifty-two sets of notes were suitable for comparison with the recommended guidelines.

Results: Of the first assessments, 40.4% were carried out within the recommended time, and 36.5% of both Specialist and MDAs met the target. Overall, only 10 (19.2%) of all assessments were carried out within 30 weeks.

Barriers encountered included: long waiting times to see professionals; parental/child reasons; and complex problems which required multiple assessments. Not all of these
Coexistence of herpetic meningoencephalitis and shaken baby syndrome: a coincidence or a consequence?

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Introduction: The signs of herpes simplex virus 1 (HSV1) meningoencephalitis are: fever, mood changes, seizures, and focal neurological signs. Without specific treatment the condition is usually fatal. Shaking (even if done by a parent to calm down a crying infant) is considered as child abuse, which is evidenced by a triad of retinal haemorrhage, subdural blood collection, and seizures. We describe an infant where, according to the initial history and clinical presentation, shaken baby syndrome was suspected but further investigations also raised possibility of herpetic meningoencephalitis. Case report: A 2-month-old male was admitted with a history of excessive crying, followed by lethargy, refusal of food, and seizures. He was stuporous and febrile; diazepam was given for generalized seizures. Cerebrospinal fluid was hemorrhagic with high protein content and low cell count. Electroencephalogram revealed diffuse slowing and, later, typical periodical focal sharp wave discharges. Computerized tomography of the head revealed fresh right temporal lobe and subdural haemorrhage, consistent with traumatic injury. Fundoscopy proved retinal bleeding. The father confessed shaking the infant in an attempt to calm him down. Due to parental labial herpes, investigations for HSV1 infection were carried out and proved positive and acyclovir was started. The child is now 1.5 years old with severe cognitive and motor disability and occasional seizures despite anticonvulsive treatment. Conclusion: Our case presents coexistence of two different severe brain conditions. The question is, whether this is a coincidence or consequence, in incidences where initial symptoms of hyperirritability and excessive crying were exaggerated and may even be worsened by shaking the infant.

Objective: A traumatic origin of the lesion at birth is generally accepted for obstetric brachial plexus palsies. During recovery of spinal nerves, functional disability occurs according to muscle imbalance of shoulder internal and external rotators and the cocontraction of biceps and triceps muscles. Those disabilities may not allow basic functional activities like hand to mouth and hand to head. The aim of this study was to evaluate the effect of a physiotherapy programme on functional ability after botulinum toxin-A injections to subscapularis and triceps muscles.

Method: Six children with obstetrical brachial plexus palsy were included in this study. Botulinum toxin-A was injected into the subscapularis muscle of three children and to triceps muscle brachii of the remaining three children. Toronto and Grossman Assessment Systems were used for the functional assessment at pre-injection and post-physiotherapy programme. In the programme, high voltage pulsed galvanic stimulation was applied to the antagonist muscle of the injected muscle three times a week for a total of 15 sessions after one week of injection. In addition, functional activity, family education, and stretching exercises were included in the physiotherapy programme.

Results: Our results showed improvement in the functional ability level of the children after the physiotherapy programme. Conclusion: Although cocontraction may be relieved by botulinum toxin-A injection, it must be applied with a physiotherapy programme to facilitate a functional activity level.

Changes of foot pressure distribution in spastic diplegia with equinus deformity following heel cord lengthening

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Objective: The aim of this study was to identify the changes of pressure distribution in the foot after surgery to lengthen the heel cord for equinus deformity in children with cerebral palsy (CP) using an F-scan system

Method: Twenty-four children (43 limbs) with spastic CP participated in this study. Children had equinus deformity of the foot and received soft tissue surgery to lengthen heel cord. Pressure distributions of the foot during standing and walking were measured using an F-scan system (Tekscan Inc, USA), this was done both before and 1 year after surgery. The data between pre and post surgery were compared.

Results: While standing, children's total contact area, contact length, and hindfoot contact width were significantly increased following surgery ($p<0.05$). However, forefoot and midfoot contact widths were significantly reduced following surgery. The mediolateral distance and anteroposterior distance of centre of pressure trajectory was not significantly different after surgery when compared to pre-surgery measurements. During walking, contact length, hindfoot contact width, and anteroposterior distance of centre of pressure trajectory during walking were significantly increased after surgery ($p<0.05$). Although the forefoot contact width was significantly reduced during walking. The mediolateral distance of centre of pres-

Effect of physiotherapy after botulinum toxin-A injection

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Objective: The aim of this study was to evaluate the effect of a physiotherapy programme on functional ability after botulinum toxin-A injections to subscapularis and triceps muscles.

Method: Six children with obstetrical brachial plexus palsy were included in this study. Botulinum toxin-A was injected into the subscapularis muscle of three children and to triceps muscle brachii of the remaining three children. Toronto and Grossman Assessment Systems were used for the functional assessment at pre-injection and post-physiotherapy programme. In the programme, high voltage pulsed galvanic stimulation was applied to the antagonist muscle of the injected muscle three times a week for a total of 15 sessions after one week of injection. In addition, functional activity, family education, and stretching exercises were included in the physiotherapy programme.

Results: Our results showed improvement in the functional ability level of the children after the physiotherapy programme. Conclusion: Although cocontraction may be relieved by botulinum toxin-A injection, it must be applied with a physiotherapy programme to facilitate a functional activity level.
Pseudomonas chest infections in children with neurodisability – infection or colonization?
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Background: Recurrent chest infections are common in children with severe neurodisability. Contributing factors include: immobility; scoliosis, poor gag reflex, gastro-oesophageal reflux leading to a risk of aspiration; and a reduced ability to cough effectively.

Pseudomonas aeruginosa is occasionally isolated from the sputum of such children, and there is currently no evidence as to whether this should be actively treated as infection, or considered as colonization only.

Aim: To evaluate the significance of P. aeruginosa in sputum of children with recurrent chest infections and neurodisability.

Methods: A retrospective case note review of five children (including two siblings) with neurodisability and recurrent chest infections from whom P. aeruginosa was isolated from sputum.

Results: In all five children, the isolation of P. aeruginosa coincided with an acute deterioration in respiratory status, with paediatric intensive care required in one patient and considered for two others.

Anti-pseudomonal treatment was instituted, and resulted in a short-term improvement of symptoms in all five children. Three children remained relatively well on long-term treatment, and two continued to require frequent hospital admissions for recurrent infections.

Conclusion: Children with neurodisability and recurrent chest infections, in whom Pseudomonas is isolated on sputum culture, should be considered for acute and long-term treatment with anti-pseudomonal antibiotics in order to maintain optimum respiratory status.

Transition into adulthood after discharge from paediatric rehabilitation: which problems do young people encounter?
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Objective: The transition phase from childhood to adulthood is considered as a critical phase in the development of participation.

With this study we aimed at a better insight into problems that adolescents and young adults with a physical impairment may encounter in their transition into adulthood and in their preparation for this transition.

Methods: Participants were 11 females and five males, aged 19 to 23 years, diagnosed with cerebral palsy, spina bifida, traumatic brain injury, or neuromuscular disease. They attended a paediatric rehabilitation department for three years prior to this study.

Present level of functioning and participation and encountered problems were assessed by means of the Barthe Index (BI), Community Integration Questionnaire (CIQ), and Canadian Occupational Performance Measure (COPM). In addition, we retrospectively documented whether they were adequately prepared for transition into adult life.

Results: Mean functional level measured using the BI was 15.1 (SD6.6). Educational level was: school for learning difficulties (n=3); secondary education (n=4); or senior vocational or higher education (n=9). Level of community integration was relatively low, CIQ total score 16.1 (SD4.1).

Several problems were identified by participants concerning transition into adulthood, scoring a problem’s importance on a 0–10 scale. Most frequently mentioned problems were:
Brain activity during precision grip lift in children with autism

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Autism is characterized by deficits in communication, impairment in social interactions, and repetitive behaviours. A previous study indicated that motor anticipation is impaired in children with autism (Schmitz et al. 2003). Development of anticipation implies that information given by the environment is properly integrated into a sensorimotor representation, which is used to anticipate. It was hypothesized that the building of representations is affected in autism. The use and updating of a sensorimotor representation involves a specific set of brain activity. A sensorimotor presentation could be correlated with abnormal brain activity.

The lifting paradigm, previously used in adults, was adapted for autistic and control children aged from 8 to 12 years. Three lifting conditions were compared: the weight of the object was kept constant, either light or heavy, for the first two conditions; and the weight of the object was changed alternately for each lift in the third condition. We used a clinical 1.5T scanner to generate 3D reconstructions of the medial gastrocnemius of nine limbs of normally developing children, six limbs of children with diplegic CP, and the affected and unaffected limbs of nine children with hemiplegic CP. All children were aged between 5 and 10 years. All children with CP had plantarflexion contracture data. Muscle belly lengths were estimated by the Euclidean distance between the posterior tip of the medial femoral condyle and the most distal point within the muscle belly. Muscle lengths were compared using a linear components model.

Results: As a function of ankle angle, the medial gastrocnemius was significantly shorter in the group of children with diplegic CP but of normal length in the group of children with hemiplegic CP.

Conclusion: Results suggest that equinus deformities in children with hemiplegic and diplegic CP are structurally different, with contracture of the gastrocnemius as a dominant feature of children who are affected bilaterally.

Comparative study of gastrocnemius length in children with hemiplegic and diplegic cerebral palsy

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Introduction: Children with spastic cerebral palsy (CP) often develop equinus deformities that limit their walking ability. Similar management principles are applied to hemiplegic and diplegic CP; yet the morphological origin of muscle contracture remains undefined and undifferentiated. Using an ultrasound technique, we measured gastrocnemius muscle belly length in children with hemiplegic and diplegic CP and compared our results with those from a group of normally developing children.

Patients and methods: An ultrasonic imaging technique was used to generate 3D reconstructions of the medial gastrocnemius of nine limbs of normally developing children, six limbs of children with diplegic CP, and the affected and unaffected limbs of nine children with hemiplegic CP. All children were aged between 5 and 10 years. All children with CP had plantarflexion contracture data. Data were collected at different ankle angles with patients lying prone on the couch. Muscle belly lengths were estimated by the Euclidean distance between the posterior tip of the medial femoral condyle and the most distal point within the muscle belly. Muscle lengths were compared using a linear components model.

Results: As a function of ankle angle, the medial gastrocnemius was significantly shorter in the group of children with diplegic CP but of normal length in the group of children with hemiplegic CP.

Conclusion: Results suggest that equinus deformities in children with hemiplegic and diplegic CP are structurally different, with contracture of the gastrocnemius as a dominant feature of children who are affected bilaterally.

Everyday physical activity and participation in young adults with hemiplegic cerebral palsy

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Objective: To assess the level of everyday physical activity and participation in various areas of life of participants with hemiplegic cerebral palsy (CP) in comparison with a healthy comparison group. Furthermore, in the patient group, to explore determinants of everyday physical activity.

Design: Cross-sectional.

Setting: Community, North and Southwest Netherlands.

Participants: Sixteen ambulatory participants with CP (25–35 years) and sixteen age- and sex-matched healthy comparison participants.

Interventions: Everyday physical activity was measured with an accelerometer-based activity monitor during two consecutive weekdays. Community Integration Questionnaire and Utrecht’s Activity List were used to assess participation.

Main measures: Outcome measures were everyday physical activity and participation. Besides participation, body fat
Assessment of ingestive skills in young children with cerebral palsy

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Background: In Utrecht, the Netherlands, we study the course and determinants of functional status of young children with cerebral palsy (Pediatric Rehabilitation Research in the Netherlands; PERRIN-CP 0–4). As part of this study we investigate the relation between ingestive skills and functional outcome.

Objective: To obtain a reliable and non-invasive instrument with prognostic validity in order to assess ingestive skills in children with CP aged 0 to 4 years.

Method: A literature review was performed using Pubmed on: ‘cerebral palsy’, ‘dysphagia’, or ‘feeding’. Then, the articles were screened by two of the authors for the assessments which were being used to determine ingestive skills. Assessments which were considered to be invasive (e.g. barium swallowing of videofluoroscopy) or which were developed purely for the use in neonates were excluded.

Results: Our search revealed fifteen relevant methods: analysis of test feeding (n = 6), often with the use of video-recording; observation of oral motor functions (n = 4); interview with parents (n = 2); electronic recording of respiration and swallowing (n = 2); and an oral praxis test (n = 1). Many methods are observations of the International Classification of Functioning, Disability and Health (ICF) ‘body function’ level. ICF ‘activity’ level information is provided by mealtime observation and an interview with parents. Most instruments are designed for discriminative purposes; psychometrical properties are mentioned for only seven instruments.

Conclusion: Although there are various discriminative assessments for rating ingestive skills in children with CP there is no widely accepted instrument for clinical practice. No such instrument with prognostic validity has been found.
Health related quality of life for children with cerebral palsy living in Istanbul, Turkey

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Children with disabilities living in Istanbul have hardly any access to rehabilitation services; therefore, the municipality began a Community Based Rehabilitation (CBR) project with the aim of improving their quality of life. The present study serves as the baseline of a CBR effect study in Kağıthane, one of Istanbul's poorer suburbs.

Objectives: To determine health related quality of life of children with cerebral palsy (CP), living in Kağıthane.

Method: The study included 35 children with CP (mean age 9.7 years; range 6–15 years) and their parents. The TNO-AZL Child Quality of Life parent form was completed by parents of 35 children. The TNO-AZL Child Quality of Life child form was completed by 13 children aged 8–15 years. Ten children were too young (<8 years) to complete the child form, and 12 children had learning disabilities which prevented them from completing the form. The TNO-AZL Child Quality of Life includes 7 domains: body function, motor function, autonomy, cognition, social function, and positive and negative emotions.

Results: According to parents, domain scores were significantly better for body function than for cognition and social function (p < 0.001). Cognition and social function domain scores were significantly better than motor function (p < 0.01) and autonomy scores (p < 0.001). In addition, children not able to fill in the child form (n = 12) scored significantly worse on cognition, social function, and autonomy compared with children who were able to do so (n = 13; all p < 0.01). Paired t-tests did not reveal significant differences between parent and child scores (n = 13). Parent and child scores were significantly correlated in all domains (0.61 < r < 0.86), except for positive emotions and body function.

Conclusions: Health related quality of life, as perceived by children with CP and their parents in Kağıthane, is affected negatively with regard to cognition, social function, motor function, and autonomy. Although motor function problems in children with CP generally persist, there is much to gain through CBR in social and cognitive functioning, and, in particular, autonomy.

Stress in parents of children with cerebral palsy: does it relate to the child’s functional (in)dependence and adaptive behaviour?

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Parents of children with disabilities, including children with cerebral palsy (CP), experience higher levels of stress than parents of children without disability. Studies on children with CP have reported that demographic, parent, child, and environmental factors contribute to the level of stress parents perceive. With regard to child factors, previous studies have found that severity of child’s CP and behavioural problems affect parental stress.

Objective: The aim of this study was to examine in detail the impact of the child’s level of functional (in)dependence, and degree of behavioural adaptability on the level of parental stress.

Method: Parents (38 mothers, four fathers) of 42 children with CP (mean age 5.11 years; range 3–8 years; Gross Motor Function Classification System levels I–III) participated in the study. Parental stress was measured with the Parenting Stress Index, which can be divided into parent (PSI-Parent) and child (PSI-child) domain scores. Functional status was measured with the Paediatric Evaluation Disability Inventory (PEDI; functional skills [FS] and caregiver assistance [CA] domains: self-care, mobility, and social function), and adaptive behaviour with the Vineland Adaptive Behaviour Scale (VABS; domains: motor, daily activities, communication, socialization, and non-adaptive behaviour). Partial correlations, corrected for age, were calculated (p = 0.001).

Results: Fourteen parents (34%) perceived high or extremely high levels of stress, on either the PSI-Child (14 %) or PSI-Parent domain (10%), or on both domains (10 %). Significant correlations were found between the PSI-Child score and PEDI domain scores (0.54 < r < 0.69) except for: FS-mobility, CA-mobility, CA-self-care. A significant correlation was found between PSI-Child and VABS domain scores (0.53 < r < 0.79), except for the motor domain. No significant correlation was found with respect to the PSI-Parent score.

Conclusions: A substantial percentage of parents perceived high or extremely high levels of stress. Child-related parental stress appeared to be associated both with child’s level of functional (in)dependence (in particular with regard to social function) and (non-)adaptive behaviour.
Functional status in 5- to 7-year-old children with Down syndrome in relation to motor ability and performance cognitive ability

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Several studies have reported that the development of young children with Down syndrome is delayed with respect to cognitive and, in particular, motor function. As children grow older their role in carrying out self-care activities increases. Although severe functional limitations in school-aged children with Down syndrome are uncommon, they do have problems with complex self-care. These limitations in daily life activities may either originate from their specific motor disabilities or they may stem from a lack in cognitive ability to adequately carry out such complex activities.

Objective: To examine the contribution of motor ability and cognitive ability on functional (in)dependence in children with Down syndrome.

Participants: Sixty-five children, selected by the Dutch Down Syndrome Foundation, were asked to participate in the study. Informed consent was given for 25 children (age 6.10 years; range 5.7–7.9 years) to participate in the study.

Method: A structural equation modelling approach was used to test the relation between functional status, motor ability, and performance cognitive ability. Functional status was assessed with the Pediatric Evaluation Disability Inventory, motor ability with the Movement Assessment Battery for Children, and cognitive ability was assessed with the Gross-Form Board. In particular, the Gross-Form Board assesses planning and spatial-temporal abilities, and memory. Data were analyzed with the program AMOS using the Bollen-Stine bootstrap method, $\chi^2$ test, and NFI index.

Results: Pearson $\chi^2$ test and NFI index indicated that the fit of the model was good ($\chi^2=1.35$, df=4, $p=0.85$; NFI=0.985). ‘Functional status’ explained 70% of the variance in the model. Standardized regression weights indicated that motor ability was a far better predictor of functional status than performance cognitive ability (0.96 vs 0.17).

Conclusions: Limitations in functional activities of 5–7 year old children with Down syndrome seem to be more related to the level of motor ability than to the level of performance cognitive ability.

Reliability of measurements of scoliosis on X-rays of children with cerebral palsy

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Background: In Utrecht, the Netherlands, we studied the course of young children (0–4 years) with cerebral palsy (CP). As part of this study, scoliosis was measured.

Objective: To determine the interobserver-reliability of different measurement methods of scoliosis, namely Cobb’s angle, the rotation by Nash-Moe, Ferguson’s angle (LS-S1), and the spinal balance, from X-rays of children with CP.

Methods: Three observers performed the four methods on 29 spinal X-rays of eight patients with CP and scoliosis. Before measurement taking, cut-off points were determined from the literature (Cobb’s angle) or by the authors (rotation, Ferguson’s angle and the spinal balance) to state whether an outcome of the variability would be considered to be reliable or not.

Results: Interobserver-variability was: Cobb’s angle, 10.3° (SD8.4°); rotation by Nash-Moe, 0.8 rotation degrees (SD0.62); Ferguson’s angle, 31.0° (SD17.8°); spinal balance, 9.7mm (SD5.2mm).

Conclusion: According to our cut-off points, the rotation by Nash-Moe and the spinal balance were considered to be reliable measurements for scoliosis. Cobb’s angle interobserver-variability was found to be higher in our study than in the literature, where it was concluded to be a reliable method. This was probably due to the relative inexperience of the observers in this study. Therefore, Cobb’s angle should only be measured by experienced observers. Ferguson’s angle was considered not to be reliable and we would not support its use.

Clinical and the lay ‘gaze’: problematic concepts of evidence and empowerment in congenital childhood disability

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Evidence-based practice, child and family centred care, and parent/professional partnership working lie at the heart of NHS modernization, governance, and recent guidance (National Health Service Plan 2000, Every Child Matters 2004). However, the basis and validation of knowledge and, thus, the enabling potential of sharing evidence in health-care interventions cannot be assumed.

Drawing on the findings of a small-scale qualitative study, this paper explores the dimensions of mothers’ lay knowledge and understanding of childhood disability and its problematic interface with formal clinical knowledge. Insights and concepts from social theory such as the Foucauldian ‘clinical gaze’ are employed to explore the nature of differing evidences, and their validating rationalities, and to interrogate the concept of empowerment. The qualities of some aspects of therapy knowledge, as a mixture of biomedical and practical knowledge, are discussed.

It is suggested that the unique nature of habilitation in congenital childhood disability enjoins us, as professionals, to use a range of theoretical perspectives to produce the scope of relevant knowledge, extend needs-based child-centred practice, and effectively communicate with and enable caregivers. In addition, evidence pertinent to the lay/clinical interface also has the potential to enhance understanding and to inform modernized service delivery across multidisciplinary and multi-agency settings. In this way, education programmes, within which clinical professionals share skills with non-clinical frontline workers, can be more effective and so enhance the environments in which children function.
Long-term outcome following non-accidental brain injury

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Objective: Evaluate children following non-accidental head injury (NABI) to identify current problems, deficits in follow-up, and to propose an effective long-term follow-up strategy. Literature suggests that neurological, psychological, and behavioural consequences of NABI may not be apparent until years after the event.¹

Design: Retrospective case audit.


Results: Forty-two patients were identified. Follow-up varied from 6 months to 13 years. Developmental assessments were completed for 78% of patients (75% had delays); neuropsychometric assessments were completed for 36% (87% revealed deficits); behavioural problems were documented for 55%, and physical abnormalities for 63% of patients. Time intervals for psychological and physical changes were consistent with the literature.¹ All school-aged children (n=18) required educational support.

Conclusion: Results indicate widespread and ongoing problems following NABI even after a period of ‘normal’ development. A structured long-term follow-up management plan is required to ensure that the child is monitored for future deficits, particularly in learning and behaviour control. We propose a plan which includes medical, developmental, and neuropsychometric reviews at key transitional times post NABI.

Reference

A developmental chart for the follow-up of cerebral palsy

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Developmental events in children with cerebral palsy (CP) deviate from the normal order and normal age of occurrence. Various scales and scoring systems are used for the follow-up of these patients. In order to create a demonstration method that would make developmental deviations clearly visible, we tried to assemble the developmental items in a graph where they are listed in the normal order on the x-axis, and age (months) is shown on the y-axis. Normal standards, based on national data obtained through the standardization of the Denver II test and other normative studies, were plotted on each graph. Four such graphs, one for each of the following developmental areas: personal-social, fine motor, language, and gross motor were organized on one page; the bottom-right corner contained a checklist for presence and degree of tone, posture, and movement abnormalities. During follow-up of a patient with CP, the child’s age at reaching each developmental milestone was marked on the chart, and the resulting line graph was compared with the normative line. The distance between graphs, any changes in the pattern, and the correlation of these changes with therapeutic interventions were easily perceived in this diagram. We feel such an eye-catching tool would help practitioners and general paediatricians make early diagnosis of developmental delays without adding to their routine work load.
Index

Ahmetoğlu E  Poster  24
Antao V  Poster  24
Autti-Rämö I  Oral presentation  13
Autti-Rämö I  Poster  24
Aydogan Y  Poster  25
Ayhan Ç  Poster  25
Banerjee KJ  Oral presentation  13
Baran G  Poster  25
Bassi Z  Oral presentation  13
Bax M  Invited speaker  3
Berg K  Poster  26
Bird A  Invited speaker  3
Bishop D  Invited speaker  3
Blackman JA  Poster  26
Blumenow W  Poster  26
Böhm B  Oral presentation  14
Bolton PF  Invited speaker  3
Bower E  Poster  27
Brogren Carlberg E  Poster  27
Brown JK  Invited speaker  4
Calvert SE  Oral presentation  14
Campbell SV  Poster  27
Cioni G  Oral presentation  14
Coates A  Poster  28
Coluccini M  Poster  28
Cormack FK  Oral presentation  15
Dabydeen L  Oral presentation  15
De Graaf-Peters VB  Poster  28
Dennis J  Poster  29
Deonna T  Invited speaker  4
Dhouieb E  Invited speaker  4
Donkervoort M  Poster  29
Dunford C  Oral presentation  15
Dutton GN  Invited speaker  4
Ekström AHL  Poster  29
Eliasson AC  Invited speaker  5
Fazlioglu Y  Poster  30
Febrer A  Poster  30
Fisher SE  Invited speaker  5
Forssberg H  Invited speaker  5
Forsyth KA  Poster  30
Garrett Z  Invited speaker  8
Gibbon FE  Invited speaker  6
Görter JW  Oral presentation  16
Görter JW  Poster  31
Gough M  Oral presentation  16
Green A  Poster  31
Green D  Oral presentation  16
Gressens P  Poster  32
Guzzetta A  Oral presentation  17
Haberfellner H  Invited speaker  6
Hadzagic-Catibusic FHC  Poster  32
Hedberg A  Poster  32
Heinemann KR  Oral presentation  17
Henderson S  Invited speaker  6
Hermansson LM  Poster  33
Holgate H  Poster  33
Hospers CH  Poster  34
Hutchon B  Invited speaker  7
Jessen EC  Oral presentation  17
Jongmans MJ  Poster  34
Kaya S  Poster  34
Kennedy CR  Oral presentation  18
Kirkpatrick M  Invited speaker  8
Klingberg T  Invited speaker  8
Koivikko M  Poster  35
Kruimlinde Sundholm L  Oral presentation  18
Law J  Invited speaker  8
Lee ZI  Poster  35
Lindström K  Poster  35
López-Sala A  Poster  36
Marder E  Poster  36
Marlow N  Invited speaker  9
Mawjee R  Poster  36
Mayor-Dubois C  Poster  37
McConachie H  Oral presentation  18
McNee AE  Oral presentation  19
Miller HE  Poster  37
Miller HE  Poster  38
Minns RA  Invited speaker  9
Mott J  Poster  38
Neubauer D  Poster  39
Newman CJ  Oral presentation  19
Norlin S  Oral presentation  19
Oskay D  Poster  39
Østensjö S  Poster  39
Park ES  Oral presentation  20
Penn A  Oral presentation  20
Prasad S  Oral presentation  20
Prior V  Invited speaker  9
Puri S  Poster  40
Ravenscroft J  Invited speaker  10
Read JM  Oral presentation  21
Resic B  Poster  40
Riva D  Invited speaker  10
Roebroeck ME  Poster  40
Röslab B  Oral presentation  21
Schmitz C  Poster  41
Scott B  Oral presentation  21
Seckl JR  Invited speaker  10
Shaffer LM  Oral presentation  21
Shortland AP  Poster  41
Shriberg LD  Invited speaker  11
Slot van der WMA  Poster  41
Staijen SH  Poster  42
Sustersic B  Invited speaker  11
Tingley E  Poster  42
Tzitisidou M  Oral presentation  22
Van der Steeg E  Poster  43
van Empelen R  Oral presentation  22
Volman MJM  Oral presentation  23
Notes