#### Conclusion

Epilepsy in children with congenital hemiparesis has a variable, mostly correlated in cases showing only simple partial motor seizures and those with classic aetiology. Through careful adherence to basic principles of diagnosis, classification, and AED use, as most individuals can be successfully managed with one- or two AEDs and enjoy positive outcomes in the areas of community integration and increased independence. The newer AEDs offer additional opportunity for improving outcomes for these CP patients.

### THE TRANSITION FROM CHILDHOOD INTO ADULTHOOD

by Ágnes Mikula-Tóth & Melanie Brown
The National Institute of Conductive Education,
Birmingham, United Kingdom

For many years CE has become synonymous with children with cerebral palsy. Much of the literature refers to the child with CP, but what of the adult? As the formal educational system draws to a close so apparently does learning and teaching. The transition from childhood into adulthood is at its best traumatic for both the individual and the family, the child with CP is no different. During their transitional years the individual needs to learn to manage changing expectations and a changing body at the same time as preparing for the future. A range of skills, previously carried out by the family, need to be learnt to equip the individual for their life ahead. For many young people with CP assessments of ability become a way of life, many of these being based on different expectations. New programmes are constantly devised and there is frequently a lack of consistency between approaches. Over a period of time the young person learns to be passive in the process, waiting for the professional to state the boundaries and rules against which they will be assessed.

For the last 9 years The National Institute of Conductive Education in collaboration with Hereward College of Further Education have been working with young people with CP aged between 16 and 25 years. Over the past year a new modular scheme of daily living skills has been piloted. This scheme is designed to record learning and provides a tool which the student can use throughout their life. This presentation will provide an overview of this tool and examples of how it can be used by adults with CP.

# CONDUCTIVE EDUCATION FACILITATES CHILDREN WITH SEVERE/PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES, TO REACH THEIR PERSONAL BEST

by Sinead O' Nuallain & Early Childhood Team Burren View C.D.C., Galway, Ireland

The Galway Early Childhood Services in the West of Ireland provide an educational and multi-therapeutic Service for people with intellectual and physical disabilities. The Services provide both a community and centre-based program delivered by a multi-disciplinary team for all age groups.

Specialist Child Development centres are situated within the community which offer a educational day-care service. Two of these centres have specialized in offering programs based on conductive education for children with multiple disabilities ranging from moderate to severe and profound, namely Burren View C.D.C. and Stepping Stones C.D.C. This includes Parent and Baby groups and Junior Infant Groups. School-aged children (6-18 yrs.) with multiple disabilities attend our special school in Rosedale that also uses a conductive education approach.

Conductive Education has proven to be an excellent framework to help our children reach their personal best, showing improvements in all areas of development. We use conductive education as our main framework and integrate other educational approaches and therapies in order to meet each individual child's needs. Through our work we value the compatibility of conductive education with other treatment-methods, such as music-therapy, Montessori education, aromatherapy and hydrotherapy to mention a few.

Our aim is to demonstrate how we adapt the principles of conductive education to meet the very specific and diverse needs of our children.

Presenting individual case studies which portrait a variety of our children we would like to demonstrate how conductive education has changed their lives

and that of their families. We will discuss the main aspects of conductive education and how it influenced the children's development using video-footage and progress-reports. We will show how various components of conductive education have helped children with profound and severe disabilities achieve their individual goals.

## LIFE MODELLING PROGRAMME AT THE INTERNATIONAL CONDUCTIVE EDUCATION UNIT

by Ildikó Tass Pásztor International Pető Institute, Budapest, Hungary

The International Conductive Education Unit was set up in 1992 to provide conductive education at the Pető Institute in Budapest for those who do not have access to a conductive programme at home. Since the Unit was created we have had Mother and Toddler groups, kindergarten groups and also school groups in outpatient form. The groups are constituted according to the child's age, condition and individual rhythm, with special reference to the goals to be achieved.

Besides traditional forms, new ways of conductive education are developed which were not used before.

The residential group with life modelling programme was opened experimentally in 1998. Pupils participating in this special programme have 13 hours of conductive education daily. The daily routine offers an appropriate framework for developing the pupils' independence and for teaching them self help skills and how to apply these in various life situations. Special emphasis is laid on the promotion of social and peer relationships, public mindedness, tolerance and helpfulness. The education programme includes learning and practising housekeeping, handcraft, do-ityourself and computer sessions. As part of the programme preparing for integration, pupils learn traffic regulations, use public transport, go shopping, pay with money, avail themselves of the service industry. The Unit generally accepts pupils for 4-8 week periods at a time. In case of staying longer, private tuition is arranged for children in their own languages. This form of life modelling conductive education is more flexible, the programmes are more interesting, the surroundings much more homely than usual. At the weekends different cultural programmes are organised for the pupils. This

comprehensive schedule assists them to learn self-care activities and to increase their independence. Special emphasis is laid on learning social skills and forming peer relationships in order to strengthen the feeling of belonging to a community.

### **PARTNERSHIPS**

by Judy Preston & Jan Robinson
The Unicorn Centre, Middlesbrough, Teesside, United Kingdom

Creating partnerships is like creating a garden. An overall vision of the completed garden needs to be retained. Many individuals can contribute to the vision in the form of ideas, structure, advice and help. Cultivating partnerships with groups or individuals with diverse and sometimes seemingly unrelated knowledge can produce exceptional results by allowing the growth of new ideas to complement tried and tested approaches, resulting in new ideas that can then be harvested for everyone's benefit.

In 1999, three members of the Unicorn Centre, a purpose built establishment for the Riding for the Disabled Association (RDA), attended the 3<sup>rd</sup> World Congress of Conductive Education. Their attendance came about through a need to explore possible avenues for future developments at the Centre. They became enthused by Dr Murai's ability to develop partnerships with diverse organizations, creating a fertile environment for a pupil's individual development towards independent living. Discussions with delegates from around the world showed them that as in the RDA (which has groups all over the UK and affiliated groups abroad), each country, each region and each group has adapted Conductive Education in individual ways depending on the external environment, available funding and the individual needs of pupils.

This presentation is about the partnerships that the Unicorn Centre has been developing in different areas of its work. It is also about the overall vision that is evolving at the Centre for the future. The presentation will be based around a video (some of which was filmed at the last conference in Urakawa). The object is to introduce a new perspective on the potential for future relationships with other organizations that have complimentary aims and objectives. To develop these relationships it is necessary to create the environment for partnerships to grow and evolve. We hope to provide

delegates with a fresh insight into creating a range of partnerships, external to Conductive Education, but which will generate the growth and dynamism for existing organizations to evolve and adapt in the complex environment that is the world we all live in today.

### A (TRANS) PERSONAL JOURNEY IN CONDUCTIVE EDUCATION

By Suzy Rab & Gabriella Almássy Auckland, New Zealand

In this paper I attempt to synthesize Conductive Education and key new insights from consciousness studies and transpersonal psychology. I shall share how my own journey came to be increasingly recognizable in the Conductive Education context, as involving processes of evolving consciousness and transpersonal experiences. On this journey I will introduce you to the idea that the concept of Conductive Education can be understood in the framework of whole/partness as best described by Ken Wilber. We will explore how each principle of the Conductive Education philosophy, each factor of the daily routine, every task of a task-series or all efforts of the participants and the conductors are simultaneously parts of a whole and represent entirety in themselves, thus weaving the complex fabric of a differentiated and integrated system. On another stage of the journey we will explore how conductors' and class members' experiences in Conductive Education can be related to a concept called 'flow' described by Hungarian born psychologist, Csikszentmihalyi. We will also see how flow and mindfulness have reference to other transpersonal ideas expounded by Grof and Kabat-Zinn. My journey increasingly involves a transpersonal understanding, as does my insight into the healing properties of Conductive Education. As you accompany me on this path, I expect there will be aspects of the experiences I describe that you will recognize. By understanding these experiences as steps on a journey of evolving consciousness we can begin to remove the blocks of self-evolvement, which can be perceived as a cause of adult motor disorders, and we can open up new relationships between conductors and clients.

## CRITICAL ISSUES OF CONDUCTOR TRAINING IN NEW NATIONAL ENVIRONMENTS'

by Tünde Rózsahegyi
The National Institute of Conductive Education,
Birmingham, United Kingdom

A crucial part of the conductive education movement worldwide is the development of conductor training in new social and cultural environments. Without producing its own conductors, no country can expect to have its own national network of provision and the profession itself would bear very little meaning within a given country's system of education and rehabilitation.

In order to be acceptable and appropriate any development of this kind needs to take place within the constraints and requirements of national systems of higher education and postgraduate training.

In the UK an established conductor-training course is provided by the NICE in partnership with the University of Wolverhampton. Last year the first trained conductors graduated from this course after their three-year training. They are now working in the UK and elsewhere. A further 28 are at various stages of the course. Plans are now being made to restructure the course for its second eve-year period, on the basis of our experience to date.

For the staff at NICE the process of delivering the training has required imaginative thinking and practice. The traditional model of conductor-training from the Pető Institute in Hungary had to be adapted and changed to match the UK system, which has its own rules, standards and quality requirements, its own mechanism for accreditation and awards. Conductor training at NICE has been part of this UK framework but has needed also to promote and maintain its own distinctive professional values and principles. It has needed to create a new profession, capable of delivering conductive education for children and adults.

This paper will draw on the first five years of experience at NICE and highlight some of the critical issues involved in the development of this training initiate and how it has continued successfully. I will particularly examine three particular issues from the Quality Assurance guidelines, which determine the organisation, content and management of courses in higher education in the UK:

- curriculum design and development
- student support in learning
- strategies for formative (continuous) and summative (final) assessment of knowledge and competence

The paper will make recommendations about principles and strategies, which need consideration when developing courses to train conductors in a new national environment. It will interest who thinking about, planning or already pursuing conductor-training initiatives elsewhere.

#### **TOGETHER OR APART?**

by Anikó Salga & Júlia Horváth International Pető Institute, Budapest, Hungary

The issues of segregated or integrated education of the motor disabled rise various problems according to the age, type of injury, social expectations and cultural background. As to the special literature children's education at an early age is carried out primarily in the family and the issues of integration emerge in school age.

Motor development of about 60% of children starting conductive education at an early age terminates successfully around or even under the age of 3. Learning difficulties or partial skill disturbances due to the brain injury might emerge later (in early school age), causing continuous disruption in the integration process, and finally, disturbing integration itself to a certain extent. Using the tools available nowadays (psychological tests and evaluations to screen learning disturbances) correctly makes it possible to discover the disturbances of partial abilities actually not experienced but expectable in the future. Statistics made about aftercare show that there is a group of children who need normal patterns, the rhythm of a normal community of the peers but who still need education carried out according to the principles, aims and programmes of conductive education. In view of this experience a conductive kindergarten integration group was set up in the 2000/2001 school year for normal children and for children whose motor development would make them able to be integrated but for other problems still need development. Children's development was evaluated with standardised tests (Kiphard, Vineland) and continuously observed with own tools (Kozma-Horváth-Salga). Parental and satisfaction was measured by questionnaires and structured interviews. Children's social relation within the group was observed from the beginning. Integration is a two-way process and both the normal society and the disabled can benefit from it. The question arose whether integrated education in the beginning of kindergarten age, in the sensitive age of a child helps future

integration and has real developmental effect. The aim of the presentation is to introduce initial achievements, parents' and conductors' experience and future steps.

### THEORETICAL AND PRACTICAL ISSUES OF QUALITY MANAGEMENT IN CONDUCTIVE EDUCATION

by Anikó Salga International Pető Institute, Budapest, Hungary

Quality management is a modern discipline based on the results of philosophy, economy and social and technical sciences. Its scope of competence increasing, by now valuable experiences have been gathered also in human areas, such as in the field of institutional education. One of these is that different processes and methods of quality management have to be elaborated for the various locations of education e.g. age specific education and it is imperative to define basic elements e.g. service, product, customer, expectations, satisfaction etc. concerning the given location. If that applies to education in general, it is especially true for conductive education. Customers' satisfaction can be taken as an example to demonstrate the importance of the problem.

Early development is an integral part of the conductive education system. One of the customers here is the infant. Measuring the satisfaction of customers is a core element of quality management. How can the infant's satisfaction be measured and is it at all necessary?

Another example is standardization that is perhaps the most controversial question of quality management. Many professionals consider creating a standardized quality management system for education impossible; others think standards can be defined once an activity is measurable. With regard to the characteristics previously mentioned and the goals expected from a quality management system, a standardized quality management system has been worked out for conductive education. It is not the creation of standards that arouses doubts but the question of applicability in different countries and different systems where conductive education is realised with different goals to meet different expectations. Due to the specific characteristics of

conductive education (A rather dynamically developing education method with specific career; not pure education, with an age range from infancy to adulthood.) basic elements have to be defined and related to conductive education. Time has come to realise this as the rapid progress and differentiation of quality management offer an opportunity and useful experiences have been gathered in the past five years while the quality management system of conductive education has become everyday routine.

## THE MODEL OF QUALITY MANAGEMENT INTRODUCED IN THE INTERNATIONAL PETŐ INSTITUTE

by Anikó Salga International Pető Institute, Budapest, Hungary

In 1996 when the standardized quality management system was introduced in the Pető Institute, quality management was almost unknown in Hungarian public education and was still in its infant days all over the world. Many professionals had doubts whether conductive education can be measured and standardized and there were even more who argued against a possible universal quality management system, which is adaptable both in Hungary and abroad. After being tested in 1996 and 1997 the system was introduced in the practising institution of the International Pető Institute. One of the significant results was that communication on professional issues started within staff. In 1999 the Comenius programme, the quality management system of public education was launched in Hungary. It was clear from the beginning that the quality management system of conductive education would have at least two basic components: one concerning proper conductive education practice and a second concerning the particular institution (school, health institution, independent centre etc.) where conductive education is applied, autonomously, segregated or integrated. As the Comenius programme was established the integration of the two quality management systems became inevitable. The model elaborated by the Pető Institute demonstrates how a quality management system required by the Ministry of Education and the quality management system of conductive education can be moulded to a coherent unity.

The lecture covers the development work, the two quality management systems, the methods applied and the elements of the systems including practical examples.

### PETŐ UK AS REFLECTED IN DATA

#### by Anikó Salga International Pető Institute, Budapest, Hungary

The successfulness of conductive education became known world wide by the 1990's but the accessibility of programmes was rather limited, concentrating mainly in Budapest. Many families could undertake the journey and spent some time there but the growing interest meant that also the number of those increased who could not afford going to Budapest. In an attempt to meet their needs, after a preparatory period of several years Pető UK was opened in London in 1992. The Centre was established with the purpose to make conductive education available to British families in their own country. The Centre has been operated as a joint venture by the International Pető Institute and SCOPE (the former Spastics Society). In the past years the forms of occupation have been improved and differentiated both in contents and volume. Basic services, however, have remained the same:

- Conductive first assessment and counselling
- Interval conductive education
- School for Parents
- Individual sessions
- Provision of parents, professionals, media etc. with general information

Conductor-teachers to the Centre are delegated by the International Pető Institute while SCOPE is responsible for operating the Centre.

In the past years 1312 families have visited the Centre. Conductive education has been recommended in 80% of the cases and 70% of the families have availed themselves of the method in some form. The Centre has a remarkable data base of cerebral palsy. What can be seen behind the data? The posters demonstrate the Centre's work of almost 10 years as reflected in diagnoses, age ranges, incidences, occupation forms and frequencies, areas of operation etc.

### PARENT'S PERSPECTIVE

by Chuck Saur
Inter-American Conductive Education Association,
Grand Rapids, Michigan, USA

Most parents of special needs children will remember that moment when they first heard someone use the word "problem" in a sentence with their child's name. That defining moment begins a long process of adjustment for the parent and special care for the child.

Our culture, in the USA, promotes and reinforces those who purport to have more authoritative power. Most often, the epitome of authority takes the form of medical or educational practitioners. For parents who are in mid-trauma from problems revealed with their son or daughter, this reverence for those authoritative roles has a curious effect. Parents will turn to these people to guide their expectations, treatment paths, educational paths and many other facets of care for their child. But the paradox is, that the authoritative reference they use may not have the answers they seek.

Conductive education has become a model of practice that we must learn more from. This approach can help us muddle through our cultural assumptions to find better ways towards our children's independence. I propose there are three major assumptions that conductive education suggests we, as parents, should begin to test:

First, determine which advice is based on sound medical practice, and which is edging on predictive guesswork.

Second, parents must distinguish between medical care and the child's own emergent learning. Conductive education teaches us that the child needs to be involved in the initiation and maintenance of their own problem solving.

And third, we must resist the parental urge to step in and do things ourselves for the sake of expedience or pragmatics. In the USA, we have laws that provide for the educational practice of "free and appropriate education" as a right for all children. Our own self-imposed constraints of systems, control and fear limit our ability to see the gaps between what we wish to provide and our current practice. Conductive education provides our son with a model and method for becoming the person *he* wishes to create.

Chuck and Sue Saur have partnered with Aquinas College to create North America's first CE teaching program.

## A POSSIBLE MODEL OF EVALUATING THE SUITABILITY FOR CONDUCTOR-TEACHER'S WORK

by Katalin Schaeffer International Pető Institute, Budapest, Hungary

Conductor-teacher work requires sound professional background. It cannot be disregarded though that certain elements of the personality are also needed in practice. Students can become good and efficient pedagogues if, in addition to academic and methodological knowledge well drilled, they can fully adapt to the conductor-teacher's function.

Can general and special skills of conductor-teacher's be fashioned or do they form themselves?

In Hungary, at the end of the first year of the four-year conductor-teacher training programme students have to pass a practical exam. A series of aspects was developed to evaluate and analyse their activity. The aspects are sorted into four categories and indicated on a scale of 0 to 10. The practice in a pedagogical situation takes place in 25-30 minute session of a group of children with dysfunction. The students select the thematic. Students are to make the group active, direct their activities and realise special development. Observation is carried out to find out the students' leading role and cooperation with the other students.

Leading the session smoothly, the dynamic organisation of the process, reaction to unexpected situations, manner (playfulness and sense of humour) are watched. The skills necessary to make relations, co-operate, communicate with the group verbally and non-verbally are in the psychological category. Written works, drafts, planning the schedule and time allocation were classified as other category.

The same senior staff members have done the evaluation of the situational

examination.

Data have been collected since 1994, and the data of 374 students treated. Data and indicators of frequency are made up with an analysis of the training structure and the organisation of the practical activity.

### EARLY HIP DYSPLASIA IN BILATERAL CEREBRAL PALSY: SOME STUDY RESULTS AND SURVEILLANCE RECOMMENDATIONS

by David Scrutton
Institute of Child Health and Guy's,
Kings & St. Thomas' Hospitals Medical Schools,
University of London, United Kingdom

Early hip subluxation/dysplasia is a problem of bilateral cerebral palsy (CP), but not of hemiplegic CP (but it is important to separate those with markedly asymmetric diplegia from the children with true hemiplegia). This study ascertained children with a diagnosis of bilateral cerebral palsy born 1989 to 1992 (inclusive) born to mothers living within the South-East Thames Health Region (population 3.65 million; 205,958 live births during the study period).

#### Methods & some results

The pregnancy and birth histories, locomotor development and physical and surgical management, together with measures from serial X-rays of the hip joints were recorded up to age 5 years. At that age the diagnoses were confirmed with the child's paediatrician and 346 children were ascertained (1.7/1000 live births). Of those surviving to 5 years (n=323), 196 hips (30.3%) in 117 children (36.2%) were in need of treatment. By 18 months the migration percentages¹ and acetabular indices³ were already significantly different from the normal population² (p<0.001). This difference from the normal range (at 18 months) in migration percentages and acetabular indices did not correlate with sex, gestation, current or subsequent locomotor ability, severity or type of CP. The significant factor was whether the hip would later need treatment (i.e. by 5 years) and showed evidence that there are at least two additional factors affecting early hip development: in bilateral CP.

The first factor significantly separates the migration percentages of the study children's hips at 18 months away from the normal population so that 25% of the children's hips already have migration percentages outside the normal range<sup>2</sup>. This factor may be poor or aberrant movement *in utero* and infancy.

The second factor causes a further significant separation of both hips of those children in whom one or both hips will need treatment by 5 years. This factor appears to be child-related. Thus the motor disorder, whilst being the immediate cause, would not necessarily be the primary cause of the dysplasia.

To test this child-related hypothesis, the contralateral (untreated) hips of children with only one treated hip (n=47) were analysed separately and were found to be more closely related to the hips of children needing treatment (p=0.08), than those of children for whom neither hip needed treatment (p=0.003); confirming that the child, not the disorder *per se*, might carry the risk.

Achieving (and age of achieving) all but one locomotor milestone was not significantly related to hip measures, the exception being that no child who had walked ten steps unaided by 30 months (gestationally corrected) had a hip problem by age 5 years.

#### Surveillance

The primary aim of early intervention (whether surgical, medical, orthotic, postural etc.) is to maintain range of movement and prevent hip dislocation. There is evidence that if the femoral head can be centralised within the acetabulum by four years of age, long-term stability is more likely. The aim of surveillance is therefore to refer children young enough for any action to be taken, whilst delaying surveillance sufficiently to reduce the false positive rate. Thus it is recommended that all children with bilateral CP are X-rayed in a standardised position at age 30 months (gest. corr.)<sup>4,5</sup>. It is preferable of course for a referral protocol to be agreed by the team supervising the child's physical care (paediatrician, orthopaedic surgeon and physiotherapist); but

some protocol needs to be established. In the absence of such an agreed protocol we recommend that those with a Migration >14% and unable to walk 10 steps unsupported be referred for an orthopaedic opinion.

The few children with CP (there were none in our study) who present with a hip problem before 30 months are *obviously outside any such surveillance scheme*.

### THE HIGHEST LEVEL OF PROTECTING LIFE

by Judit Sipos & Gábor Szilágyi International Pető Institute, Budapest, Hungary

This poster treats the knowledge and opinions of the students of Pető Institute Budapest on abortion. It is often stated, that conductors as workers of healthcare do have a calling for protection of life, as they are working with disabled people who were *personae non gratae* in traditional societies. The *Taygetos Syndrome* is spread in contemporary societies as well, although the administrational ideologies are against it. In these circumstances conductors are supposed to represent the highest ethical level in their opinions concerning protection of life.

What does this 'highest level' mean concerning abortion? The answer is based upon a research made by a student in Budapest Pető Institute this spring. Over 40 percent of the students were asked about their knowledge about abortion and law, information, attitudes and about their preferences of values. Each county of Hungary the students are come from is represented in this survey. The social and the religional background, and the sexual culture of the students are also to be mentioned.