

1. Introduction

Cerebral palsy is a common co-morbidity in people with intellectual disabilities. The prevalence of CP in people with intellectual disabilities is 12 times as high as in people without intellectual disabilities (Schrojenstein Lantman-De Valk 1998). She found among patients of GP's motor handicap in 6 % of patients with, and in 0.5 % of patients without intellectual disabilities. In people with intellectual disabilities, living in institutes, the prevalence of CP is up to 25 %.

So we are talking about a serious problem.

In most of the countries the care for children with CP seems to be well organised. Evidence based guidelines, community based care, multidisciplinary approach, these are the most essential qualifications of the care for children with CP.

We wondered how the care is organised for adolescents and adults. To get some impression of the subject we send out a questionnaire to experts in almost all European countries.

We asked simple and generally formulated questions:

How is the treatment of adolescents and adults with cerebral palsy in your country?

Treatments,

Organisation of care (hospitals, orthopaedic clinics, rehabilitation centres; coordination, accessibility)

How, do you think, should the treatment be of adolescents and adults with cerebral palsy?

Treatments,

Organisation of care (hospitals, orthopaedic clinics, rehabilitation centres; co-ordination, accessibility)

What is needed to realise the wished treatment and organisation of adolescents and adults with cerebral palsy

The response came mainly from northern European countries, you may say, it covers the countries in which MAMH is best known and has the majority of her members: the Nordic countries, the UK and The Netherlands. However, with some effort, we also got information about Greece and Portugal.

In all these countries the care for children with CP is well organised: In these countries these children are diagnosed, treated and supported by multidisciplinary teams with all medical and paramedical therapists: including child neurologist, physiotherapist, occupational therapist, speech therapist, and psychologist. Most of the time it starts when the child is about one year of age.

The care is policlinic and integrated in mainstream education as much as possible. In most countries this approach ends when the child reaches the age of 15 till 20.

After this age the care is less self-evident. It often depends on the initiative of the person himself and his family, and of the knowledge and interest of the primary care physician.

The main question is: is this enough. Do adolescents and adults receive the care that allows them to live a life as normal as possible, or are there shortcomings which may withhold them from such an - as normal as possible- life?

If so, is there an organisational concept for adolescents and adults, which can guarantee the supply of the best support.

Maybe we have found some answers at the end of this conference? Maybe we need to continue this discussion to develop a model for care for adolescents and adults with CP.

2. Let us first have a focus on the care in some European countries

My presentation gives you no more than an impression. The information per country comes from one person, a physician, working in this field. Some respondents gave extended information, others were much summarized.

Norway

In Norway there are multidisciplinary rehabilitation centres for adults, about one centre for 100.000 till 400.000 inhabitants.

Mostly these habilitation unites are ambulatory working in close cooperation with first-line, but also with cooperation links to other special health services on second and third level.

These units for adults do not necessarily meet all adults with CP, but if the disability is severe enough the clients should be, according to national claims, within the target group of habilitation unites for adults.

But, shortly said: regularly follow up in adult years is not guaranteed. There is not a diagnose-based register.

Coordination of medical care is a responsibility of the general practitioner, coordination of all needed care and support is given by the rehabilitation centre and is a task for a so-called personal coordinator.

Sweden:

There are habilitation teams including habilitation doctors up to 16-18 years of age organized all over Sweden. Consultation with orthopaedic surgeon and hand surgeon is routine.

Spasticity treatment is quite common, and there are national guidelines for the treatment with botulinum toxin. Treatment with baclofen pumps is available in six centres.

Regarding adults: I

The treatment and follow-up is organized in adult habilitation teams (multidisciplinary: physiotherapist, occupational therapists, speech therapist, social worker, psychologist...), however, the medical issues are referred to general practitioners, rehabilitation doctors or psychiatrists with special interest in the field. Sometimes a neurologist is involved in special cases, like severe epilepsy, or baclofenpump treatment. There are local variations. In some districts there are rehabilitation clinics that follow up some of the adult patients, but only those without cognitive impairment. Accessibility to treatment like intrathecal baclofen varies, but is less than for the children.

The wish for the future is the recognition of the medical needs in adults with CP. There is work going on regarding a follow-up program (with focus on range of motion, orthopaedic and spasticity management, physical therapy and occupational therapy). This is already successfully implemented in children with CP all over Sweden, and should be developed for adults with CP as well.

Economical resources and also a change of view on political and administration level are needed for this to happen.

Finland:

All children with CP are thoroughly checked, diagnosed and assessed in child neurological units of central hospitals, which can also be university hospitals.

They are evaluated by a multidisciplinary team including child neurologist, physical therapist, occupational therapist, psychologist, nurse, social worker and rehabilitation counsellor.

Young children usually attend the unit several times per year, later on at least once per year.

All necessary aids like special chairs, other aids for daily living activities, wheelchairs, standing and walking supports, orthoses, communicators etc. are available. They get regular therapies in health centres or by private therapists. Special day care services and special schools work closely together with the hospital team and personal therapists.

This is a good working system. However, it stops at the child's age of 15-16.

At that age the person is referred to a neurologist for treatment of epilepsy and so on, but is for other care dependent on a health centre.

Adolescent and adults with CP are not regularly checked by anybody. Depending of their own activity and family's assistance they contact physiotherapists in health centres in order to get their wheelchairs and other aids to be repaired or changed. They contact doctors in health centres if they have some health complaints. All handicapped in Finland are repeatedly dependant on certificates of their handicap and their needs. These written documents are needed for further education. They are necessary for national health insurance to get certain pension-like economical assistance and for further rehabilitation in the sense of therapy, rehabilitation course etc. Certification is needed for some equipment for second stage studies like personal computer. The main problem is that GP's don't know and cannot be expected to know what to suggest and how to assess the needs of handicapped persons, so the certificates and recommendations are difficult to get or of low standard and a bureaucratic official can too easily reject the application. All officials are in words "serving" but in practise too often like trying to get rid of difficult decisions if possible.

In **Denmark** children and adolescents with CP are looked after by paediatricians until the age of 18 and sometimes 20. Thereafter the care has to be taken over by the general practitioner, but this only happens when there are problems. These adults are not followed by rehabilitation centres. Orthopaedists and neurologists show a lack of interest in adults with CP. Maybe local based rehabilitation centres can offer a solution.

UK:

Children with CP mainly have their care coordinated by an interdisciplinary, community based team, with good liaison with the education authority. The emphasis is on trying to integrate the children into main-stream education as much as possible, to try to minimize the disadvantage of their impairment.

Interventions such as botulinum toxin injections are managed on regional basis - or at least from two or three centres in a region - according to evidence-based protocols. Care for adolescents and adults is dependent on own initiative.

The Netherlands:

The care for children with CP is well organised. In The Netherlands recently a guideline has been developed for diagnostics and treatments in children with CP.

Children with CP are referred to a rehabilitation centre, usually by a paediatrician around the age of one year. At that age questions rise about aids, especially to support sitting, care and move. At this age you also can find signs of spasticity and a tendency to develop contractures. Treatment will start with botulinum toxin and orthoses, general spasticity with baclofen, sometimes with a baclofen pump. At the beginning very young children have individual treatments, but, in accordance to the severity of their disabilities they receive a

multidisciplinary approach in a therapeutic toddler group. There is a close cooperation with education. Some children are going to a special school, others to regular schools, supported here by professionals from the special schools. At the age of 5, 6, 7 year treatment is mainly focussed on the spasticity (botulinum toxin) and the strengthening of muscle power to restore the muscular disbalance. Besides this there is the support via orthoses.

Children with CP are an important group in the rehabilitation medicine. They are evaluated until they enter puberty. At that age they intend to withdraw from medical support. That raises the idea of a transition policlinic. Youngsters with a disability are invited, not specifically for control but also for contact with other youngsters in the same situation; some kind of a living room design. Support by meeting companions in distress.

The rehabilitation physician is for the adults with CP available as consultant for care and day centres for people with intellectual disabilities.

There is no systematic control of adults with CP. It depends on questions raised by the person himself. Adults with CP and an intellectual disability who are living in institutes, or who visit day centres are probably in better control than adults with CP and no intellectual disability.

Greece:

Treatments: physical therapy and occupational therapy are mostly provided in private schools with financial support through public insurance covering about 70-80% of the costs.

Alternatively, there are municipal or state day facilities mostly in smaller cities or townships, with full financial coverage by the state.

In big cities there are several high schools for youngsters with motor disability who provide education and additional physical therapy and occupational therapy. These are called "Special High schools for the motor disabled". They do not accept youngsters with mental retardation. They are willing to accept children with borderline IQ and those with specific learning disabilities.

The more severely disabled may be "placed" in live-in facilities (private or non profit) where institutional care is provided which includes paramedical therapies. The cost is covered mostly through their state pension, but usually the family has to subsidize 20-30% of it.

Organisation of care is poor compared to that provided to younger age groups. Mostly, provided and co-ordinated by individuals and clinics (mainly within the NHS) interested in CP. If these exist in the area where the patient lives, they are accessible with the usual limitations that exist within the NHS (waiting lists for appointments etc) but they are available and they do provide adequate services. Things deteriorate with increasing age because the care of older adolescents and adults with CP depends mostly on the interest and initiative of the family of the patient and on their financial means. There are just few general hospitals and few rehabilitation units, spread over the country.

Portugal:

The Portugese respondent gave just a short answer on our questions: In Portugal there are many, many problems regarding cerebral palsies in adolescence and adulthood.

The best period for the families and children is between 0-15 years. The biggest problems start thereafter.

Recapitulation:

In children:

Multidisciplinary approach towards all children with CP, starting at the age of one year or earlier,

Good relations with education. Normal schools if possible, often with specialist support when needed.

Regular controls to offer them the best support, including therapies and expedients.

In adolescents and adults:

All treatments are available, but it is more dependent on own initiative and on the interest and knowledge of general practitioners and specialists. Coordination is not guaranteed.

Wished situation: there should be regular attention on the medical, psychological and social aspects in adolescents and adults with cp.

Promising concepts:

Rehabilitation centres for adolescents and adults with a personal coordinator (Norway).

Transition polyclinic, living room design, a meeting point for persons with CP, not only for control on their medical needs but also for social aspects (The Netherlands).