Invited Speakers

Participation and quality of life of children with cerebral palsy across Europe

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Whilst it is important to measure the key outcomes of participation and quality of life (QoL) in epidemiological studies, intervention studies, and clinical care, this presentation will mainly discuss epidemiological studies, especially of children with disabilities in Europe and North America. Over the past 10 years, there has been much progress in understanding what is meant by QoL and participation and how they should be measured. There are now many studies reporting these outcomes in children with cerebral palsy (CP) but the results sometimes appear to contradict each other. This may be because the name of an instrument does not correspond to the concept the instrument captures, or because samples are small or non-representative.

In the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE), 818 children with CP aged 8 to 12 years in seven European countries were visited. Given the large size of the sample, its representativeness, and the use of modern instruments with excellent psychometric properties, I will argue that the SPARCLE data are important for understanding QoL and participation, the factors which influence them, and whether or not there are differences between children with CP and the general population. Results from the study will be presented.

Critical reflections on the treatment of muscle tone and/or muscle strength in children with cerebral palsy

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Physical therapy has been a mainstay of treatment in cerebral palsy (CP) for decades despite minimal support of its effectiveness in improving the level of motor disability. This is surprising given the emerging awareness of the importance of physical activity for neural development and recovery after injury. The logical conclusion from these two observations is that therapists were probably focusing their efforts on the wrong things (e.g. inhibiting reflexes) or perhaps some of the right things in the wrong amounts (insufficient practice of motor skills), or were deliberately not focusing on things which now appear to be beneficial (e.g. strengthening). Therapists have been far too complacent for far too long by continuing to pursue treatment strategies that are less than optimal, and may fail to realize that this poses an ethical dilemma. It is the opinion of this presenter that failure to provide the best medical treatment available is as wrong in a chronic disorder as it is in a life-threatening disease; the consequences are just not as glaringly obvious.

So, what does the scientific evidence suggest that therapists should be focusing on? Which patient-specific functional goals are more effectively and efficiently achieved by other medical and surgical treatments than by therapy practices? This presentation will offer evidence-based suggestions for optimizing current and lifespan functioning for individuals with CP, focusing on the changing, but still unique and very important role of the therapist.

Nature and nurture in the development of children with a disability II: how neuronal group selection theory may facilitate the understanding of limitations and possibilities of intervention

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Currently, insight has deepened into the epigenetic cascades governing motor development. In particular, Edelman's neuronal group selection theory (NGST) proved to be helpful in gaining understanding of the mechanisms directing developmental motor disorders, such as cerebral palsy (CP).

According to NGST, typical motor development is characterized by two phases of variability. Variation is not random, but determined by criteria set by genetic information. Development starts with the phase of primary variability, during which variation in motor behaviour is not geared to external conditions. Next, the phase of secondary variability follows during which motor performance can be adapted to specific situations. In this phase, selection based on afferent information resulting from self-produced motor behaviour plays a crucial role.

Children with an early lesion of the brain, such as those with CP, suffer from stereotyped motor behaviour produced by a limited repertoire of primary (sub)cortical networks. In addition, these children have problems with selection of the most appropriately adapted strategy out of the repertoire. The deficient capacity to select is related to deficits in processing of sensory information and to the fact that the best solution may not be available due to repertoire reduction. The implications of these problems for guidance of the child with CP will be discussed, including the limitations and possibilities of intervention. Here, specific differences between the NGST and the dynamic systems approach will be highlighted.

Does early nutrition programme brain function in later life?

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Nutrition has been unjustly ignored as an influence on the development of brain and behaviour by most cognitive neuroscientists. Early studies examining the effect of diet on cognition were mainly observational studies in developing countries, with the results confounded by social factors that could themselves affect cognition. The introduction of

randomized trials has helped to elucidate cognitive effects of diet, establishing that early nutrition can act as a programming stimulus. Until recently, determining nutritional programming effects on brain structure was only feasible in animals, but the advent of neuroimaging techniques has allowed extension to humans.

I will first describe two such techniques, volumetrics and voxel-based morphometry (VBM). Then data will be presented using these to study early dietary influences on human brain structure.

Determining the volume of the caudate nucleus in a group of adolescents born preterm (n=76) showed that the volume at adolescence was influenced by early diet, but only in males. In line with their cognitive findings, the effect was selective to Verbal IQ but not Performance IQ. We used VBM to compare brain images from two groups of adolescents who, as preterm infants, had been assigned to a control diet (n=29) or a nutrient-enriched diet (n=21), and showed differences between groups in the local distribution of grey and white matter in the parietal lobe of the brain.

These studies establish the principle that early diet can influence brain structure. A discussion of future issues to be addressed will conclude the talk.

Inclusion, social participation, and peer culture: children with disabilities in Swedish preschools and schools

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Educational institutions are complex social systems, with learning, caring, and peer culture arenas coexisting closely. Inclusion and participation in the full sense implies that all these arenas are accessible for the individual child, and that her/his presence is accepted by other participants. For 'typically developing children', such participation and acceptance is determined by multiple factors. Functional impairments and disabilities, however, constitute a systematic influence on participation. According to preschool and school studies, peer culture inclusion presents an especially great challenge. But also consistent is the finding that children in mainstream education have a more elaborate social network than comparable children in segregated settings.

Swedish preschool studies indicate a high degree of inclusion in the learning and caring cultures of mainstream education but a more complicated pattern in the peer culture. Detailed process studies demonstrate how functional differences create problems in situations such as peer group entries, play negotiations, and conflict solutions, which are difficult to handle according to typical and prevailing peer cultural norms. Teacher interventions may present temporary solutions, but with a low degree of generalization to other contexts in space and time. School is even more challenging, with a tendency towards increased social distance between students with disabilities and typically developing peers. Subcultures of peers with similar functional prerequisites seem to become increasingly important with age, but being 'like the rest' and not being a victim of social exclusion and stigmatization is also important. The dilemma thus created will be discussed as a responsibility for the school organization.

Congenital hemiparesis with different types of cortico-spinal (re)organization: neuromodulative effects of constraint-induced therapy

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Objectives: Constraint-induced movement therapy (CIMT) is an effective functional approach focusing on improvement in motor performance of the hand in hemiparetic patients. Here, we asked whether, in congenital hemiparesis: (1) CIMT induces neuroplastic effects; and (2) if neuroplastic and behavioural effects differ with regard to different patterns of cortico-spinal (re)organization.
Methods: Two patient groups with different patterns of cortico-spinal (re)organization were recruited: Group 1 (mean age 16y 11mo) consisted of seven patients with unilateral cortico-subcortical stroke and preserved crossed cortico-spinal projections from the lesioned hemisphere to the paretic hand. In Group 2 (mean age 16y 7mo), eight patients with unilateral periventricular lesions and (re)organized ipsilateral cortico-spinal projections from the contra-lesional hemisphere were included. Before and after CIMT (12d, constraint 12h/d, individual 'shaping' lessons 2h/d), all patients were studied by the Wolf Motor Function Test (WMFT), transcranial magnetic stimulation and functional magnetic resonance imaging (fMRI).
Results: Motor function of the paretic hand improved in all patients after CIMT. However, WMFT results revealed that the behavioural benefit was less in Group 2 compared with Group 1. Both groups showed significant neuroplastic changes after CIMT. Interestingly, the direction of the observed changes differed between the two groups. When the primary motor representation (M1) was still located in the lesioned hemisphere (Group 1), motor evoked potential (MEP) amplitudes and fMRI activation increased after therapy, whereas when M1 had been reorganized into the contra-lesional hemisphere, MEP amplitudes and fMRI activation decreased.
Conclusion: We have shown that CIMT induces neuroplastic changes in congenital hemiparesis and these changes differ with regard to cortico-spinal reorganization.

Neurodevelopmental events in the human cerebral cortex

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This review reveals new data on corticogenesis and provides examples of distinct features of the developing human cortex. The neurodevelopmental events (proliferation, migration, and differentiation of neurons; axonal growth, synaptogenesis, and cell-death) take place in transient cellular zones: ventricular (VZ), subventricular (SVZ), intermediate (IZ) and subplate,

cortical plate, and marginal zones. Neurons are generated in VZ and SVZ from the neural stem cells by asymmetric and symmetric divisions between 4 to 22 postconceptional weeks (PCW). Distinct features in humans are: (1) increased numbers of mitotic cycles; (2) local generation of GABA-ergic interneurons; and (3) ganglionic eminence as the source of thalamic neurons.

Newly generated neurons migrate along radial glia through IZ and form embryonic columns. The disturbance of proliferation and migration results in migratory disorders. During the second half of gestation, thalamocortical (THC) pathways 'wait' in the subplate, the thickest lamina with early synaptogenesis, endogenous neural activity, and neuronal differentiation. THC fibres grow into the cortical plate after 24 weeks followed by callosal fibres (after 34PCW) and long associative pathways. These pathways intersect in periventricular crossroads rich with axonal guidance molecules and their damage results in cognitive, sensory, and motor deficit. Synaptogenesis begins around 8PCW, but massive production of synapses take place after birth parallel with environmental interaction.

Neuro-ontogeny is characterized by developmental 'windows' with increased intensity of specific cellular events, most likely also the most vulnerable periods. The transient cellular zones are sites of selective vulnerability and potential for developmental plasticity.

Certainty and uncertainty of determinants of long-term developmental outcome: lessons from longitudinal studies

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Among the most challenging questions parents ask professionals are those that concern their child's functional prognosis. How well can we predict future development from current information? Using examples from studies of motor development in children with cerebral palsy (CP), this presentation will address both what we know and do not know, and how clinical skills and experience still play an important role in how we answer these questions.

CP Motor Growth Curves relate one aspect of development (gross motor function) to two clinical markers (age and Gross Motor Function Classification System level). These group data can have considerable value for epidemiological and policy purposes. However, as illustrated by the large within-level variation in motor function, prediction for individual children is a very different challenge. Thus, there is an essential need to blend population-based data with our clinical experience and the perspectives of the people who know children best – their parents!

When prognosticating, we need to understand the distinction between people's capacity and their performance. What influences children's function? What factors potentially enhance and impede what children actually do? The International Classification of Functioning, Disability and Health framework can help us at an individual clinical level to think about the forces that might have an impact on a child's function. There are also many fascinating issues concerned with assessing and predicting people's 'quality of life' – and the reality that we cannot and should not judge the book by the cover!

It is hoped that this talk will provoke thought and discussion among colleagues, and help us to move these complex issues forward.

International Classification of Functioning, Disability and Health version for children and youth: a new tool to document disability in childhood

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The development of the International Classification of Functioning, Disability and Health version for children and youth (ICF-CY) over the past 5 years has involved the expansion of content and increased specificity of detail to cover body functions and structures, activities, participation, and environments to capture the dynamic characteristics of infants, toddlers, children, and adolescents.

With the approval of the ICF-CY by the World Health Organization Family of International Classifications in October 2006, there is expanding interest in the promise of the ICF-CY as a tool for use in various health settings serving children with health conditions and disabilities. Of particular significance is the potential utility of the ICF-CY as a common language for sectors and systems involved in services and policy work on behalf of children and youth. Social, health, and legal systems as well as public education are all engaged in services and supports for children and, for the first time, will have a taxonomy with direct applicability to their spheres of work that can be shared across settings and disciplines.

The ICF-CY contributes to practice, policy, and research by: (1) providing a framework for interdisciplinary practice; (2) yielding profiles of child functioning; (3) clarifying clinical diagnoses and comorbidity; (4) providing a functional basis for planning personalized treatments/interventions; (5) offering codes for identifying intervention outcomes; (6) providing the basis for documenting the gradient and hierarchy of change of functioning; and (7) standardizing documentation of variables in research. As implementation of the ICF-CY requires measures to document the specificity and severity of ICF-CY codes, a pressing priority is the development of instruments for surveillance, intervention, and research activities mapped to the ICF-CY.

Nature and nurture in the development of children with a disability I: dynamic systems approach to organisms' inherent plasticity that underlies options for therapeutic intervention

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The human system is a complex one, comprising many interacting neurophysiological and biomechanical subsystems and influenced by a host of environmental factors.

Understanding how these elements interact and influence the development and function of the organism is fundamental in determining whether to intervene if behavior varies from typical and if so, in what ways. Complexity theory, or dynamic systems approaches, explain the self-organization of patterns at multiple levels, from that of the brain to overt behavior, over developmental time. Research involving fetal and neonatal animals, as well as work involving infants and children with disabilities, argue that our innate biochemistry (genes) prescribes less than traditional neural maturation approaches suggest, particularly with regard to behavior.

The role of plasticity in the human system is fundamental, which leads both to the exquisite adaptability we enjoy in our everyday movements, as well as to the many ways a system is and can be impacted during development that affects its behavior. To illustrate these issues I will present results from studies in my laboratory involving infants born with a neural tube defect, spina bifida. I will also briefly review results from studies on the impact of intense activity on spinal-cord-lesioned animals and current therapeutic efforts to restore walking in adults with traumatic spinal cord lesions.

In all cases, the organism's own repeated attempts to act and to incorporate the perceptions arising from those actions are critical, even to the effectiveness of various pharmacological therapies. The exciting results of such studies offer new and creative avenues to supplementing traditional intervention approaches and moving closer to optimizing behavioral outcomes.

Neuromodulation induced by non-invasive transcranial stimulation in hemiplegia

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Motor performance of hemiplegic patients can be transiently enhanced when cortical excitability is accurately modulated by transcranial stimulation. Besides a non-specific boosting of cortical activity, such neuromodulatory interventions may actually release latent neuronal plasticity. Potential applications in paediatric patients could be extrapolated based on adult stroke patient's studies.

Recently, repetitive transcranial magnetic stimulation (rTMS) and transcranial direct current stimulation (tDCS) – two non-invasive neuromodulatory interventions – have been used successfully to improve motor performance in adult hemiplegic stroke patients. On the one hand, the cortical excitability of the stroke hemisphere can be up-regulated by high-frequency (≥5Hz) rTMS or anodal tDCS; this results in a motor function improvement. On the other hand, down-regulating the intact hemisphere with low-frequency (≤1Hz) rTMS or cathodal tDCS can improve motor and cognitive functions in those hemiplegic patients in whom an unbalanced interhemispheric inhibitory drive acts as a brake on the functioning of the stroke hemisphere.

Ultimately, the priming of neuronal plasticity through transcranial stimulation could result in long-term functional recovery when applying these neuromodulatory interventions over cumulative sessions in combination with rehabilitative training. Since the potential for effective neuronal plasticity declines as maturation progresses, paediatric patients could theoretically benefit more than adult patients from neuromodulatory approaches. Conversely, potential adverse effects should be carefully pondered before applying transcranial stimulation to developing central nervous systems. So far, tDCS has not been used in paediatric patients whereas rTMS has been applied in less than 40 paediatric patients suffering from attention-deficit–hyperactivity disorder, depression, or intractable epilepsy.

To treat or not to treat: reflections on dilemmas in neonatology

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End-of-life decisions in newborns with incurable conditions are controversial. In the Netherlands there appears to be a consensus among paediatricians for ending the life of newborns after a justified decision of withholding or withdrawing treatment for: (1) newborns who have a very poor prognosis and a poor quality of life but who will not die in short term after withholding treatment and who suffer intolerably; and (2) newborns who have survived thanks to intensive care but for whom it becomes clear after intensive treatment had been completed that the quality of life will be very poor and for whom there is no hope for improvement.

In the latter case the doctors feel a special responsibility because of their former interventions. There is further controversy about ending the life of newborns who are not and have not been dependent on intensive medical treatment but for whom a very poor quality of life, associated with sustained suffering, is predicted. The so-called Groninger Protocol (2005) addresses this decision-making process of ending the life of a newborn who suffers intolerably outside the context of withholding and withdrawing treatment.

The Groninger Protocol has been fiercely criticized by the international press. Although we recognize the moral sensitivity of this Protocol, we also think that some of the criticism labours under some serious misunderstandings. In this workshop we will first present the Groninger Protocol. Secondly, after clearing up some of the misunderstandings, we will discuss some of the lingering moral questions with the Protocol, especially the notion of hopeless and unbearable suffering.

The role of parents and professionals in participation and inclusion of children with profound disabilities

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In the care, education, and treatment of children with profound disabilities, complexity and vulnerability are key words. Apart from their cognitive, motor, and, frequently, sensory impairments, these children are at risk of developing several

severe additional health problems. Given the complex needs and physical vulnerability of these children, parents and professionals do tend to get extremely caught up in day-to-day challenges, and concepts such as inclusion and participation are likely to be put off for the future, as these concepts seem to aim at independence and autonomy, and offer insufficient prospects for these children.

Parents, however, are expected to make decisions concerning their child's future and necessary support. Many parents have scant information concerning their child's future possibilities and about what the various professionals have to offer. It is, therefore, extremely important that parents are given the opportunity to cooperate with professionals. Such cooperation should focus on incorporating the experience and knowledge of both parents and professionals, while at the same time adding to their existing knowledge and skills.

In this presentation, the problems that parents and professionals face, especially problems related to the physical vulnerability of these children, are outlined and supported by data. The need for an integration- and participation-related perspective for children with profound and multiple disabilities is stressed. A prerequisite to establish such a perspective is that both parents and professionals recognize their need for cooperation.

Early intervention in Slovenia and Croatia: a comparison

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Croatia and Slovenia are neighbouring countries linked by a common history and traditionally good cooperation, although there have always been certain differences between them. In recent times, those differences have become larger as Slovenia is now part of the European Union, whereas Croatia is not. This survey will compare the systems of Croatia and Slovenia in the rehabilitation of young children with developmental disorders or those at risk of developing them.

Educational systems for early intervention work, organization of services, diagnostic methods, and work methods will be compared. There are similarities, but also differences, in all four segments. For example, recently Croatia has introduced specialist training for early intervention work in the education field while Slovenia has a network of developmental clinics and more sound experience in neurodevelopmental therapy (Bobath). Their early diagnosis and work methods are similar to a certain extent, but also different in many respects, in particular with regard to teamwork and the inclusion of family in the (re)habilitation.

We conclude that a further fostering of communication and cooperation between the two countries and adopting of good models would further therapeutic and counselling work as well as developmental outcomes in children at risk of or with developmental disorders.