CEREBRAL PALSY
TRAINEE BOOKLET
For Parents and Teachers

Development of Supportive Packages for Parents and Teachers of Children with Cerebral Palsy (03-18 Age Group)

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This project has been funded with support from the European Commission. This publication [communication] reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein.
Introduction

This is a training booklet worked within the scope of the European CP-PACK project. It is to be used in connection with 7 different training modules about children and young people with Cerebral Palsy (CP) in the age of 3-18 years. The booklet addresses parents and teachers of children with CP (trainees), attending one or more of the training modules as well as trainers of the training modules. Trainers are also referred to Trainers’ guide, another material of the training modules to be used along with the training booklet.

Cerebral Palsy (CP) is a congenital, neurodevelopmental disorder that involves a vast variety of symptoms and subsequent difficulties. As a result, this implies different, varying challenges and needs among the children in question as well as their parents and teachers in school.

Thus, the aim of CP-PACK project has been to improve actual approaches on supporting parents and teachers to cope with children and young people with CP.

Among other outputs the central output of the project is the seven training modules of which this booklet concerns. The modules are produced in accordance with a need analysis accomplished in each of the 6 countries represented by the partnership of the project: Turkey, Portugal, Italy, Greece, Romania and Denmark.

See the General Need Analysis Report as well as the 6 national Need Analysis Reports at the project website, www.cp-pack.eu. All the national Need Analysis Reports are derived from the results of focus group interviews and questionnaires among parents and teachers of children with Cerebral Palsy. The general report gathers up the national results and draws the conclusions that led to the topics of the 7 training modules.

The titles of the 7 training modules are:

1. Knowledge about CP (for parents and teachers)
2. Legal and financial matters (for parents and teachers)
3. Acceptance and inclusion (for parents and teachers)
4. Rehabilitation techniques, training and health care systems (for parents and teachers)
5. Assistive technologies (for parents and teachers)
6. Quality of life (for parents only)
7. Individualized education program (for teachers only)

It is possible to perform and attend each module independently. However, the order of the modules is intentional, as the first module mentioned, Knowledge about CP, is considered optimal basis of the following modules.

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1  See the General Need Analysis Report as well as the 6 national Need Analysis Reports at the project website, www.cp-pack.eu. All the national Need Analysis Reports are derived from the results of focus group interviews and questionnaires among parents and teachers of children with Cerebral Palsy. The general report gathers up the national results and draws the conclusions that led to the topics of the 7 training modules.
The partnership of CP-PACK Project

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Disclaimer

The CP-PACK project has been funded with support from the European Commission.

The information in this document is the result of the collaborative work of the partners in the partnership. The primary aim of the document is to be a guideline for any potential user. Consequently, the document cannot be considered as an exhaustive approach on the Cerebral Palsy field. The information presented is a result of the partners’ limited experience based, mainly, on the specific work and life situations of the partners. The user is strongly advised to his or her own situation and context and to understand this document as a proposal for a complex approach of CP.

None of the information presented in the document can be considered as official recommendation or advice. The entire content of the document can and should be adapted according the very special situation in a given place or environment. Some of the opinions expressed hereof are general and can be applied as such. Other are more limited and need to be understand as a possible solution. The CP-PACK partners, individually or as a whole, cannot be made responsible for any negative consequence, damage, or loss, direct or indirect, which may arise applying the advices or solution contained hereof.

Hopefully, this work will contribute, even in a limited way, to a better life of those affected by CP.

For further information about CP-PACK project, please visit the project website: www.cp-pack.eu

CP-PACK Project Team
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This is primarily a theoretical training module that will approach different aspects of the subject based on the latest knowledge about the brain and neuroplasticity. We consider, additionally, that parents and teachers contain a lot of valuable knowledge and skills that result from practical experiences. Therefore, the course will also be a place where participants (parents/parents, teachers/teachers and parents/teachers) get an opportunity to discuss and share their own practical experiences. This way, participants will be inspired by each other in how to translate the latest knowledge into praxis.

Goals

The main goal of this module is to improve participants’ knowledge about cerebral palsy – what it is, how it occurs and what can be done to compensate for accompanying difficulties. Specifically, we intend to:

1. Improve awareness of the most recent knowledge derived from research about how the brain works, and the complexity of the diagnosis.
2. Improve the understanding of CP in its aspects of motor- cognitive- and learning disabilities.
3. Improve the understanding of the special conditions of having a disability in adulthood.

Aim

In General

Cerebral Palsy is a condition to which there is no definite cure. Nevertheless, the brain can be trained and, therefore, be able to work and function in a better way, increasing the ability to learn new skills.

The aim of this module is to increase the understanding of different essential aspects about CP.

Learning outcome

With this module, we expect participants to be informed about CP based on the most recent knowledge derived from research. This includes knowledge about CP as a brain damage and how the brain works. Viewing CP as a brain damage, participants will also be aware about the complexity of the diagnosis and the understanding of CP in it’s aspects of motor- cognitive- and learning disabilities. As such, participants will know that CP occurs within the specific child in it’s own particular and personal ‘edition’, even though some traits may be common among children with CP.

Also, the participants will become aware with other parents’ and teachers’ experiences, acquire new/different perspectives upon their own situation and may be inspired by others when it comes to new initiatives and actions.
For Parents

Participants are aware that these are important issues in order to understand and meet their own child with CP and it’s individual CP related challenges in every day life.

For Teachers

In general, participants will learn that it is possible and desirable to comply with CP related challenges among the students, if their work is based on updated knowledge about CP in order to identify and work with adequate pedagogical approaches, strategies and tools.
Chapter 1
General Knowledge about CP

Learning Outcomes

The participants will know the latest definition of the diagnosis “cerebral palsy” and will understand the condition as a brain lesion to which there is no definite cure. The participants will know the etiology of the diagnosis and they will know about the wide range of symptoms that are possible consequences of the brain damage.

Chapter Contents

Cerebral Palsy today

Today, cerebral palsy is regarded as a multifaceted disorder typified and marked by developmental disorders that have versatile affects within the enormous diversity and complexity of the brain. This implies that cerebral palsy must be described and defined as an ample complex condition characterized by great individual differences and bridging the overall range from motor to cognitive behaviour.

Despite of the fact that there is no definite cure for cerebral palsy, rehabilitation strategies, including training and learning programs, can often increase the capabilities of the individual child if provided in sufficient amount and within up-to-date best-practice. The main objective is to enhance the individual potential to live a full life by doing everything possible to surmount the impairments and realize new ways to compensate and thereby accomplish the tasks that comprise difficulties.

Rehabilitation strategies should be directed, if at all possible, at preserving and improving the developmental process through all its facets and stages at appropriate ages. Research demonstrates that directive techniques aimed at specific disabilities do not bring better results.

What is cerebral palsy?

By far, the greater numbers of the developmental malfunctions in the brain that lead to cerebral palsy occur before birth. A few characteristic types of brain damage establish the core contributory causes to a broad range of cerebral palsy cases.
These brain damages cause either the appearance of degeneration or crumbling of brain tissue, or some type of haemorrhages within the brain tissue, which result in varying degrees of damage of the nerve fibres.

These damages imply that the extremely complex communication materializing in the neural circuits is disturbed and damaged by disruption or regular destruction of the nerve fibres, thereby compromising the fragile interaction from neuron to neuron. Subsequently, injuries of this nature could have substantial influences on the fundamental function of the large-scale circuits in the brain.

Among the symptoms resulting from these types of brain damage are, most importantly, a reduced overall attention and capacity of sustaining attention. More specifically, people affected by these types of brain damage are lacking in capacity for completing a process, some degree of absent concentration and imbalance of tonus (tightening) in the muscles. Also, motor behaviour controlling balance and precision of single movements are affected. Studies on brain imaging indicate that the brain damages, preceding cerebral palsy, are often found in the deep-lying areas of the brain’s white matter around the brain nuclei where supporting handlings of decoding sense stimuli are concentrated.

These fundamental processes systematize the global task of organizing, controlling and managing all the sense stimuli that is computed in the brain. The brain is a multisensory processor in which inputs from different senses complement, modulate, and interact with each other, regardless of the specific senses involved in order to select, regulate, increase or inhibit, integrate memory and simulate motor actions etc.

**Suggested Readings**

Further material: www.cp-pack.eu / Knowledge about CP
Chapter 2

General Knowledge about the Brain and Neuroplasticity

Learning Outcomes

The trainees will achieve a generic understanding of how the brain works in circuits and how these are not static or rigid, but quite reversible and they will understand the consequences of this knowledge on how to address the symptoms of Cerebral Palsy.

Chapter Contents

The human brain contains approximately 120 billion neurons each assumed to be in contact with up to 10,000 other neurons within large-scale networks that span over several areas of the brain. The single synapses within the active circuits develop and work in interplay with other synapses to adjust the neural connectivity across the brain.

The whole nervous system, including the brain, continually undergoes structural and functional modifications adapting to changes in both inner and outer environment and to new information to be processed and stored.

The fundamental systemic mechanism of the brain is characterized by neuroplasticity, i.e. the capability of the neural circuits to change and remodel in accordance with learning and new experiences. The concrete functional shaping is generated by altering the number of active synapses and adapting the strength of the single synapses.

The circuits of the brain are not static or rigid but, quite the opposite; they are extremely adaptable, permanently changing to mirror the modifications that emerge in the individual neurons. The neurons, on their part, respond to changes in our body and in the outer world. Furthermore, the adjustments of brain circuits represent and echo that an individual, in one way or the other, is in continual action. Even in so called states of resting or daydreaming the brain is never idle – it is ready to remodel at any time. The fundamental property of the brain is plasticity, i.e. the ability to change in accordance with inner and outer demands. As individual beings we are persistently on the move.

Sometimes we are close to other beings (people or animals), other times we move away from them. In the world of hands-on we move to touch objects and then move
away again or, as we sense a taste, we are also bound to experience that the taste goes away. Being engaged in a conversation implies that it will come to an end. Sensory inputs from the body parallel different emotions. In fact, the full context in which the brain is situated is under constant changing either from pre reflective influence or from the stimuli of our actions. The circuits of the brain develop permanently in an appropriate way. So, in terms of biology, there is no off switch in the brain.

One pivotal aptitude of the brain is the feature of learning. It implies functional changes within the circuits, which has the effect of strengthening the synapses. A more powerful synapse is one that improves in firing and so facilitates the interaction of neurons. Training and learning are, in this respect, two sides of the same coin. Also the capacity of memory originates in this process. Memory is information kept within stable networks and is retrievable when synapses open up the network by being activated.

Suggested Readings

Further material: www.cp-pack.eu / Knowledge about CP
Chapter 3
Training and Learning Based on Neuroplasticity

Learning Outcomes
The participants will know which theoretical aspects must be taken into consideration, if any remaining and positive results from training shall be expected. On this basis, participants will learn about ideas and tools to implement training in many everyday activities at home and in school/institution.

Chapter Contents
Intensity and sufficiency Children with brain damage require multi-facetted training and learning strategies. The present economical resources do not allow offering sufficiently intensive and persistent motor and cognitive training. Therefore new technology must be taken into account in order to concentrate the intensity of the rehabilitation programs.

Learning and training is a process that, irrespective of the method of learning, is imparted through the body by means of the senses and motor function. At the core of this approach is the understanding that awareness, cognition and movement are really indivisible, and that the development or recovery of ability within any of these domains requires the integrated co-operation of the individuals with impairments and their brain in all of these aspects of rehabilitation. This signifies that isolated impairment in “movement” or “awareness” or related “cognition” is a human impossibility.

Motor function and muscular activity are entirely controlled by ‘feedback’ from our bodies and brains, and so, movement control is guided, very directly, by the cognitive resources that guide all of our behaviours. They will be weaker or stronger, enabled or disabled together. Neurological processes that control the flow of cognition and thought are not really different from those that control the flow of movement — and, in fact, are totally and utterly entangled.

Inducing the brain’s plasticity in order to drive beneficial changes requires a carefully laid out individual learning or training program with precise stimuli delivered in a proper sequence with accurate timing. To obtain this, the training program must be:

1. Intensive - and continuous over a sufficient period of time.
2. Repetitive - and progressively challenging.
3. Executed with total commitment - and paying close attention.
Sensory experiences apply a powerful influence on the function and future performance of neuronal circuits in the brain. Remodelling of synaptic connections is believed to be one mechanism by which neural circuits store information about the sensory world. Learning and daily sensory experience leave minute but permanent marks on neural connections and storing of lifelong memories is confined to such large stable connected networks.

**Learning**

The expansion of the neural networks is a transient occurrence that serves to expand the pool of neurons that respond to behaviourally relevant stimuli so that neural mechanisms can select the most efficient circuits to accomplish the task.

To be more precise, neural plasticity is used to recognize the minimum number of neurons that can accomplish any given task.

Learning results when individuals select the most efficient circuits and essentially relate these neural responses with the appropriate behavioural response.

The steps to follow in learning and training comprise the following:

1. Initial learning generates a population of new connections in the neural circuits
2. This population is then reduced to a small subset; and
3. Skilled performance is maintained by this small but stable subset of new connections

The conclusion is that the brain is plastic and dynamic and that it functions in large-scale complex networks – (circuitative). Furthermore, there appear to be no true difference between cognition and motor behaviour – they share the same subjacent systems (circuits). Obviously there are areas in the brain that may be “critical” for a particular behaviour, but the behaviour itself arises from combined actions of many areas.

Training and learning programs that motivate simultaneously body and thought are, therefore, well suited to improve ability in the child with cerebral palsy.

**Suggested Readings**

Further material: [www.cp-pack.eu](http://www.cp-pack.eu) / Knowledge about CP
Chapter 4

Food - the Importance and Effect Related to Neuroplasticity

Learning Outcomes

The participants will obtain increased awareness about dietary effects on the brain and practical advise about the implementation of a healthy diet.

Chapter Contents

Just as the muscles need protein to be able to gain from training, the brain needs a variety of important substances to be included in the diet (sometimes exclusively from the diet: vitamins, minerals, essential amino-acids and essential fatty acids, including omega-3 polyunsaturated fatty acids) to be able to develop and function optimally. For a long time, it was not fully accepted that food can have an influence on brain structure and function, including cognitive and intellectual performances. But most micronutrients (vitamins and trace-elements) as well as macronutrients (glucose, amino acids and fatty acids) have been directly evaluated in the setting of cerebral functioning.

So, while the brain is active – which means around the clock, all life through – it needs nourishment and energy.

The greater part of the nutrients that the brain uses are produced in the brain itself with the remaining deriving from other organs in the body. The necessary condition for the correct nutrients to be produced is the adequate access to precursors of these ingredients. There is only one source from where the precursor nutrients can enter the organism, and that is our diet.

“The belly rules the mind”. This is certainly true when it comes to the brain and the nutrients needed to develop the neural networks and increase the efficacy of the synapses. Fortunately, it is quite easy to obtain the right ingredients as most of them are found in what could be characterized as “ordinary” food.

Two main aspects exist in relation to diet and cerebral palsy:

1. Impact from the congenital brain damage on intake and metabolism: A brain damage often has an effect on the metabolic control resulting in lack of intake from the food being digested.

2. Optimal learning and plasticity depends on special precursors in the diet: This is true for all brains.
The relative quantity of specific nutrients might affect cognitive processes and emotions. Dietary factors can have a direct influence on neuronal function and synaptic plasticity and research have revealed some of the vital mechanisms that are responsible for the impact of diet on brain health and mental function.

It has been demonstrated that the rates at which brain cells produce a number of the most important compounds, for example the neurotransmitters serotonin, dopamine, and acetylcholine - depend on brain concentrations of their precursors.

Infants with significant prenatal brain damage have increased nutritional requirements in the first postnatal year so these children require a greater-than-average energy and protein intake to achieve appropriate growth rates or to catch-up growth in the first year.

Just like a muscle needs protein to be able to gain from training, the brain needs the right precursors of substances to be able to learn and develop. The three fundamental nourishment needs in relation to the brain are:

1. Building materials,
2. Control of mood, motivation and learning capacity,

Questions for reflection

- How often and what type of food does the child eat during the day?
- Does the child eat breakfast (and if yes, what kind of breakfast)?
- Does the child eat a great variety of food, or is he/she very fussy about what he/she eats?
- Does the child seem tired or moody throughout the day?
- How well does the child’s glucose-regulation work. Could it be monitored for a few days?
- How many of the micro- and macronutrients does the child eat on a regular basis?
- What kind of fats and proteins are the most prevalent in the food of the child?
- Is it relevant to make any changes about the “type and timing” of the meals?
- Do we ever notice any difference in mood and behaviour of the child that could relate to intake or avoidance of a particular food-item?

Suggested Readings

Further material: www.cp-pack.eu / Knowledge about CP
Food, the importance and effect related to neuroplasticity (by Kirsten Caesar) - www.cp-pack.eu / Knowledge about CP
Figure showing the core ingredients regarding the brain (by Peder Esben Bilde) - www.cp-pack.eu / Knowledge about CP
Chapter 5

Behavioural and Cognitive Difficulties and Compensation Strategies in Relation to CP

Learning Outcomes

The trainees will gain a better understanding of how sensory input is processed. This session will cover a brief walk through the seven senses with emphasis on the proprioceptive sense, the vestibular sense and the visual sense, and how it affects a child with CP when sensory integration does not work properly. In addition, participants will gain insight of some of the compensatory strategies that can be used and integrated into daily life.

Chapter Contents

Sensory Integration is not an either/or matter. We don’t have perfect sensory integration or none at all. None of us organizes sensations perfectly. If the brain does a poor job of integrating sensations, this will interfere with many aspects of life. There will be more difficulties and less success and satisfaction in life. Sensory Integration takes place unconsciously, by organizing the impression from all 7 sensory systems (balance and movement, muscle and joint, sight, feel, hear, smell and taste) and giving meaning to what we experience by sorting all the information we receive and selecting what to focus on. This makes it possible for us to act or respond appropriately to the situation we are in and that is the foundation on which learning and social behavior rests in.

Many children with CP have difficulties in terms of developmental disabilities due to insufficient processing of sensory information. These difficulties can sometimes lead to major limitations in their learning and mastery of activity in daily life. In this session, the main focus will be on sensory function, the sense of touch and the proprioceptive and vestibular sense.

Children who are hypersensitive (overly sensitive) in the tactile area, do not like clothes that are tight, have marks or seams. Often they have a few favorite things that they want to wear all the time - jogging pants and soft shirts. They hate and fear getting their face washed, getting dirty hands, and getting their nails clipped, etc. They do not like to touch greasy sticky stuff like clay, finger paints, etc.
They can get very upset over an unexpected touch and it can cause trouble distinguishing between threatening and non-threatening touch.

Eating Problems can also be caused by tactile hypersensitivity. Some children with CP do not like to get food with a certain consistency in the mouth. Tactile sensitive children have often difficulty in moving from milk to solid food, and they often get food stuck in the throat. Problems with sensory processing of the tactile area can also cause speech problems - the child may have problems shaping the sounds right because of difficulties interpreting and processing sensory impressions from the mouth and being able to feel the speech organ positions.

The proprioceptive sense, in children with CP, can be influenced by disturbances in the sensory process because the child gathers atypical sensory experiences because of motor disorders. It may be disturbances in the sensory system, leading to reduced sensory information from muscles and joints, causing difficulties in perceiving, processing and interpreting sensory input, focusing on relevant sensory input, placing them in a relevant context and being able to ignore irrelevant sensory input.

Children with proprioceptive dysfunction spend a lot of energy to concentrate on each movement, because although the brain may know what to do, they can’t figure out how to make their body do it. They are more dependent on vision than others, knowing how much pressure is needed to complete a task for example hold a cup of water, hold and write with a pencil, turn the page of a book, etc. The ability to hold and maintain one’s postural muscles and responses, giving you a sense of security during movement is very often difficult for children with CP. For them, it can be difficult to stand still for a long time; they may have a great need to support their head, hold a hand or both under it - or even put your head on the table to read and write. These children get fatigued faster than other children and may need many breaks during the day. Children who are unable to move and use their body effectively like others can, thereby, become frustrated, give up, and lose self-confidence. The vestibular sense provides information using the inner ear about balance and movement, and where our body “is” in space. It is the vestibular sense that can tell us whether we are sitting down or standing up, falling, and so on. The vestibular sense detects the body’s ability to keep itself up against gravity, the body’s equilibrium, which means that we can keep the body upright when we are walking and stabilize the eye, while the head is in motion, which enables us to maintain a stable visual field, so the things we see do not flicker when we move.

Because of intolerance to moving, the child may feel discomfort during fast movements, which, for example, can result in motion sickness.

Next to breathing, so is balancing security our main focus: to maintain attention to read a magazine or listen carefully to a radio broadcast, requires that we have a postural (balance) security. The same requirement applies for us when we are going to perform fine motor activities such as eating or writing. First, we secure ourselves
from falling, or restore balance to feel safe and physically comfortable. Only then we are able to read, listen or sew.

Visual perception is the process which ensures that we are able to perceive and interpret visual impressions. Many children with CP have visual perception difficulties. The child will be slow or unable to perform tasks, especially when the child is going to use an object or performing tasks that require cooperation with both hands. It may be difficult to brush one’s hair while looking in the mirror or put on an elastic in the hair, put on a necklace or to take toothpaste on the toothbrush. Those things can be a big challenge. Clothes and buttons require also good visual perception. Coloring, puzzles, developing reading and writing skills can also be affected by poor visual skills. Just as it can be difficult to find your way around in the neighborhood or find things in a drawer. It can also be a challenge to learn to use computer keyboards and telephone. Play and leisure activities may also be limited by visual perception difficulties.

Arousal can be explained as a feature of the nervous system that describes how “awake” (alert) a person is in order to concentrate and stay focused on a task, that is appropriate for optimal learning.

Many children with CP can have difficulties obtaining, maintaining and changing arousal appropriate to the activity or situation that they are in. If you imagine that your brain and body is like a car engine, sometimes it runs too fast (high speed) and sometimes it runs too slow (low gear) and sometimes it runs just right. Through this engine analogy we can teach both children and adults with CP strategies to self regulate “their engine” so that parents, teachers and educators can give children with CP optimum opportunity for learning.

Suggested Readings

Further material: www.cp-pack.eu / Knowledge about CP
Chapter 6

Most Common Cognitive and Behavioural Problems and Strategies for Compensation Related to CP

Learning Outcomes

Participants will acquire up-to-date knowledge about common cognitive problems associated with CP drawn from recent, relevant empirical studies. Participants will become aware of how learning problems arise from individual cognitive problems but emerge in particular social settings and learning environments, where they are shaped by the organisation of the learning activities and the presence or absence of the right support of the child.

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This session will cover the relations between the brain lesions associated with CP, the most common cognitive problems and how they are expressed as learning problems that need to be addressed by teachers and parents in cooperation.

The cognitive problems associated with CP can be separated into non-specific and specific cognitive problems. The non-specific type of cognitive problems covers fatigue, varied performance level and slower information processing. Non-specific cognitive problems can be manifested in all types of activities. Even though they may be manifest in a daily basis, they are among the most invisible consequences of CP and are often misunderstood as laziness, reluctance or stupidity of the child.

In addition, CP is associated with a group of specific cognitive problems. The particular constellation and severity of cognitive problems vary a lot between children with CP. Specific cognitive problems cover visuo-perceptual and visuo-constructive problems, problems with attention, memory and executive problems and communication problems. In this session, special attention will be given to specific cognitive problems in attention and executive functions.

Impairments in attention and executive functions give rise to problems in many areas of learning, but often they are more pronounced in particular situations and school subjects than others. Attention is a compound function that covers both the ability to direct and shift attentional focus. Other parts of attention are the ability to control and maintain attention and to work with material within the attentional system. The last two are also considered part of the executive system. The executive
system is another compound function that covers many different sub-elements: planning, monitoring, shifting, working memory, initiative, inhibition, and emotional regulation. They are subserved by different neural networks in the frontal and subcortical part of the brain and because they draw on information from many parts of the brain, problems in executive functions are common in children with CP. Often, they are most pronounced in behavioural problems: impulsive or interruptive actions, uncontrolled emotional reactions, chaotic behaviour, lack of flexibility, lack of ability to organize school work and many more. Executive functions mature late and must always be evaluated in relation to the age of the child. Problems in attention and executive functions often cause problems in both learning and social participation.

It is important to know about the cognitive impairments associated with CP, because the knowledge may help to interpret the child’s way of acting. However, the cognitive impairments are only one side of the learning problem. The other side is how the learning of the child is organized through the teacher’s demands and structural support. Cognition can be supported or constrained by both brain lesions and the learning environment. The learning problems experienced by many children with CP arise from a mismatch between the child (with brain lesion and cognitive impairments) and his or hers learning environment (without the right support). Barriers for learning are not solely in the child, but exist in the relation between the child and the learning environment. If supported rightly, the cognitive activities of the child have the potential to give feedback to the neural system and change and develop it. However, the development of both cognitive functions and neural processes are dependent on the proper support of the child’s participation in learning activities.

The typical learning problems of children with CP emerge and evolve in relation to the pedagogical and didactic structure and demands throughout the child’s school trajectory. At times, the learning goals will be similar to same-aged peers without CP, at other times the learning goals need to be adapted to the current developmental level of the child. Relevant learning goals can be reached by roundabout ways (e.g. computers for writing) or scaffolding (e.g. the teacher structures the work process for the child that cannot identify the steps on its own).

In primary school, it will often be necessary to evaluate the adequacy of the teaching and the teaching material in relation to the cognitive challenges of the particular pupil with CP. The child with CP might work towards the same goals as his or her peers, but the teacher might need to adapt the child’s learning activity according to the child’s particular impairments. For example, due to motor, visuo-perceptive or visuo-constructive impairments, handwriting is often more strenuous for children with CP, over and above the challenges experienced by all new writers. If the goal of the activity is to practice calculation rather than the writing of numbers, then
child might solve the exercises orally, on a computer or by getting someone else to write the solutions. Another typical challenge can be found in children with executive dysfunctions who need explicit instructions and training in how to get ready to learn. If the child with CP has attentional dysfunctions, support of the child will include a reduction of distracting stimuli.

In middle school, new subjects and an expanding curriculum increase the challenges experienced by children with CP. A slow writer or slow reader might be supported by the introduction of new aid’s that enable the child to focus its effort on the content of the material. The slow information processing might become more salient with rising demands and the teacher may need to adapt the learning activities of the child accordingly, either by granting extra time or by reducing the content to be covered by the child, e.g. amount of reading or number of exercises.

Demands on the child’s executive functions usually increase through middle and secondary school, as the child is required to work more independently and with more complex exercises. The executive dysfunctions of many children with CP become increasingly salient and require support and/or explicit teaching of how to plan and work with larger assignments.

**Suggested Readings**

Further material: www.cp-pack.eu / Knowledge about CP
Chapter 7
Pain/Pain Management – How to Deal and Compensate

Learning Outcomes

The participants will increase their knowledge about pain; its complex, psychological nature and how different elements influence the experience of pain. This knowledge will make it easier to understand the specific child’s experience and the way he or she handles the pain.

The participants will know complementary treatments and to influence the way the child will cope with pain and, by that, help the child in decreasing the feeling of pain.

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Because of inappropriate weight on joints, inappropriate ways of moving and working with the muscles, involuntary movements, uneven growth of the spine, etc., some children with CP may develop pain which can be acute, but can also develop into chronic pain.

This session will present a short description of the difference between acute and chronic pain, the subjective nature of the pain as well as how it will be able to influence the child’s sleep, appetite, social life, physical activities, school life and other everyday activities. Also a pain scale and a pain figure will be introduced as tools that can help when talking to a child about pain.

Most people know the feeling of an acute pain, i.e. the pain one feels when visiting the dentist, having a blood test or falling and hurting oneself. But for some people – and among these are some children with CP – it becomes a condition growing up and living with chronic pains, which means pain lasting more than three to six months.

These feelings of pain can become very serious, resulting in an affection on the ability to sleep through the night, on concentrating on other things during a day, and on the motor and social life and development, as the pain may prevent the child from physical activities and playing with peers as well as being able to fully concentrate on what is going on in the classroom, with the consequence of reduced learning ability. This means that the child is in risk of feeling different and left out as well as developing the feeling that some experiences will be lost as a direct result of the pains. The feeling of pain is subjective. It is very different from person to person
to which extent the perceived pain is registered. Some people have a lower pain threshold than others. Therefore it is not possible to perform a direct measurement of a pain, the only way to get a knowledge about how a person experiences his or her pain, is to interview them about this, and using a pain scale or figures where the child gets the opportunity to mark the pain. In these cases it is very important to understand how the age of the child and the mental development influences the child’s ability of thinking and experiencing pain.

Every child is unique and has its own personality, its own resources and its own vulnerabilities as well as its own handling strategies – exactly as the expression of the cerebral palsy condition appears very differently from child to child.

The most important factors that may increase the child’s feeling of pain will be explained. Among these are fear, depression, loss of control, focus on the pain. Also the way the surroundings react and handle the child’s pain influences the way the child experiences pain. In order to meet the needs of the child and to support it in the best possible way, it is important to investigate how the pain influences the individual child. In which situations does the individual child feel that the pain is influencing in a negative way and how does people around the child respond to this? In other words, both the surroundings and the psychology of the child have an impact on the way the child experiences pain and is able to cope with the feeling of pain. This means that there are some psychological factors that will affect the feeling of pain both in a positive and a negative direction.

Some aspects with an impact on how intense the feeling of pain is for the individual child are the ability of coping and the way the child acts in relation to the pain. It is known that a lack of understanding of the causes of the pain, and/or fear or insecurity of the child or the parents related to the pain, can increase the feeling of pain, like when feeling helpless and with negative thoughts. Opposite to that it is known that distracting strategies can cause a considerable pain-killing effect (i.e. reading a story, watching television, talking to a pet animal or drawing), as well as being comforted and getting the feeling that the parents are understanding and supportive. The focus in this session will be on which exact factors will be able to decrease the feeling of pain (i.e. distraction) and on complementary treatments that will be mentioned (i.e. visualization, hypnotherapy, cognitive therapy, physiotherapy, white noise and acupuncture).

Depending on the age of the child and their cognitive abilities, it may be relevant to present a brief introduction to the parents about visualization and how the child can be supported by this technique – either by providing a CD containing pain visualization for children, or by visiting a psychologist who can produce a visualization CD for the specific child.
It is of great importance that the child learns to recognize the pain – learn how to listen to the signals from the body and take care of him- or herself. The child must know the consequences of overloading the body and how this may cause even more pain, and learn how to feel his or her needs and limits and become able to express what is acceptable and what is not.

**Suggested Readings**

Pain/pain management

By Charlotte Jensen: www.cp-pack.eu / Knowledge about CP

Further Material: www.cp-pack.eu / Knowledge about CP
Chapter 8

Aspects of Developing into Adulthood, What is Special Concerning CP and other Disabilities When Growing into Adulthood and Getting Older

Learning Outcomes

The participants will know the importance of acceptance of the disability in order to be able to live an adult life as an active member of society.

The participants will know the threats to the mind and the physical and biological body of growing up with a physical disability.

The participants will learn – inspired from a discussion in the group – how these threats can be met before they take over.

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To grow up and into a life of adulthood with a disability and at the same time to retain an individual personality intact is quite a challenge. It involves different steps of awareness and acknowledgement, which all are essential and necessary, to move ahead in the process of learning and accepting to live with cerebral palsy.

One of the most significant steps is to allow for mourning. Both the individual with disabilities, the family as such and in particular the parents are in a state characterized by grief when it becomes a fact that the diagnosis in question is cerebral palsy. Mourning is the first step to take, to make life with cerebral palsy as meaningful and comfortable as possible. This process is essential for both parents and child to prepare for the next step aiming at acceptance and recognition of the disability. If this process of self-development is neglected many will be induced to block out the fact of having a disability, which could result in another situation where motivation and focus are so narrowed down to the attempt of being normal that demands and expectations on the child with disabilities become unrealistically high. This often causes numerous daily defeats and frustrations. According to the research it is of vital importance for both parents and the child with disabilities to recognize the limitations that exist because of the impairment and this will only be possible if the process of selfdevelopment receives necessary attention.
By recognizing and accepting the impairment – its strong sides and also the limitations – it will become possible to live with cerebral palsy and to participate within social interaction and be an active member of the local community.

Medical Conditions and Ageing

Before the Second World War, only a small number of children with cerebral palsy survived to adulthood and an even smaller number achieved to make it into old age. At that time, the standard showed an evident gap between life expectancy for people with cerebral palsy compared to people without disabilities. Nowadays, primarily due to improvements in medical care, development of rehabilitation, and assistive technologies, the majority of children with cerebral palsy live into their adult years and the gap in life expectancy is more or less eliminated. Living this long with a disability often involves an increase in medical and functional problems – some of them beginning at a relatively early age – including the following:

Premature Aging

The majority of individuals with cerebral palsy will experience some form of premature aging by the time they reach their 40s because of the extra stress and strain from the condition. The developmental delays seen as a consequence of cerebral palsy keep some organ systems from reaching their full capacity. Organ systems such as the cardiovascular system (the heart, veins, and arteries) and pulmonary system (lungs) therefore have to work harder and they age prematurely.

Research show that the premature aging factor in people with cerebral palsy could range from 1.5 – 5 compared to normal aging.

Depression

The rate of depression is approximately 25 % higher in people with cerebral palsy. There seems to be no obvious relation to the severity of the disability, but rather in how well people with cerebral palsy cope with his or her disability. The extent of emotional support, how good they are at coping with frustration and stress, and whether or not they have an optimistic outlook about the future, all have a significant impact on level of happiness and exclusion of depression.

Pain

Living with pain often goes unrecognized by professional healthcare people because many individuals with cerebral palsy may have experienced some degree of pain right from birth and therefore do not comprehend the condition as pain. Others may
not be able to describe the extent or location of the feeling of pain. In cases where pain is managed properly, the condition often averts becoming chronic.

**Pain, Fatigue and Weakness (PFW)**

Many adults with cerebral palsy at one time or the other experience what is known as PFW, a combination of pain, fatigue, and weakness due to overuse or misuse of the body because of muscle abnormalities, bone deformities, and arthritis. Fatigue by itself is often a challenge, as individuals with cerebral palsy use three to five times the amount of energy that people without disabilities use during their daily life to move about.

**Additional Medical Conditions**

Adults with cerebral palsy have higher than normal prevalence of secondary medical conditions, such as hypertension, incontinence, bladder complications and dysphagia. Scoliosis (curvature of the spine) is seen in some cases to progress after puberty, when bones have matured. Also luxation of the hip appears in up to 12-15% of the children. People with cerebral palsy have an overall higher incidence of bone fractures.

Adults with cerebral palsy should attend regular visits to their general practitioner to make a point of ongoing evaluation of their medical status. It is important to have physical complaints analysed to make sure they are not due to an underlying condition. For example, adults with cerebral palsy are likely to experience PFW, but PFW also could result from an undiagnosed medical condition that might be treated.

Today it is a fact that increasingly more individuals with cerebral palsy than before outlive their families and caregivers. Consequently, the issue of long-term care and support should be taken into account and planned for in due time.

**Suggested Readings**

Further material: www.cp-pack.eu / Knowledge about CP
Legal and Financial Matters - (LFM)

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This training module was produced in the scope of CP-PACK project and in accordance with the Need Analysis Report derived from the results of the focus group interviews and questionnaires collected among parents and teachers of children with cerebral palsy. This is primarily a theoretical training module, which is based on the international legal instruments regulating rights of people with disabilities and on the main legal framework available in partners’ countries. This training module should be used as a starting point on how to deal and understand applied law. This module is not and cannot be understood as a legal counselling.
Chapter 1

Legal status of a person with CP at international and EU level

Learning Outcomes

Trainees will be expected to;

1. understand to what extent the international and EU legal framework can be implemented in their countries
2. understand what can be done to have an improved and more appropriate national legal system.

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Countries that join in the Convention engage themselves to develop and carry out policies; laws and administrative measures for securing the rights recognized in the Convention and abolish laws, regulations, customs and practices that constitute discrimination.

As a change of perceptions, it is essential to improve the situation of persons with disabilities, and ratifying countries are supposed to combat stereotypes and prejudices and to promote awareness of the capabilities of persons with disabilities.

Countries are to guarantee that persons with disabilities enjoy their inherent right to life on an equal basis with others, ensure the equal rights and advancement of women and girls with disabilities and protect children with disabilities.

Children with disabilities shall have equal rights, shall not be separated from their parents against their will, except when the authorities determine that this is in the child’s best interests, and in no case shall be separated from their parents on the basis of a disability of either the child or the parents.

Countries are to recognize that all persons are equal before the law, to prohibit discrimination on the basis of disability and guarantee equal legal protection.
Countries are to ensure the equal right to own and inherit property, to control financial affairs and to have equal access to bank loans, credit and mortgages. They are to ensure access to justice on an equal basis with others, and make sure that persons with disabilities enjoy the right to liberty and security and are not deprived of their liberty unlawfully or arbitrarily.

Countries must protect the physical and mental integrity of persons with disabilities, just as for everyone else, guarantee freedom from torture and from cruel, inhuman or degrading treatment or punishment, and prohibit medical or scientific experiments without the consent of the person concerned.

Laws and administrative measures must guarantee freedom from exploitation, violence and abuse. In case of abuse, States shall promote the recovery, rehabilitation and reintegration of the victim and investigate the abuse.

Persons with disabilities are not to be subjected to arbitrary or illegal interference with their privacy, family, home, correspondence or communication. The privacy of their personal, health and rehabilitation information is to be protected like that of others.

On the fundamental issue of accessibility, the Convention requires countries to identify and eliminate obstacles and barriers and ensure that persons with disabilities can access their environment, transportation, public facilities and services, and information and communications technologies.

Persons with disabilities must be able to live independently, to be included in the community, to choose where and with whom to live and to have access to in-home, residential and community support services. Personal mobility and independence are to be fostered by facilitating affordable personal mobility, training in mobility skills and access to mobility aids, devices, assistive technologies and live assistance.

Countries recognize the right to an adequate standard of living and social protection; this includes public housing, services and assistance for disability-related needs, as well as assistance with disability-related expenses in case of poverty.

Countries are to promote access to information by providing information intended for the general public in accessible formats and technologies, by facilitating the use of Braille, sign language and other forms of communication and by encouraging the media and Internet providers to make on-line information available in accessible formats.

Discrimination relating to marriage, family and personal relations shall be eliminated. Persons with disabilities shall have the equal opportunity to experience parenthood, to marry and to found a family, to decide on the number and spacing of children, to have access to reproductive and family planning education and means, and to enjoy
equal rights and responsibilities regarding guardianship, wardship, trusteeship and adoption of children.

States are to ensure equal access to primary and secondary education, vocational training, adult education and lifelong learning. Education is to employ the appropriate materials, techniques and forms of communication. Pupils with support needs are to receive support measures, and pupils who are blind, deaf and deaf-blind are to receive their education in the most appropriate modes of communication from teachers who are fluent in sign language and Braille. Education of persons with disabilities must foster their participation in society, their sense of dignity and self-worth and the development of their personality, abilities and creativity.

Persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability. They are to receive the same range, quality and standard of free or affordable health services as provided to other persons, receive those health services needed because of their disabilities, and not to be discriminated against in the provision of health insurance.

To enable persons with disabilities to attain maximum independence and ability, countries are to provide comprehensive habilitation and rehabilitation services in the areas of health, employment and education.

Persons with disabilities have equal rights to work and to gain a living. Countries are to prohibit discrimination in job-related matters, promote self-employment, entrepreneurship and starting one’s own business, employ persons with disabilities in the public sector, promote their employment in the private sector, and ensure that they are provided with reasonable accommodation at work.

Countries are to ensure equal participation in political and public life, including the right to vote, to stand for elections and to hold office.

Countries are to promote participation in cultural life, recreation, leisure and sport by ensuring provision of television programmes, films, theatre and cultural material in accessible formats, by making theatres, museums, cinemas and libraries accessible, and by guaranteeing that persons with disabilities have the opportunity to develop and utilize their creative potential not only for their own benefit, but also for the enrichment of society. Countries are to ensure their participation in mainstream and disability-specific sports.

Countries are to provide development assistance in efforts of developing countries to put into practice the Convention.

To ensure implementation and monitoring of the Convention, countries are to designate a focal point in the government and create a national mechanism to promote and monitor implementation.
A Committee on the Rights of Persons with Disabilities, made up of independent experts, will receive periodic reports from States parties on progress made in implementing the Convention.

An 18-article Optional Protocol on Communications allows individuals and groups to petition that Committee once all national recourse procedures have been exhausted. It is to be underlined that petition right can be used only if the national authority in charge is not providing or granting the right according the Convention’s provisions and the interested person has followed all the national procedures in order to achieve these rights. The Committee examines the complaint and the observations of the State, and on this basis formulates its views and recommendations, if any, forwards them to the State, and makes them public.

The following distinction is made by the World Health Organization between impairment, disability and handicap:

**Impairment:** Any loss or abnormality of psychological, physiological, or anatomical structure or function.

**Disability:** Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

**Handicap:** A disadvantage for a given individual, resulting from an impairment or disability, that, limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.

The following definitions are developed from that perspective. The relevant terms of action proposed in the World Programme are defined as prevention, rehabilitation and equalization of opportunities.

Prevention means measures aimed at preventing the onset of mental, physical and sensory impairments (primary prevention) or at preventing impairment, when it has occurred, from having negative physical, psychological and social consequences.

Rehabilitation means a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment.

Equalization of opportunities means the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.
Legal status of a person with CP at national level

In different countries, there are different approaches to the legal status of persons with Cerebral Palsy. These approaches vary from a specific and special legal framework for individuals with CP to a more general one, were individuals with CP are included in the more general category of persons with disabilities (in certain countries, the term used is persons with handicaps). The situation of affected children is, consequently, differentiated. In some countries, children with CP are considered to be a distinct category within the general category of children with disabilities. In other countries, children with CP have no special statute comparing with other children with disabilities.

Despite these differences, all EU countries recognise and grant several rights to all persons with disabilities, including children. Depending on the national legislation and administrative systems, these rights are grouped taking into account the different levels of social needs of persons with disabilities. In order to facilitate the international approach on the topic of legal status of a person with CP, a screening of the main rights was made and the rights were grouped under two categories. One category comprises those rights that are granted ex-oficio. These kinds of rights are recognised by simply proving of the status of the person, without any other administrative formality. Another category of rights comprises rights granted under the condition of fulfilling certain administrative procedures.

Children with a disability, including children with cerebral palsy (CP), benefit of the following rights:

- Protection of their health, prevention, treatment and recovery, education and professional training,
- Social support, meaning social services and social benefits,
- Home, arrangement of personal life environment, transportation, access to the psychical, informational and communication environment,
- Opportunities for leisure, access to sport, culture and tourism,
- Legal support,
- Financial benefits,
- Evaluation and re-evaluation at home for persons who cannot be moved, made by the evaluation commission within a certain period.

A little law practice!

Identify three topics of interest for you in the international convention. Motivate your choice. Now, describe to what extent those international provisions are included in the national law.
Name at least 5 differences between what is written in the international legal instrument and the actual implementation in practice. Try to explain why these can happen.

How can an individual legally ask to have his/her international recognised rights acknowledged in actual practice?

**Suggested Readings**

# Chapter 2

**Administrative support for disabled and CP persons**

## Learning Outcomes

Trainees will be expected to;

1. understand how the public administrations work
2. understand how the responsibilities of observing the rights of people with disabilities are shared between different entities

## Chapter Contents

Observance of rights of persons’ with handicaps lies usually on local administrative authorities. Complementary or subsidiary role on observing these rights lies on central administrative authorities, civil society and families or legal representatives of persons with handicaps. In this respect is to be noted that a better implementation of legal framework for persons with disabilities can be achieved through cooperation between local administrative authorities and NGO’s.

Depending on the specificity of administrative systems in each country, different public or private entities in charge with administrative support for children with CP can be identified. In some countries, there are in place administrative procedures for registering persons with CP. In other countries, persons with CP are not registered on the basis of their specific diagnosis, but on the basis of the gravity of the disability.

Since CP has a variety of legal approaches, this module will use mainly the general term of disability.

There are several rights of persons with disabilities and several obligations of institutions and organisations, which are considered special. When these rights are breached and obligations are not fulfilled, there are established financial penalties against the irrespective institutions or organisations. The designated authority enforces the penalties. Interested persons must announce the rights breaches and the non-fulfilment of obligations.

When a right is granted upon an individual request, non-granting of the right or the delay in granting can be subject for a case in front of the court of justice. Usually there are ex-oficio lawyers able to support the persons to open the case and the opening of case and legal support are free of charge.

The above mentioned rights and obligations are:

a. Free and equal access of persons with disabilities to any form of education,
b. The right of persons with disabilities, within educational process to:
   - Supportive educational services,
   - Technical equipment adapted to the disability,
   - School manual and courses accessible to pupils and students with visual impairments,
   - Use of assistive equipment and software during the examinations.

c. Once per year, a free of charge place in recreational camps for children with disabilities together with their personal supporting assistants.

d. The obligations of public authorities in relation with persons with disabilities access to education providers to:
   - Promote and grant access to education and professional training of the persons with disabilities,
   - Assure home education for persons with disabilities which can not be moved during the compulsory education and education trough the involvement of supporting/travelling teachers,
   - Assure access to continuous education according the needs of persons with disabilities,
   - Support cooperation between main or special education and families or community,
   - Support the professional training of teachers from regular education in order to allow them to adapt the educational practices for pupils with disabilities,
   - Assure the sport practice to any person with disabilities and the training of teachers for specific medical and technical practices,
   - Assure educational support services for persons with disabilities and their families trough special psycho-pedagogy specialists,
   - Assure access in educational organisations.

e. To grant priority to the persons with disabilities to rent an apartment at lower buildings’ flats in public owned buildings

f. Persons with severe disabilities have the right to a supplementary room in the rented apartments and to the lowest level of renting price. The same right is recognised to the family or legal representative of a persons with severe disabilities during the care period,

g. Child with disabilities and accompanying person benefit of free entrance to shows, museums, performances,

h. In order to assure public transportation of persons with disabilities, the local public authorities are obliged to buy adapted public transportation vehicles or to adapt the existing vehicles and to create transportation programmes for persons with disabilities
i. Persons with severe and marked disabilities benefits of free urban public transportation,

j. Persons with severe and marked disabilities benefits of a number of free long-distance travels on public transportation,

k. The relevant public authorities are obliged to take the required measures in order to facilitate the transition of young persons with disabilities to the system of protection for adults,

l. Obligation to grant the right of social support in the form of social services upon request or ex officio,

m. Obligation to admit a person with disabilities into a residential centre when home care or other types of community services are not possible,

n. The organisations are obliged to adapt buildings, to arrange and allow access to parking places on the benefit of persons with disabilities,

o. Obligation of publishing houses to make available digital patterns used to print books and magazines in order to be transformed in a format accessible to persons with visual impairment,

p. Obligation of public libraries to established sections with books for persons with visual or reading impairment,

q. Obligation of phone companies and bank services operators to make available services and information services to the persons with disabilities,

r. Hotel owners obligation to adapt at least one room for persons with disabilities, to mark with tactile signs the entrance and reception and to mount elevators with tactile signs

s. Public and private authorities and organisations obligations to make available for their public relations interpreters for persons with hearing impairment and to make available other information services to persons with disabilities. These measures apply to internet available services as well

t. Employers with more than a certain numbers of employees are obliged to employ at least a percentage of their staff from persons with disabilities or to pay to public budget a special tax

u. The protected units have the right of exemption on payment of certain taxes.

Administrative provisions on the benefit of education and therapy of children with disabilities/CP

Each European country has created different systems to support education and therapy of children with disabilities/CP. Depending on the general administrative and legal framework, these supportive systems are public, private or a combination of the other two.
The most common approach in each country is the establishment of a public body to deal with children with disabilities/CP. Depending on the local conditions, there are kindergarten, schools or other facilities. The facilities can be integrative, were children with CP are hosted together with children without disabilities, half-integrative, were children with CP are educated and treated together with other children with disabilities or specialised facilities, dedicated only to children with CP.

On the other hand, in most of the countries, there are specialised facilities that can provide specialised, professional therapy for CP and other, similar disabilities and impairments.

Since CP is not a very common disability, it is possible to find that a specialised education or therapy facility is not available in the proximity of the child and his/her family.

Teachers and therapists need to know that, according the international and EU treaties and conventions, they are entitled to ask and receive with priority different kind of support from public authorities. For instance, the public authorities must introduce in their budgets the required amounts to support the development and improvement of activities of schools, therapy centres and of other facilities designated to support children with disabilities/CP.

A little law’s practice!

Using your common knowledge, name the authorities or organisations in charge with adaptation of the homes of people with disability.

Verify your opinion using the written law.

Motivate each of the following assumptions:

- The family have the main legal obligation on protecting the rights of the family members with disabilities.
- The public authority is obliged only to provide advices and some financial support.

Suggested Readings

Guidance available on public authorities websites, on private, specialised, organisations or on international organisations websites (UNESCO, UNICEF, UN)
Chapter 3

Logistic support for persons with disabilities/CP

Learning Outcomes

Trainees will be expected to;
1. better understand the differences between different types of psychological support
2. be able to avoid confusion between various types of support

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Since a person with CP is a person with disabilities, the general right of persons with disabilities apply to them as well. The logistic support might cover free access to various services, reduced prices to different services, accessibility in premises and buildings, access to free or reduced prices supportive devices and techniques, modified supportive services, materials and techniques and so on. Some of these rights are granted upon a individual request and other are assumed to be granted ex officio by different organisations.

It is to be noticed that in many cases the logistic support for persons with disabilities is recognised as a general right. In this respect, an individual is not entitled to ask individually for these rights, which are incumbent to public or private organisations. For instance, the right of access and the associate support can be granted by the meaning of marked tracks on the access-ways, accessible buses for wheelchairs etc.

Generally, the support might cover:

a. Right to have a personal accompanying assistant
b. Free medical devices, free medical treatment and medicines
c. Free ticket to SPA treatment for the person with disabilities and his/her personal accompanying assistant
d. Free accommodation and meals services in hospitals, SPA facilities and other similar services
e. Parking-free permit for persons with disabilities
f. Extra-room in public-owned buildings in case of rented home
g. Access to a public supporting centre for children with disabilities without a family or other supportive persons
h. Right to have a specialised interpret during the legal procedures in order to facilitate communication
i. Access to therapy and supportive public facilities.
Logistic measures to be taken by schools on the benefit of children with disabilities/CP

Schools, therapy centres and other facilities designated for children with disabilities/CP need to know that public authorities must provide them with several types of supportive devices or works.

For instance, the public authorities have to support the specialised organisations, public or private, to build ramps, install elevators or escalators. Also, the public authorities need to provide specialised organisations with assistive technologies and devices as:

- Books, games, educational materials
- Wheelchairs, neck, backbone, leg, arms supporting devices, adapted chairs and tables

It is important to know that certain types of support for schools can be provided using indirect manners. In this respect, the research and development for new or improved assistive devices are available usually to universities and research institution. In order to reach such support, schools needs to ask such research entities to develop common projects to be funded.

Also, in many countries, the responsibilities to support schools and therapy centres are shared by different public bodies. For instance, a ministry or other national-level authority might have in their budget the required amount of money to be used for supportive and assistive technologies and a different public body to cover the expenses to modify and adapt buildings.

Nevertheless, all teachers, therapists and other staff working with children with disabilities/CP are entitled to ask to participate in various trainings in order to develop their competencies. In many countries, the training systems for teachers and therapists do not cover adequately the training needs of teachers and therapists. In order to overcome this situation, teachers and therapists need to know that there are available several funding opportunities to participate to international training events (conferences, seminars etc.).

On the other hand, schools are able to cooperate with NGOs and other private organisations. In many cases, this cooperation can have a shape of “hosting” organisation, were a school can allow a private organisation to develop its own supporting actions on the benefit of children with disabilities/CP.

A little law practice!

Make a list of the rights granted by a public body as a normal functioning approach.

Make a list of the situations when a legal right was not granted by the public authority in charge.

Suggested Readings

Guiding materials provided by different authorities and NGOs
Chapter 4

Financial Support for Persons With Disabilities/CP

Learning Outcomes

Trainees will be expected to;

1. know which financial support needs to be asked for
2. understand the difference between money payment as financial support and other types of support

Chapter Contents

Usually, the financial support is granted according to a specific procedure fulfilled by the persons with disabilities, or, in case of children with disabilities, by their parents. Financial support can be granted to the person only and/or to their family members (parents) or personal accompanying assistant.

In case of financial support for children, usually parents needs to accomplish several administrative procedures in order to reach the support. More often these procedures are very simple and can be fulfilled after the childbirth. In other cases, the disability certificate or other registration proof needs supplementary papers or procedures in order to lead to a support.

Financial support measures:

• Exemption on payment of hire in case of rented house within public-owned buildings
• Paid holidays with a variable duration and within certain amounts for one of the parents of a children with disabilities, depending on the gravity of the disability.
• Free access to tickets to museums, shows and performances and other similar cultural and sport events. This right is granted also to the personal accompanying assistant
• Free tickets and subscriptions to public system transportation, both on local, mid-range and long-distance transportation. Depending on each administration regulations, the free tickets and subscriptions can cover unlimited trips on all transportation means or a certain number of travels on specific means of transportation. This right is granted also to the personal accompanying assistant
• Exemption on tax over houses, buildings or land, when these properties are owned by a person with disabilities
• Public-supported interest over bank loans needed to cover the expenses for modification of houses or procurement of supportive devices and adapted vehicles
• Exemption on tax for adapted motorised vehicles
• Monthly fee when the parents or family of a child with disabilities decide to have no personal accompanying assistant for the child.
• Increased or supplementary monthly fee for children with disabilities until the age of adulthood.

Financial support from which schools can benefit in relation with children with disabilities/CP

Public-owned schools are directly financed by public budgets. This means that public budgets have to cover all types of expenses which may be incurred by the education and therapy of children, including the financial coverage for educators and therapists training. In order to receive the needed financial support educators and therapists need to formally submit their request to schools management and to the public authorities as well.

Public-owned therapy centres have they expenses covered as well by the public budget. Thus, comparing with educational entities, the patients will pay an amount of money in order to benefit of certain types of therapy.

In case of private-owned schools and therapy centres, their expenses are covered usually from donations or payments made by the children’s families. Thus, even private-owned schools or therapy centres are entitled to receive financial incentives from public budgets. In order to happen this, these organisations must comply to certain criteria and conditions. The public financial support will cover mainly the expenses for a minimum level of educational or therapy services.

A little law practice!

Without using any guidance, fill in a request form you think is necessary to ask for financial support. Now, use the guidance presented in the legal paper and fill in, again, the same request form. Take note on the differences and discuss them with your fellow trainees.

Explain why it is not necessary for a solicitor to know exactly all the details needed for using official forms.

Suggested Readings

Informational materials about how to reach the support to which disabled/CP children are entitled.
Chapter 5
How to Obtain Support to Which Persons are Entitled

Learning Outcomes

Trainees will be expected to;

1. Avoid confusions and mistakes during the requesting process
2. Know what to do when a request is not approved
3. Make the best use of all the legal facilities

Chapter Contents

The actual support can be obtained after fulfilling a certain administrative procedure by the child’s parents. The basic procedure is the registration of the child after birth. In this case, the registration is made on the basis of the parent declaration alongside with a medical certificate to prove the existence of disability and its gravity.

In some countries other individual rights are granted upon a specific and more elaborated administrative procedure. For instance, assistive devices can be provided only if parents submit a formal request and other official document to an authority in order to receive the devices as such or an equivalent amount of money. On the other hand, there are countries were NGOs or other private organisations are entitled to process the requests from parents.

In order to receive an individual support, the parents need to know exactly what procedure they have to fulfil. The actual grant of support may vary very much in a specific country from case to case. When a request does not receive a positive answer it is advisable for parents to either sue the public authority or to ask for help to an NGO dealing with persons with disabilities.

How to obtain the support to which schools are entitled

Depending on which specific country, the public support for educational or therapy centres is granted according the legal status of the entity. The public-owned entities must submit each year a formal request for budget. Teachers and therapists may propose to the entities’ management their proposal for educational materials, therapy tools or training.
In case of private-owned entities, first they must comply with the conditions of public financed private organisations. Then, every year they submit the request for money and at the end of the year the organisations will report on how they spent the money.

Private support can be reached by submitting requests to various sponsors or donors, according to their rules. Some donors support organisations only, while others make grants or other types of support available to individuals as well.

A little law practice!

Which are the reasons for not granting a specific right?

How long took until a request for a right was positively answered?

Except the basic request, which other actions were took in order to receive the legal support?

Suggested Readings

Attorneys of law and specialised NGOs websites, forums
The major goal of this module is to improve participants’ knowledge and understanding of several aspects concerning the inclusion and acceptance of a child with cerebral palsy – in the school, the classroom, at home and in the community (family, friends of the family, meetings with the surrounding society etc.). Specifically, we intend to explore the meaning of inclusion and acceptance and the tools that can be used to promote them in several ways:

1. Improving the level of understanding of acceptance and inclusion of children with CP in the school, at home and in the community.
2. Increasing the number of “tools” that help ensure acceptance and inclusion of a child with CP.
3. Improving the ability to increase the inclusion and acceptance of a child with CP in the school and in the classroom.
4. Improving the ability to increase the inclusion and acceptance of a child with CP in the family and the networks around the family.

Aim

In General

Cerebral Palsy is a multifaceted disability with many different expressions in the child’s appearance, and in the way the child acts and behaves in different situations. Independently of the appearance and behavior, many children with CP have to cope with the challenges of participating in a classroom and with peers with no disabilities, as well as peers and teachers also have to cope with a pupil with CP.

The same situation is to be found at home: the child with CP has to manage living in a family, surrounded by a network without disabilities – and the family and network have to deal with a relative having CP.

These facts can cause many different and difficult situations, but knowledge of the subject and knowledge of tools that can help to compensate this, can help the child as well as the people that surround him or her, dealing and coping with this situation in a respectful and meaningful way.

This is a theoretical training module, which, on the basis of latest knowledge in the field, will approach different matters about the subject.

We also consider that parents and teachers have a lot of valuable knowledge that result from practical experiences. Therefore, the course should also be a place where participants (parents/parents, teachers/teachers and parents/teachers) get an opportunity to discuss and share their practical experiences. This way, participants will be inspired by each other in how to work on and incorporate inclusion and acceptance of the child in many situations.
For Parents

In the need analysis, many parents expressed a feeling of lack of acceptance and inclusion of their child – in the school and in many cases also among the family and friends and in the surrounding society.

The first step for parents to be able to help and facilitate other people in their including and accepting attitude when meeting their child in different situations, is that they have personally learned to accept the child as he/she is and the situation of the child and the family.

Another important aspect is knowing how to deal with and appropriately help the child appropriately when situations arise, where the child expresses grief and sorrow because of the situation of being disabled and not able to function like the peers.

A way to reach (the) understanding and (the) acceptance and from that the ability to think of ways to help compensate and trim the surroundings with the aim of facilitating a life for the child where the disability will cause as few obstacles as possible in fulfilling a life with friends, education, work and participating in leisure activities, is knowledge and concrete tools of how to work on this.

For teachers

The need analysis indicates that teachers coping with children with CP in the classroom, can benefit from increasing their knowledge about how to include and work on the acceptance of a child with CP.

Providing the teachers with knowledge about different aspects of inclusion and acceptance as well as raising opportunities to discuss how and which tools can be used in praxis to increase the ability for their disabled pupil, will help them to focus on the situation and influence the peers of the child, the physical surroundings as well as their own approach towards the child with CP.

Learning outcome

Participants will learn about acceptance and inclusion of children with CP from professional experts providing them with the most recent knowledge in the field.

The parents will learn how to deal with their own shock and grief, as well as the child’s, in order to increase their ability to understand and accept the child and the challenges connected to the disability and to gain the knowledge needed to be able to facilitate others to approach the child with an accepting and including attitude.

The teachers will learn which difficulties have an influence on the acceptance and inclusion of a child with CP in a classroom mainly containing pupils without a disability. They will learn how to deal with this and compensate for this, through affecting his/her own attitude (how to focus on successes) the attitude of the peers, changing physical surroundings etc.
Chapter 1

Coping with the mood (shock, denial...)

Learning Outcomes

At the end of this chapter, participants will identify the typical reactions and phases one has to go through when living through a crisis.

They will become aware of the difficulties that may arise between the parents as a couple and how to react to that before it may be too late.

The participants will know the importance of informing relatives about facts regarding the diagnosis, helping them to understand the situation of the child.

They will understand the importance of assisting grandparents and other relatives and close family friends through their period of crisis.

The participants will know tools to help “good cooperation” between the family and relatives to grow in a fruitful way that everybody can benefit from.

The participants will know about the phases of grief and crisis connected to its own limited situation that the child with CP may have to live through, and will identify tools to handle these phases.

Chapter Contents

It is always very hard to learn that one’s child has cerebral palsy or any other kind of disability or disease.

Some parents will know the moment the child is born while others will have been through a period of worries and anxiety because the development of their child has not followed the normal patterns.

Some parents will feel relieved when they finally get a diagnosis and know what they are dealing with, but most parents will experience sorrow and a crisis. A feeling of loss can follow getting a child with a disability like CP. A loss of the child one had expected as well as a loss of the life one had imagined with a child growing up, becoming more and more independent. When getting a child with CP, the parents have to change their ideas about how long it will be necessary to take care of and support the child.

Crises contain different phases like shock, reaction, processing and a new orientation. How these phases will show in the individual cases is different from couple to couple, from parent to parent (– and some parents may end up never accepting the fact that they have a child with a disability.)
Very often it feels like being in the middle of an emotional chaos - which can be even more difficult to handle if the mother and the father of the child do not react in the same way to the situation.

It is very important to receive help and talk to other family members, friends and professionals about the situation. It may also be a good idea to talk to a professional psychologist or other therapists who may be able to help the parents in dealing with all the chaotic feelings. This is important if the parents intend to reach an acceptance of the situation and find the strength necessary to cope with all the following tasks of having a child with cerebral palsy. It is also important because there may be siblings in the family whom it is very important to take care of as well. They will very often find themselves in a situation where they feel that they are put aside and do not get the attention they are entitled to. The sibling with cerebral palsy gets a lot of attention because of the worry and because of all the tasks that have to be taken care of resulting from his or her condition.

Very often the anxiety and the worries about the child with cerebral palsy and about the future result in a situation where the parents forget they are a couple and tend to isolate themselves from friends and relatives. It is important to be aware that this should not happen.

Parents, siblings, grandparents, at the rest of the family feel grief and sorrow and need to be taken care of. Grandparents will very often be able to become a very important support in the everyday life of a family with a child with CP. But it is very important to supply them with the relevant knowledge about the diagnosis in order to better understand the situation, and with that work through their own grief and sorrow which again will lead them to become an even better support in the family with a child with disabilities.

**Activities/Reflective questions**

A group work will be carried out.

In the introduction to the group work the trainer will present the reflective questions to be addressed to the trainees.

The trainees will be placed in groups of 4-5 persons.

Examples of a form for the group work:

Choose one or two participants in the group to present their personal story to the rest of the group - how was your reaction when you became aware that your child had CP? How was the reaction from grandparents and other close friends and relatives? How was the reaction from siblings? Have your child with CP him/herself expressed or shown signs of grief, depression or so because of his/her situation as disabled?
In the group, think about what you have just heard and discuss in the group what would be the best way to help this family through a crisis? What would be a good way to address the reactions from relatives and friends? What would be a good way to address reactions from siblings - and what would be a good way to take care of the child him/herself if expressing or showing sorrow or depression because of his/her own situation?

**Suggested Readings**

Emily Pearl Kingsley: ‘Holland’ - a poem about getting a child with a disability:
http://www.our-kids.org/Archives/Holland.html

About Emily Pearl Kingsley:
http://en.wikipedia.org/wiki/Emily_Kingsley

Ariel - a case story (go to page 34):
Chapter 2

Arrangement of home environments

Learning Outcomes

The participants will identify tools that can help them in their efforts, naturally including and integrating the child with CP at home and in several situations, like social arrangements and sport activities. They will also learn the best way of mediating information about the child to others.

The participants will also, for example, learn a specific technique to communicate and be together with the child with CP.

Chapter Contents

About the workshop – the yoga technique:

By using a certain yoga technique it is possible to regain intuitive communication with the child with CP, even if the ability of expressive communication is poor.

The technique works on enhancing or producing a balance of the cerebral hemispheres, stimulating the function of the right or left hemispheres, developing intuitive communication with children, developing relaxation techniques in the presence of children, developing the ability to relax the children by contemplating one’s own physical reactions and resistances to the children’s presence and behavior, emptying aggressive communication through pranayama, i.e. breathing techniques developed for individual needs, and teaching children simple techniques to improve brain activity.

Parents and children affected by brain pathologies, i.e. CP, can effectively improve their level of communication with meditation, Kundalini Yoga exercises to stimulate intuition, tolerance, compassion and effective communication. Sequences and meditations are meant for parents to intensify relational abilities with their children, and using intuition as a means to establish closer contact by moving from conventional/rational patterns of relationship to contemplative ones. Basic Sat Nam Rasayan exercises will be practiced to create a state of deep communication through relaxation.
Activities

A workshop will be carried out to demonstrate a yoga technique that may help to promote communication with the child.

Suggested Readings

National Network for child care
http://www.nncc.org/Diversity/divers.disable.special.html


Kundalini Yoga meditation for emotional balance http://www.youtube.com/watch?v=fhlS8f5q7U

Kundalini Yoga breathing techniques http://www.kundaliniyoga.org/pranayam.html

Short history of Sat Nam Rasayan http://creacicle.com/blog/?p=1774 (Spanish)

Sat Nam Rasayan http://www.sat-nam-rasayan.de/ (German)

Sat Nam RArsayan and Guru Dev Singh http://www.satnamrasayan.it/gurudevsingh.php (Italian)
Chapter 3

Tasks and responsibilities in inclusion
(in school, supportive services, etc.)

Learning Outcomes

The participants will get to know tools that can help them in their efforts to include and integrate the child with CP in different situations: school, classroom, sport activities, at social arrangements etc., and what is the best way to mediate information about the child.

Chapter Contents

It is important to underline that inclusion is not exclusively the task of the school, but a daily task with the attention of all the institutions supporting the child/young girl/boy with cerebral palsy.

Educational care, rehabilitation and assistance cannot be put in the hands of the individuals (parents, teachers, rehabilitators, educators), but it needs to be linked to a logical system. Cooperation and commitment, in terms of shared responsibility between school and family support services are the basis of success of the life project for the student with cerebral palsy.

Collaboration and shared responsibility mean all the participants are willing to build conjoint plans and training, and to participate in moments of confrontation to verify its fulfilment and effectiveness.

The specific tasks of each individual and the individual responsibilities cannot be separated from a common project to socialize, learn, and rehabilitate, all aspects that encourage the global growth of the student.

The social model of disability, in part reformulated by ICF (International Classification of Functioning, Disability and Health, 2001 - World Health Organization), has allowed to focus not only on the difficulties encountered by people with disabilities due to their biological condition, but also and above all on the context in which the person is included. The model set in schools and support services proposes the idea of an inclusive education and culture.

The duty of the school and of the services is to take care of:

- The relationship system,
• The methods of personalized and individualized work,
• The organization of spaces and work times,
• Cooperative learning,
• The dialogue between peers,
• Continuous update and professional growth of the figures who work there and that creates the conditions for an inclusive approach of the student with cerebral palsy,
• The responsibility to provide inclusive opportunities to the students, which is explicit, above all in the organization of an environment where each student will be able to express its potential, to find the right answers to its needs, and to participate in community life.

It is not enough for schools and services to be able to respond to the person’s needs only in terms of technical and economical resources and of specialized personnel. It is also important that they question concepts as, being “normal”, school success, and research of performance. It is important to question, with a strong sense of responsibility and honesty, about the meanings of “education, training and socialization”. “Disability” and “special needs” cannot be interpreted as “interference of the system”, but as constant and widespread variables of the normal processes of society. The risk is that school and the various support institutions for people with disabilities “get lost every day on the way.”

**Activities**

The work of this session will take place in 3 hours.

In the first part (lasting 1 hour) the topic will be presented, indicating the duties and responsibilities of schools and services to promote inclusion. The lesson will take place with the presentation of slides, using diagrams and mind-maps to focus on the most important elements.

For the following 2 hours there will be group work. It will offer opportunities to use inter-subjective learning and training methods. It will promote discussions and the willingness to accept that the same problem can be faced and solved in different ways.

The aim of the group work and discussion is not to ensure that the points of view coincide, but to find answers that take into account the specificity of all the thoughts expressed.
Reflective questions

1. In your experience as teachers and parents what do you believe are the duties and responsibilities of schools and services to make the inclusive action effective?
2. How have you lived the relationship system among the various figures involved?
3. What is the dialogue between the child/young boy/girl with cerebral palsy? Where is this dialogue preferred? How does it take place?
4. Has the school and services a structured way of work, time, and space suitable for the growth of the child/teenager?

Suggested Readings

http://www.milieu.it
http://www2.unescobkk.org/elib/publications/243_244/Teaching_children.pdf
http://books.google.it
http://books.google.it
Chapter 4
Increasing Social Acceptance

Learning Outcomes

The participants will know and become aware of which mechanisms in society (in school, at home, in the contact with social - and health services, etc.) can be obstacles for social acceptance and they will know tools that can prevent this from happening.

The participants will know which mechanisms and feelings may occur in the child with CP when having to deal with an excluding and not-accepting attitude from the surroundings and they will know tools that can prevent this from happening.

Chapter Contents

People with disabilities arouse to a great extent, positive feelings, such as solidarity, admiration for their will power, the determination that they transmit and the wish to be useful. Generally people feel calmer when they face situations that are considered close to normal. But there are also widespread feelings of embarrassment and controversial discomfort. Some even feel afraid to face the possibility of experiencing the same pain. There is also strong concern of hurting or offending a person with disabilities inadvertently either by what we say or do. Few people are indifferent, and think it is a problem that does concern them at all.

However, complete social acceptance is still limited. Prejudice is strong towards those who are not considered productive, able to make a efficient contribution to society, so that the value of these people is perceived as inferior. The external view contributes in removing these people from what is seen as the image of perfection and aesthetic beauty that meets all standards outlined by the media, so much so that some people may feel embarrassed if seen in the company of people with disabilities. What are the principal actions that can be implemented so that these people can be considered as others? Some suggestions that should be pursued at the level of social policies are:

ELIMINATING IGNORANCE: the first step towards real social acceptance of disability starts from knowledge to avoid misunderstandings and fall into old stereotypes. It is therefore necessary to talk about disability, what it means, its forms, problems, including it in educational programs.
BEING AWARE THAT DISABILITY IS AND CAN BE PART OF EVERYONE: if one starts from the idea that disability is one of the possible characteristics of the human condition, we can talk about an experience that everyone could find and live in their life and as such could be considered normal. Pain and suffering is part of life. This subject is not treated - the fear that it might hurt or even the fear that disability can be part of us.

It is important not to exaggerate pain but be aware that it exists, which can belong to anyone, in the same way as disability. This is too often understood only when disability is tangible.

TO ACCEPT THE PERSON WITH DISABILITIES, IT IS IMPORTANT TO ACKNOWLEDGE THE PERSON WITH DISABILITIES: the real injustice that affects the person with disabilities is not the term that refers to them: disability, handicap, of other abilities, but having to waste their remaining energy to get what should be taken for granted. If the person with disabilities or their family do not activate themselves, do not have someone who might represent them, they do not get and at times they do not even ask, for the false fear that asking for what is due will only be given as a favor, and that it will make people aware of the “diversity”, that indeed exists!

INSERT THE PERSON WITH DISABILITIES FOR THEIR PRIMARY ABILITY: work is certainly a key element, through which the person feels integrated in society, feels useful in the world.

NECESSARY SKILLS AND KNOWLEDGE FOR THOSE WHO SHOULD APPLY THE LAW: so that inhumane efforts are not required to obtain what is granted in a discourse of solidarity.

Few recognize the sacrifices that the person with disabilities makes to be as the “normal ones.

The principle of solidarity has brought about great improvements thanks to laws that protect us, but nevertheless you must always fight hard to get everything that is granted by law.

ARCHITECTURAL BARRIERS: how are the rules that favor their removal applied? The culture of those who work to eliminate these barriers is still by and large distant.

Greater independence is encouraged for the person with disabilities; however, they are always viewed as being accompanied.

Suggested Readings

• Schianchi Matthew, La terza nazione del mondo. I disabili tra pregiudizi e realtà, Feltrinelli, Milan, 2009.
• http://icarefumane.jimdo.com/
• http://www.un.org/disabilities/default.asp?id=150
Chapter 5

Educational Inclusion, Applications of Educational Inclusion and Variety of Educational Inclusion

Learning Outcomes

The participants will know about and receive tools to build a school with equal room and space for all children/students – with disabilities or with typical development – in an atmosphere of mutual respect of individual difficulties and differences.

The participants will know about possibilities of alternative communication and will learn from each other about other tools available to include children with CP in the school.

Chapter Contents

The principle behind every definition of inclusive education is that all students should learn together, regardless of difficulties or differences. Difficulties and differences that are also within the same type as cerebral palsy. Each child has its own history, unique features, their own difficulties and their own potential. “Disability is not a problem of a minority group within the community, but rather a condition that everyone can experience during their lives” and every child has the right to find the right answers to their needs regardless of their physical, psychological, relational and social condition.

The approach to education, rehabilitation and care of children with CP should be set in a global framework that includes direct interventions on the child and on the environment (family and school). The work of all those who support the child with CP (teachers, paediatric neurologist, psychiatrist, physical therapist, speech therapist, social worker) must be well designed to promote both the educational and rehabilitation aspect, the emotional-relational aspect of the child/teenager and of the parents who will be accompanied along all their growth, which will bring the student to be both author and protagonist of his development.

The aim of social inclusion and education is a priority and should not be subject to the achievement of certain pre-treatment goals. As all the other children, the child with cerebral palsy needs to understand all the possible opportunities from its environment. A well-designed and prepared environment (the school) is often crucial to the ultimate success of the treatment practised.
Inclusion should be one of the key points in the Training School Plan and be recognized as a value that gives quality.

Features of an inclusive environment:

- Opening to the idea of “normal special”,
- Flexibility of the organization and of educational, rehabilitative, social proposals,
- Correct functioning of collegiality,
- Interdisciplinary and coordinated work,
- Availability of human and material resources,
- Extensive training programs and qualified educational staff,
- Use of technology and customized tools,

In particular, in the school:

- Trained and qualified professionals (teachers,...),
- Enhancement of the families, according to the principle of subsidiarity (the families, the first subject of education, are empowered and called to cooperate with the school in the ordinary educational activities),
- Collaboration among all the figures who work for schools and social inclusion,
- Involvement of the head-teacher,
- Enhancement of teacher collegiality and shared care (not to delegate to others, to renunciation, etc.),
- Reception and acceptance of peer group (no rejection, exclusion, etc.),
- Methodological articulation (individual activities, in pairs, small group, class)
- Use of software and educational technology
- Removal of architectural barriers at school

Activities

- The activities to propose for this session aim to be experimental and innovative: Actually we intent to experiment with teachers and parents a inclusion on the contrary: (to use in classrooms and external environment as pedagogical and educational experience). It Means: Let’s all of us experiment situations of disabilities.
- The training experience developed will tent to move the attention from the CP Pupil to ( with his/ her difficulties and limitations) to the context. This context have to be understood as environment and material, like classrooms mates / group. Inclusion first of all means to create a welcoming and integrating environment for the educational special needs pupil: n environment where it should be possible to
set up relationships, stimulate close friendships and availability to dialogue and communication.

**Reflective questions**

1. Try to play situation of movement disability avoiding the use of the dominant hand (individual / groups games, educational/ didactics activities
2. Try to draw and colour wearing a big glove imitation or obstacle your movements.
3. Write on narrow spaces, respecting the lines and squares with reductions and movement obstacles.
4. Draw using rulers and compass, use calculator wear the gloves, or binding your fingers
5. Draw with your foot
6. Let’s play basket in wheel-chairs

**Suggested Readings**

http://comforty.com/inclusionseries/webresources.htm
http://www.learningrx.com/making-special-education-inclusion-work-faq.htm
www.eenet.org.uk/resources/docs/Index%20Italian.pdf
Chapter 6

Rationale of mainstream

Learning Outcomes

Participants will realize the importance of a well working inclusion strategy and plan if mainstream schooling is to become a success for all children.

Participants will understand the importance of a very conscious strategy of ensuring that teachers are well educated in the field of inclusion, and they will know about the importance of the cooperation between parents and school.

The participants will know the value of children being helped and taught to join a fellowship with children of different kinds and with different difficulties.

The participants will know the value of an including mainstream school system as a way to secure an inclusive and democratic society for all citizens at all levels and from all parts of society.

Chapter Contents

Inclusion is a dynamic and ongoing process in which social and professional relationships increase the possibilities of presence, the feeling of fellowship, active participation and a high degree of learning among all children. It means that all children have the right to become part of professional and social fellowships, as long as it is meaningful to the specific child and the fellowship as a group. The child has a right to be heard and to feel acknowledged. The main task is to see that all children are feeling well and get the opportunity to develop in the social and professional relationships in which they participate, and that they will be able to develop good relationships with each other.

As many children as possible should attend mainstream school in order to stay in the common offers in the local community and stay part of that fellowship.

This intention can be achieved through differentiated pedagogic strategies and teaching, tailored to the specific child, while cooperation between different professions will support the best possible strategy for the child.

An inclusive pedagogy requests that the children learn from each other’s differences - also from the ones who have difficulties i.e. as a consequence of a disability like cerebral palsy. This presents specific demands to the professionals - they need
to become very aware about their own part in the daily life at school - how can the individual teacher contribute to the fact that all children should gain from the fellowship?

The Salamanca declaration points out that an inclusive school is the basis for the development of an inclusive and democratic society for all citizens at all levels and from all parts of the society.

Therefore the good inclusion should think of growing up in inclusive fellowships among children, in school, institutions and leisure time activities, as the basis for the development of an inclusive and democratic society locally, nationally and globally.

Inclusion is a way of looking at people and society - not a method or a concept. It is the right for all children to be included, to experience affinity and to be able to contribute and exploit from the relationships in which they participate.

Fellowships are dynamic relations between people, committing themselves to each other, and differences should be looked upon as strength and a good thing for the development of dynamic and developing fellowships for all children.

**Suggested Readings**

Do Special schools lead to discrimination? – a video

(Micheline and Lucy Mason join parent Jonathon Bartley on the Big Questions BBC show. They are successfully arguing that inclusion in mainstream schools is the only way to end the discrimination caused by attending segregated special schools and units. The argument is won. Children and young people should be included in local ordinary schools with all the support they need).

http://www.youtube.com/watch?v=P38tJ1w-dRA
Chapter 7

Applications of inclusion at different educational levels

Learning Outcomes

The participants will know which aspects in childhood are important to take into account when working on integration in school situations. They will know which aspects are of prior importance and which are secondary to that.

Chapter Contents

Childhood

Facilitate the use of operational methods as well as those of a transmissive,
Give importance to the psycho-motor work,
Stimulate expression through all languages,
Promote a social life characterized by peaceful conviviality,
Promote acceptance of differences and diversity of all kinds.

Primary

Favor the use of operational methods as well as those of a transmissive,
Take into account the learning curve required by all students,
Recall experiences and aspects of daily life,
Promote acceptance of differences and diversity of all kinds,
Provide an environment that is simultaneously stimulating, peaceful and conducive to positive relationships between the members of the class.

Secondary

Promote cooperative learning,
Use technology and multimedia,
Counter the negative perception of peers against students with disabilities, foreigners, in trouble,
Actively involve the learner in a process that links knowledge and personal formal and experiential,
Organize support differences,
Design interventions on the network with the territory,
Promote acceptance of differences and diversity of all kinds.

Activities

The work of this session will take place in one hour and thirty minutes.

In the first part (about half an hour) the topic will be presented, indicating the inclusion of suggestions to different levels of education. The lesson will be carried out with the presentation of slides, making use of diagrams and mind-maps to focus on the most important elements.

For the following hour there will be group work. It will offer opportunities to use inter-subjective learning and training methods. It will promote discussions and the willingness to accept that the same problem can be faced and solved in different ways.

The aim of the work and discussion is not to ensure that the points of view coincide, but to find answers that take into account the specificity of all the ideas expressed.

Reflective questions

1. What is the relationship between the classmates and the child with cerebral palsy?
2. Which interventions most affect the acquisition of the child’s skills?
3. With reference to the age of your child or student what do you believe are its most important needs and desires?
4. How has the work been carried out so far to give continuity to the process of inclusion? What horizontal continuity (among the different departments) and vertical continuity (among different school grades)?
5. Has a joint educational project been built for the child / student with cerebral palsy or has there been a separate program and a lack of choral interventions?

Suggested Readings

www.sinpia.eu/atom/allegato/152.pdf
http://web.accaparlante.it/paralisi-cerebrali-infantili
http://education.jhu.edu/newhorizons/Exceptional%20Learners/Inclusion/General%20Information/inclusion_preschool.htm
Learning Outcomes

The participants will know about the important moments (milestones) in the school life of a child with CP where decisions must be made in order to help the student follow the right path for further education in life – taking into account abilities and possibilities.

Chapter Contents

As in many other situations, the transition from secondary school to some kind of post-secondary education, like high school, technical colleges, professional training centers, further education, etc., in many cases calls for more planning when concerning a child or young person with CP than with child or young person with typical development.

A lot of important issues have to be taken into account, like physical and personal support, economy, transportation, living and so on.

On the one hand, United Nation High commissioner for Human Rights states that “persons with disabilities have a right to education”. With a view to realizing this right without discrimination and on the basis of equal opportunity it must be “ensured an inclusive education system at all levels and lifelong learning”. It is also stated that persons with disabilities, such as CP, should be offered possibilities of using their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential.

It must be ensured that persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability.

Reasonable accommodation of the individual’s requirements should be provided and persons with disabilities should receive the required support, within the general education system, to facilitate their effective education.

Despite this declaration of intents the reality appears different.
It is not easy to find exact statistical material about the situation of adult persons with CP when it comes to educational level.

Denmark constitutes a difference. In Denmark there is a Cerebral Palsy register in which ALL persons diagnosed with CP are registered. This makes it possible to carry out research based on statistical material. Of course there is no evidence that results from Denmark are completely similar to results in the other European countries, but considering that Denmark represents a relatively average example compared to other European partner countries, their studies can be interesting and serve as an example for reflection.

In 1995 the Danish CP register analyzed how status was for ALL persons born in the years 1965-1978 (18-30 years of age). This material showed that only 33% had some education beyond primary school – only 29% were self-supporting and 70% were to be found in the lowest income group. Neither of this was dependent on the motor level of the disability.

Another model study taken from the same register regarding educational level, showed that out of 28 men and women, 17-48 years of age with a mean of 33,2 years showed that despite the fact that 28,6% of the participants in the study passed a high school education and 32,1% passed an exam at the end of secondary school, 50% of all participants never got any further education.

• These results indicate that in spite of the good intentions in the statements of United Nations, there is still a long way to go, until they become a reality to young people with CP.
• The main idea of this session is to present the difference between the good intentions of the World Community and the reality in a specific country. To point out which goals have not yet been reached and to make the trainees of the course discuss which obstacles are yet to be overcome – and which tools and efforts must be found and used to develop a situation where inclusion and acceptance follow the child with cp from secondary school into high school or further education.

Activities

The work of this session will take place in 3 hours.

In the first part (2 hours) the topic will be set, indicating the Applications of educational inclusion and Variety of educational inclusion.

The presentation will take place through slides, use of diagrams and mind maps to focus on the most important elements.
For the following hour there will be group work. It will offer opportunities to intersubjective use of learning and training methods. It will promote discussions and the willingness to accept that the same problem can be faced and solved in different ways.

The aim of the work and discussion is not to ensure that the point of views coincide, but to find answers that take into account the specificity of all the ideas expressed.

**Reflective questions**

1. Is transition an endless process or an expression of isolate moments in the daily school life of a CP pupil?
2. What does transition of a CP pupil mean? What are the important aspects of a guided action?
3. The PEI – Individual educational plan has been set up for transition of the pupils too? It is possible to transform it for a short term project to Life long one?
4. Which kind of teacher’s, family’s and social service’s intervention is necessary?
This training module was produced in the scope of CP-PACK project and in accordance with the Need Analysis Report derived from the results of the focus group interviews and questionnaires collected among parents and teachers of children with cerebral palsy.
Chapter 1

Family Life

Session 1.1: Activities of Daily Life

Learning Outcomes

Trainees will be expected to learn how they can help and support their children with CP to feel and be more independent in Activities of Daily Life.

Chapter Contents

The term Activities of Daily Life refers to the individual's performance of self-care daily activities and to the care of the indoor and/or outdoor environment he/she lives in.

Activities of Daily Life are defined as the things we usually do on a daily basis, such as feeding, bathing, dressing, grooming, working, taking care of our family, taking care of household and having fun in our free time.

Let’s think and write!

Seven Activities of Daily Life in which your child with CP is participating (alone or with support):

The classification of Activities of Daily Life includes:

- Personal care
- Functional communication
- Movement Functionality
• Social Relationships
• Response to distress

The child with CP has to be trained in activities of daily life and this is very important for himself/herself and for his/her parents. The child, while getting more and more independent, feels that he/she is capable to perform many personal activities (e.g. toilette, dressing, etc.) and feels more confident in general.

As far as parents concern, they know the exact abilities/skills of their child and as the child is growing older, the responsibility of care is getting lower (depending on child’s abilities).

Let’s think and write!

Mention some assistive devices to support your child’s Activities of Daily Life.

Let’s think and write!

Why is it important to train a child with CP in Activities of Daily Life?

Suggested Readings

Learning Outcomes

Trainees will be expected to;

1. Acquire a clearer understanding about the various meanings, uses and benefits of play for children with CP.
2. Distinguish and contrast the use of play: as a motivator, as an enjoyable activity or as a context.
3. Choose the adequate play activity according to the limitations of the children with CP.
4. Understand the role of the adult in fostering, facilitating and enhancing a play activity, including or not including siblings without disabilities.
5. Be able to make the right selection of toys, games and play materials.

Chapter Contents

Child’s play

- Childhood play and playability
  Playing is a central activity during childhood and, as the famous educator Maria Montessori used to say, “play is the work of the child». You may come across a child playing and you will be sure he/she is having a good time. However, there is more to the picture than meets the eye. Parents should realize that interacting and playing with their children offers an ideal opportunity to fully engage with them.

- Play definitions
  According to C. Garvey’s definition, play is a term employed in ethology and psychology to describe physical or mental activities normally associated with pleasure and enjoyment. What distinguish play from other forms of human activity are its qualities of spontaneity and self-initiation.

- Benefits of play
We often hear the phrase “child’s play” bandied about when something is deemed easy or unimportant. In reality, true child’s play is anything but easy or unimportant. Play is the mean by which children explore their world and make sense of their surroundings, which is what ultimately informs their worldview and opinion.

Play is so important to optimal child development that it has been recognized by the United Nations High Commission for Human Rights as a right of every child. In fact, play is essential to development because it contributes to the cognitive, physical, social, and emotional well-being of children and youth. But it also offers an ideal opportunity for parents to engage fully with their children.

Let’s think and write!

Benefits of playing according to their goals and their effects.

Play value according to the children’s age or stages of social, intellectual, and cognitive development and to their needs

a. Stages of children’s social, intellectual and cognitive development.

b. Different stages of child’s play.

c. Types and categories of child’s play: multiple uses and goals.

d. Assessment of play in the selection of toys, games and how to choose the adequate play activity. Types and categories of child’s play: multiple uses and goals

Disability and play

The effects of disability on play skills can be managed and adapted to the child’s difficulties and needs.

A disability, handicapping condition, or delay can affect how a child plays, the kinds of play the child engages in, and the child’s ability to use play as an avenue to learning and generalizing new skills or concepts.

Because most disabilities can have an impact on more than one area of development, it is important to be aware of
individual differences in the development and use of play skills. Careful observation of children's interactions with objects and with people will provide a better picture of how a child's disability affects her/his play.

**Importance of play for children with cerebral palsy**

The disability of a child and its effects can be managed with advices and tips directed to his/her difficulties. Those strategies while playing can help a child to improve his/her motor skills or even to practice his/her coordination or to work his/her imagination, spending some time with his/her parent. The cooperation of parents in home handling and promoting play is essential to the successful treatment of children with cerebral palsy, as it maintains strong parent-child bonds, while also reinforcing the relation between the child with cerebral palsy and his/her siblings.

a. *Sensory development*. The sensory development, called also “sensory integration”, is the brain’s ability to organize sensations from the world around us and from our own body for use, the brain must organize all of these sensations for a person to learn and behave functionally. When the brain is able to organize sensation well, then it uses the sensations from perceptions and behaviours.

b. *Motor and fine motor skills*. Toys that promote gross motor activity are those that involve the large muscles of the body: legs, arms, trunk and neck. This can be further broken down into toys or activities that promote eye-foot coordination: kicking, climbing, jumping, dancing, walking a balance beam or jumping over ropes; eye-hand coordination

c. *Cognitive development*. The beginning of cognitive development comes with intentionality, the discovery that they can perform an action on purpose. Learning that the individual can produce behaviour volitionally and that such behaviour has an effect on the world around him or her is a major accomplishment.

d. *Social development*. The range of opportunities for the child with CP when it comes to play and social development with vary considerably depending upon the level of challenges the child faces.

e. *Creative communication*. Children enjoy the opportunity to creatively express themselves in whatever way they find possible.

**Strategies and tips to support play and engage a special relation between parents and child**

Encourage him/her to play with other children

Substitute toys and objects as characters, instead of having a child physically act things out

Encourage a pretend play style that relies on voices rather than action

Recognize the creativity in a child by having him/her be the “director”

Toys are the tools of play and they can be as elaborate and expensive as you desire, but often the best toys are simple household objects or throwaways
Present to the child the toys, by encouraging him/her to reach and grasp them with the hand that is more difficult to use, but allow the child to use whichever hand he/she chooses

**Let’s think and write!**

Which daily activity could be a new play activity for you and your child?

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**Let’s think and write!**

Which daily activity could be a new play activity for the whole family?

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**Activity**

**Group Discussion**

The trainer and the trainees will discuss issues raised during the presentation and/or other issues that concern them. The participants should be seated in a circle, where everyone can see each other. During the discussion, the trainees will present the ways they have been using until now to play with their child with CP. The purpose of this discussion will be to provide solutions to parents’ difficulties and/or to give them guidelines.
Reflective questions

Did this session give you ideas for spending more time with your child?
Do you think that you can enhance a new activity with your child?

Suggested Readings

- Freud S. (1905)“Three essays on the theory of sexuality”.(trad:“Drei Abhandlungen zur Sexualtheorie )
- Kennedy M. (2001)“My perfect son has cerebral palsy, a mother’s guide of helpful hints», Paperback.
- Finnie N. (1997)“Handling the young child with cerebral palsy at home”, FCSP

Websites
http://www.caringforcerebral palsy.com
http://cerebralpalsytoysandplayaids.com
http://palsycerebral .org/paralysie-cerebrale-jouer
http://www.childdevelopementinfo.com

Session 1.3: Activity Play Workshop

Learning Outcomes

Trainees will be expected to:
1. Design ways of playing with children with CP
2. Orientate play towards specific or multiple targets (e.g. recreation)
3. Prepare the children for play and physically assist them in the best possible way.
4. Use activities of daily life to play with children with CP.
This is a practical session. It is very important to have both parents and their children with CP participating. It will be very useful if siblings can also participate.

It is suggested to divide the group into three sub-groups:

I. Group for parents and their children aged 3-7 years old

II. Group for parents and their children aged 8-14 years old

III. Group for parents and their children aged 15-18 years old

The trainers, according to the children’s ages and the information gathered from a form that each parent will fill concerning their child prior to their participation in the workshop, will prepare an Activity Play Workshop that will meet the needs of the trainees and their children.

I. Group for parents and their children aged 3-7 years old

This group is suggested to play in pairs (parent-child) or in small group activities, using sensory stimulation, somatosensory and body contact.

II. Group for parents and their children aged 8-14 years old

In this group, children with CP, their parents and siblings are suggested to cooperate to create a story plot and make puppet characters from the story, using parts of household equipment.

III. Group for parents and their children aged 15-18 years old

In this group, participants will be taught how to adapt a specific Paralympic sport (Boccia) and/or other sports for recreation.
Chapter 2
Social Life

Session 2.1: Support Network

Learning Outcomes
Trainees will be expected to know about:

1. The levels of a support network
2. What a support network can provide to the individual and/or the family
3. The use and the usefulness of a support network

Chapter Contents
Support Network

A support network operates on many levels, from families up to the level of the state, and plays a critical role in determining the way individuals are dealing with or solving their problems and the degree to which individuals succeed in achieving their goals.

There are informal and formal ways that support can be provided to the individual/family:

• **Informal Supportive Resources – Family members, and so on.**
  
  When people are asked to indicate who they turn to in times of crisis and emotional distress, they typically say family members and friends who they consider “natural helpers”. The network of relatives and friends with whom they have day-to-day contact is an important part of their lives – it is a pattern of life of many ordinary families.

  Family members, friends, peers, neighbors and others can provide various forms of support, aid and assistance and can be a constant informal supportive resource. Support networks formed by these informal helpers are thought to have a major impact on the life of a person as they can assist them in sustaining or improving difficult situations, in finding solutions to their problems, in progressing in their life, etc.

• **Formal and/or Informal Support – Community Services/Resources**

  Support at another level can be provided by the services - formal or informal services - that exist in the community of the individual. The notion of a community
implies the existence of a network of reciprocal social relationships that, among other things, ensures mutual aid and gives those who experience it a sense of “well-being”.

- **Formal Support – State Services/Resources**
  The State-Central Government has a responsibility to operate specialized services, public or private, to make laws, to issue regulations to relieve difficulties and problems people face, etc. People can use these services, can make use of the laws and can ask for the regulations that apply to their case in order to be able to relieve their difficulties or solve their problems.

**Let’s think and write!**

What do you consider as your support network?

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**What a Support Network can offer to the Individual /Family**

- Human Interaction
- Participation and Togetherness
- Information, Increase Knowledge and Experience
- Bridge/Reach
- Status and Influence

**Ways of using Support Networks**

It is better for individuals to have connections to a variety of networks for support, like family, friends, work, activity groups, community formal or informal resources etc., rather than many connections within a single network, like their family or their friends. It is very helpful and supportive to have a group of friends to whom we can turn to or do things with, share common interests, experiences or problems, etc. However, it would also be helpful if we could have an open network too, i.e., a group of individuals with connections to other social worlds. In this way, it is more likely to be able to have access to a wider range of information, or to be introduced to new ideas and opportunities, etc. Also, as a member of this open network, the persons is able to exercise some influence in the decision making on issues of disability, etc.
It is not necessary to formalize the support network with regular meetings. A coffee break with a friend at work, a quick chat with a neighbor, a phone call to a member of our family, even a visit to a church are all ways that can offer us support.

**Benefits of a Support Network to the Individual/Family**

Numerous studies have demonstrated that having a network of supportive relationships contributes to psychological well-being. Having close friends and family on whom we can count has great benefits for our health. A strong support network can help us through the stress of tough times, whether we have had a bad day at work or a year filled with loss or chronic illness.

**Let’s think and write!**

In what ways the support network you have helped you in coping with a child with CP?

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**Activity**

Group exercise

The trainer will conduct an open discussion with the participants on issues concerning the supporting network of families with children with CP. Participants and trainer should sit in a circle so they can have visual contact. The reflective questions that follow are part of the themes to be developed.

**Reflective questions**

- What do you consider as your support network?
- Who are the people that support you?
- Are you satisfied with the support network you have and why?
- Do you feel that you are supported by your immediate and/or the wider environment?
• In what ways the support network you have helped you in coping with a child with cp?
• Do you think you need more support and what would this be?
• How would you go about finding more support?
• What is your experience of your support network?
• Do you feel that sharing your support network experiences can help other parents of children with cp?
• Do you feel the Session helped you and in what way?

Suggested Readings

• Mary A. Slater and Lynn Wikler, (1986): “Normalized” Family Resources for Families with a Developmentally Disabled Child, National Association of Social Workers

Session 2.2: Social Activities for children with CP and their families

Learning Outcomes

Trainees will be expected to.
1. Understand how important is to participate in social activities for the family.
2. Know what specialists can help and support their family.

Chapter Contents

Everyday family social activities

Family should participate in everyday social activities together with the child with CP. Social activities means:

a. Development of social relations
   » Visiting relatives and friends of the family during the weekend, the holidays, etc.;
Visiting classmates of children with CP;
Organizing celebrations and events in the family home;
Having joint holidays with friends.

b. Contact with the community to meet the needs of the family
   Participation of children with CP in family activities such as shopping, going to
   supermarket, etc.;
   Involvement of families and children in local artistic, sport or cultural
   associations and/or activities.

Let’s think and write!

Which is the favorite social activity for your child with CP and why?

The value of social activities
The participation of a child with CP in family social activities brings significant benefits
to all areas of development.

The children are mentally and socially strengthened through social interaction.
Alongside, the social activities can have educational meaning also (e.g. learning
about the use of money). Finally, the participation of all family members in social
activities enhances the family dynamics and significantly reduces the development
of affective disorders in family members.

Support and information from the specialists
The systematic cooperation between the parents and the specialists (physiotherapist
– occupational therapist – speech therapist - social worker) act as a catalyst and
enhances the participation of the child into family social activities, as they can
provide solutions to practical issues (e.g. the purchase of a suitable wheelchair
makes the child more functional and independent). Moreover, the therapists can
design the educational content of a family social activity (e.g. learning about money
management).
Learning Outcomes

Trainees will be expected to;

1. Know the value and the importance of leisure time for themselves, both as partners and as parents of a child with CP.
2. Overcome the difficulties that prevent them from dedicating time to them.
3. Learn methods to manage leisure time.
4. Learn about the wider social network and services that can mobilize and facilitate parents to have leisure time.

Chapter Contents

The importance and the value of leisure time for people in general and specifically for parents of children with CP

Presentation of the importance and the value of leisure time. Especially, for the parents of children with CP there is also a risk for the entire family dynamic to be manipulated and influenced, when the parents do not spend time independently and as a couple.

We all know, the presence of a child with CP alters the family dynamics and many parents remain in social isolation. As the family focuses on the needs of the child, the relations between family members are neglected. Also, parents neglect themselves (My brother and me, Cerebral Palsy Greece-Research Dept., Athens, 2004).

Leisure time management – Methods and Solutions for mobilization

Presentation of the wider social network and of the services of organizations (public-private entities) that mobilize and facilitate the leisure time of parents.

Activities

- Demonstration of good practices, videos, photos or presentation of programs which promote or support the leisure time for parents of children with CP.
- Group Discussion / Parents Counseling

It is suggested to divide the parents into two groups with one trainer in each group and have a group discussion-parents counseling for 20 minutes, through standard expressions/statements as below:
a. Many parents often experience feelings of distress, anxiety stress, etc. and fail to experience the satisfaction that the family life can offer.

b. Pursuing a more restful work in the upbringing and care of children with CP seems to be impossible, but with methodical and organized effort it is feasible.

c. Some parents fear and refuse to trust their children’ care to people from their supporting network or to assistants.

d. Counselling, information, practical assistance and training on free time management to all members of a family with a child with CP. Participation in parents groups and/or parents associations/federations.

e. Participation in activities and programs of the broader social network.

Parents should be encouraged to present their own ideas, suggestions for leisure activities (e.g. participating in that group can eventually build friendships between parents and children and possibly parents could trust their child to each other), so there would be benefits for parents (leisure time), for children (socialization and friends) as well as for families (groups and each other).

Suggested Readings

- Croustalakis G., (200). “Children with special needs”, Athens, Phychopedagogiki Paremvasi

Session 2.4: Recreation and leisure time for children with CP

Learning Outcomes

Trainees will be expected to;

1. Understand the importance of leisure time for a child with CP;
2. Know where they can get information about good use of their child’s leisure time;
3. Have general criteria for the selection of companion/assistants on payroll for their children.
The importance of leisure time for the child with CP

Leisure time and its proper use through play and recreational activities help the child with CP to develop social relationships, to improve his/her mental and emotional health and to improve quality of his/her life.

The involvement of children with CP in recreational programs is equally important with his/her involvement in therapeutic and educational programs and improves his/her social development as a healthy member of the society.

Activities in which children with CP can participate during their leisure time

The motor-sensory difficulties of children with CP are often presented as the causes for which most of their leisure time is spent watching television or movies, listening music or watching the activities of other family members. According to recent surveys (Mactavish & Scheien, 2000), the most common and popular forms of family entertainment reflect five general categories of activities:

- Passive activities (e.g. watching television or movie);
- Play (e.g. board games);
- Physical activity (e.g. swimming);
- Social activities (e.g. friendly and family visits);
- Special occasion (e.g. participation in a party).

The differences which were observed in popularity and frequency of these activities, depend on the participation of the family, its socio-economic status and the nature of disability (Dr. Feluca Vasiliki, People with motor disabilities and their free time, article, 1grpe.eyv.sch.gr/ypost/ypost117.doc).

Indoor and outdoor activities for children with CP and his/her family

- Indoor activities
  - Use of pc with special adjustments can function as an entertainment tool;
  - Play family games: the most significant benefit to a child with CP is the strong sense of “belonging” to the family group, which is enhanced by communication and laughter during a family game. At the same time skills like hand-eye coordination and manual dexterity are being reinforced through play;
» Play games using ordinary household objects: by using household objects in various ways the child with CP will enhance his/her physical, emotional and social image;

» Television and its correct use: watching educational and recreational programs (e.g. watching a football game with his father);

» Other activities, like drawing, etc.

- Outdoor activities
  » Camping programs: the child with CP becomes more independent and autonomous while spending time away from his/her family, enhances his/her confidence and self-image, makes new friends and relationships, is trained how to cope in conflicts with friends as well as how to express positive emotions and attitudes in order to build friendships.
  » Sports activities (e.g. riding, swimming, playing Boccia, etc.).
  » Recreational outings with family, friends, assistants.

**Family cooperation with Companion/Assistants on payroll**

The involvement of other persons of the wider society in the life of a child with CP is being estimated as a relief both for the child with CP as he/she will participate in social activities without his/her parents, as well as for his/her parents, who can have free time for them.

Various social services have developed programs for people with CP which offer the family the opportunity to cooperate with an assistant/companion. The cooperation of the family should be in a systematic basis, with a certain pre-agreed fee, specifically focusing in contact with the community, development of socialization and entertainment.

**Let’s think and write!**

In which activities could your child participate with a companion/assistant?

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________________________________________________________________________
General criteria for the selection of Companions/Assistants on payroll

The family should choose an appropriate assistant/companion for the child with CP with great care, taking into consideration the following criteria: age, language, gender, experience in disability issues, personality. The family could contact social services which develop similar services, as well as disability associations.

Activities

- A video interview of a parent and a child with CP who cooperate with an assistant;
- A video interview of an assistant presenting his/her opinion about recreation and leisure time for children with CP;
- A group discussion.

At the end of the session a booklet should be given to participants including information about good use of leisure time.

Suggested Readings

Dr. Feluca Vasiliki, People with motor disabilities and their free time, article, 1grpe. eyv.sch.gr/ypost/ypost1l7.doc
Chapter 3

Cooperation with interdisciplinary team

Session 3.1: Cooperation with an interdisciplinary team

Learning Outcomes

Trainees will be expected to;

1. Recognize the issues that have to be addressed by the interdisciplinary team
2. Take full advantage of the rehabilitation team services.

Chapter Contents

Presentation of the interdisciplinary rehabilitation team

An appropriate and efficient rehabilitation team is the most important rehabilitation tool for children and adults with CP.

Rehabilitation physicians are trained in organizing and coordinating the Rehabilitation Team, an interdisciplinary team which is the main carrier of rehabilitation services. Its members are the physical medicine and rehabilitation specialist (PMR specialist), the paediatric-neurologist, the paediatric-orthopaedic surgeon, the physiotherapists, the occupational therapists, the speech pathologists, the psychologists and other therapists (music therapists, drama therapists, sensory therapists, etc.) the teachers, the social workers and the specialized nursing staff.

Auxiliary members who could work with the Rehabilitation Team on a case basis, include other medical or non-medical specialists, such as the developmental medicine specialists, the paediatric psychiatrists, the ENT doctors, the ophthalmologists, the gastroenterologists, the neurosurgeons, the dentists, the orthotists, the biomechanical engineers, the experts in alternative communication technologies etc. The Rehabilitation Team would meet regularly with its regular members to assess the children, their progress, their particular needs, any adjustments required to the rehabilitation program and to review the short and long term goals.

The rehabilitation program includes all therapeutical techniques and methods, depending on the needs of each individual, and is expanded with medical interventions that may be required at various stages of follow-up (botulin toxin injections, serial casting, muscles or tendon lengthening, etc.). The rehabilitation program is tailored
for each child depending on their medical problems, abilities and needs. Selection of a specific method is very much linked to the clinical picture of the child and on many occasions a combination of methods may be chosen for optimum results.

**Presentation of interaction ways between the team and the family**

The children and their families must be as involved as possible in this endeavour, they must be aware of the propositions made and goals set by the experts, agree and participate in what needs to be done and also express their own expectations, perceptions and attitudes, guiding the rehabilitation goal-setting. Working with the family is fundamental. In a specialized CP Center, parents should be able to reach the members of the team at a short notice and notify them about medical, educational, psychological, behavioral and family issues concerning their child with CP. The team in its regular or irregular meetings should address the matters outlined by the parents and adjust the rehabilitation process accordingly. Parents should be instructed by the rehabilitation team on how to use the rehabilitation services provided and should be informed regularly on their child’s rehabilitation process.

A smooth transition from the paediatric to adult rehabilitation services is of great importance to children with CP and to their families. The rehabilitation specialist and team should ensure the proper follow-up and continuation of an individualized rehabilitation care into adulthood.

**Activity**

Following to the presentation of the main idea-information of the session there will be a discussion between the participants.

**Reflective questions**

- Interaction of the rehabilitation team and community services – community-based rehabilitation.
- Transition from paediatric to adult rehabilitation services.

**Suggested Readings**

- White Book on Physical and Rehabilitation Medicine in Europe
  Copyright© 2006 by Section of Physical and Rehabilitation Medicine and European Board of Physical and Rehabilitation Medicine, Union Européenne des Médecins Spécialistes (UEMS) and Académie Européenne de Médecine de Réadaptation.
• UN Standard Rules to provide persons with disability full participation and

• Rehabilitation and integration of people with disabilities: policy and integration.
  Strasbourg: Council of Europe Publishing; 2003. 7th ed. p. 369

• L. Gagnard et M. Le Metayer, Rééducation des Infirmes Moteurs Cérébraux,
  Expansion Scientifique Française, 2000
Module 5
TRAINEE BOOKLET

Individualized Education Program (IEP)

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TURKEY

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Chapter 1

Medical and Educational Evaluation, Placement of Children into an Educational Curriculum

Learning Outcomes

Trainees will be expected to:
1. Comprehend medical / educational evaluation of student with CP.
2. Discuss if a student with CP is placed into the appropriate curriculum.

Chapter Contents

Usually the difference in the child is noticed by the parents or the teachers. The answer to the question whether the child is different from his/her peers is studied.

The earlier notice of the visible physical disabilities in the children with CP means earlier medical evaluation and earlier medical treatment when compared with the other disabilities by the health care personnel. On the other side, since rehabilitation intervention process (e.g., surgeries, botox or physiotherapy) of the children with CP takes long time, it could result in disruption and even delay in the educational evaluation process of these children.

“Following the birth in the hospital, my doctor said that my child has Cerebral Palsy. Then we received a series of surgeries, interventions and therapies. My daughter is 13 years old now. We newly noticed that we ignored education.”

Educational Evaluation and Placement

After the completion of the medical diagnosis process, the first stage is the educational evaluation of the children with special needs. At this stage;

- Standardized tests related to the developmental and sensorial characteristics of the child are used.
- Information is provided from the family and the persons working with the child. For instance;
- Standardized development evaluation tools as Stanford Binet, WISC-R, Leiter, Portage, Peabody, GEÇDA,
• Control lists (evaluation forms based on the curriculum)
• Family interview forms can be used.
As a result of these, whether the disabilities of the child imply the need of special education is decided.

**In the second stage:**
Under the light of the information obtained in the first stage, the student who has special needs is placed to the suitable education program.

**Turkish practice in Diagnosis, Evaluation and Placement**

![Diagram](image)

**Let’s think and write!**

According to your opinion, what should be taken into consideration during the placement of individuals with special needs to the suitable educational environment?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
The students with special needs can be placed to “segregated environments” or “mainstream setting”, according to their characteristics. In the segregated environments the students with disabilities are together, while in the mainstream setting the students with and without disability receive the education together. In the placement of the students with special needs to a suitable educational environment, we are guided by the term “the least restrictive educational environment”.

The least restrictive educational environment: These are the environments in which the student can mostly accomplish most achievements while being together with his/her peers. However, the term “the least restrictive environment” varies according to the individual characteristics of the students. Special boarding school can be the least restrictive environment for one student, while it is the most limiting environment for another student.

Let’s think and write!

The student is placed in your educational environment; however, you think that this is not suitable placement for student. What must you do?

As it varies from one country to another, the educational evaluation, diagnosis and placement process that takes place in Turkey is described in the following.

Guidance decision is taken for the individuals for whom the special educational needs have been identified by the “educational diagnosis, monitoring and evaluation team”. Special education services board takes the decision for these individuals to be placed in the mainstream schools and classes or the schools and classes of special education. The monitoring of these placements is carried out in cooperation with the school, educational diagnosis, monitoring and evaluation team and special education services board.

The improvements of the student are monitored regularly at certain intervals. At the end of a monitoring period of three months following the enrolment, guidance and psychological counselling services board in the school may apply directly to the special education services board for the student who is not considered to be properly placed.
In the application, they prepare a detailed report about the student and the measures taken. This report is the “individual development report” of the student. If the report is approved, the special education services board work in cooperation with the educational diagnosis, monitoring and evaluation team to initialize a new evaluation process and notifies the result to the guidance and counselling services board the latest in one month’s time.

**Portugal Practice in Diagnosis, Evaluation and Placement**

Medical diagnosis is not required under the Portuguese laws. If it exists it’s the product of health care services.

The evaluation of the child is done within a transdisciplinary team, including always, the classroom teacher, the special education teacher, the parents and, according to specific cases, psychologists, physiotherapist, occupational therapists, doctors, and whoever else might be considered useful. The person responsible for the process is, always, the classroom teacher. The transdisciplinary team uses the International Classification of Functioning, Disability and Health, Child Version (ICF-CY) as a framework to establish: 1) what areas have to be assessed for each child; 2) who is going to be responsible for which evaluations; 3) what kind of measures are going to be collected. After gathering all the data, a functional profile of the child is produced and is based on that that the eligibility to special education services is made.

The parents are free to choose the school they want and children with have priority enrollment. Nevertheless, the government organized the system to have some schools particularly prepared and equipped for some specific needs, in this case, schools for the blind, the deaf, children with autism spectrum disorders and children with profound disabilities. Still, the parents may choose a school that is not a part of that network.

In all cases the aim is to place the child and center the program in the regular classroom. For some children, due to their own characteristics and to the characteristics of the group, the transdisciplinary team might decide to take the child out on certain periods to work specific skills, for instance.

The teacher is always a part of a transdisciplinary team and those decisions must be discussed and approved by the team. The parents have the last word on this process, because they must participate in the construction of the IEP and accept and sign it.

**Italy Practice in Diagnosis, Evaluation and Placement**

Medical diagnosis is realized by a social officer working with professional local medical units (considering the type of disability) appointed by a Medical Commission for Social Disability.
The educational evaluation of the student is completed at the same as the diagnosis and the experts use ICD-10 in Italy. (The 10th Review of International Statistical Rating on Health Problems and Illnesses).

The families decide about the school in which the student will be placed after receiving recommendations from the experts.

After medical diagnosis and educational evaluation, according to the international laws the students are placed in public schools.

**Romania Practice in Diagnosis, Evaluation and Placement**

The initial information about the children with disabilities is reached by the medical authorities (usually hospitals and family’s doctors). Each child is evaluated against specific criteria and receives a diagnostic. This diagnostic it is communicated only to the families of children. After the diagnostic is established, the concerned individuals are registered using a code for disabilities classification (easy, medium, hard, very hard). This code does not allow identifying the name of illness or other specific information. The distribution of children in the educational system is made according the disability code without any reference to the diagnostic. This means that children with CP or other types of mental of physical affections are approached in the educational system in the same manner, without any possibility to create a specialized approach according to the very specific affection.

**Suggested Readings**

- [http://www.european-agency.org/country-information](http://www.european-agency.org/country-information)
  [http://dx.doi.org/10.1080/1034912X.2011.570496](http://dx.doi.org/10.1080/1034912X.2011.570496)
Chapter 2

Individualized Education Program; definition and advantages of IEP

Learning Outcomes

Trainees will be expected to;
1. Know the definition of IEP
2. Know the advantages of IEP

Chapter Contents

Individualized Education Program (IEP): Individualized Education Program is a written program prepared according to the individual needs of the child, which contains the annual measurable long and short-term goals, support services, venue, time and assigned staff.

Benefits of IEP: Preparing an IEP provides various contributions to the student with Cerebral Palsy, to his/her family, to the teacher and to the community which s/he lives in.

Let’s think and write!

In which aspects we provide contribution to the student by preparing IEP?
Let’s think and write!

In which aspects we provide contribution to the family of the student by developing IEP?

- We establish efficient communication and cooperation between the parents and the school.
- Parents have the opportunity to decide on the educational rights of their children.
- Parents learn about their duties and responsibilities in their children’s education.

Let’s think and write!

In which aspects developing IEP contributes to the teacher?

We provide contributions to the student, because:

- We clarify the different needs of the student originating from his/her disability.
- We organize the educational activities according to the needs of the student.
- We follow and evaluate the educational plan and progress of the student.
- We give opportunity to the student to be independent and a productive member in the community.

We provide contributions to the family of the student, because:

- We establish efficient communication and cooperation between the parents and the school.
- Parents have the opportunity to decide on the educational rights of their children.
- Parents learn about their duties and responsibilities in their children’s education.
We provide contributions to the teacher of the student, because:

Teachers see clearly the competencies and needs co-existing in the student.

Develops interdisciplinary working skills.

Efficient management of education and evaluation processes are provided.

We take necessary measures for the transition planning of the student.

Suggested Readings

Chapter 3

Individualized Education Program; members of IEP, their duties

Learning Outcomes

Trainees will be expected to;

Define the members of IEP team, their duties and understand interdisciplinary collaboration

Chapter Contents

Let’s Write

Who are the members of IEP team? Write your estimations in the diagram below.
**IEP Team**

The members of the IEP team are assigned in the preparation of the IEP for the students with special needs at the school. After the preparation of IEP for the student, IEP team should meet regularly. IEP is evaluated in the monthly or bimonthly team meetings. In these meetings, the improvement of the student is evaluated and necessary changes are done.

*Tasks of IEP Unit Coordinator/Chair:*

- Chairs the meetings.
- Determines the members of IEP team.
- Establishes IEP development unit.
- Provides motivation and efficient communication for the IEP team members to work together.
- Invites the members to participate in IEP team meetings when necessary.
- Takes measures in the school according to the needs of the student determined in the IEP.

*Tasks of Classroom/Branch/Counsellor Teacher:*

- Assumes efficient role in the preparation, implementation, evaluation and reporting of the IEP.
- Works in cooperation with the other members.

*Tasks of the family:*

- Determines the needs of the child and it’s own needs in IEP development process.
- Organizes in/out school activities to support the gains of IEP.

*Tasks of the student:*

- Indicates the gains that he or she wants to be included in the IEP, Fulfils the responsibilities to acquire these gains.

*Suggested Readings*

Chapter 4

Steps of IEP Development

Learning Outcomes

Trainees will be expected to;

1. Define steps of the IEP development
2. Determine student’s needs
3. Describe the student’s performance
4. Define long and short terms objectives
5. Determine start and end dates of IEP and responsible persons in the IEP

Chapter Contents

During the preparation of IEP, the following steps are taken.

Step 1: Determination of student’s needs

In this step, the difference between the behaviours required as per the grade of the student and the behaviours actually presented by the student is determined. In order to achieve this,

- Firstly the goals and behaviours existing in the program should be written and converted into a check list form. While writing the goals, curriculum and supplementary books can be used. The list of goals is presented in the syllabus.
These lists can be adapted and used. The goals in the syllabus should be written in behavioural terms, in other words these should be observable and measurable.

The table below contains examples for appropriate and inappropriate actions.

<table>
<thead>
<tr>
<th>Appropriate Actions</th>
<th>Inappropriate Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Writes</td>
<td>Knows</td>
</tr>
<tr>
<td>Says Distinguishes</td>
<td>Understands</td>
</tr>
<tr>
<td>Draws Matches</td>
<td>Feels</td>
</tr>
<tr>
<td>Removes Counts</td>
<td>Believes</td>
</tr>
<tr>
<td>Compares</td>
<td>Develops</td>
</tr>
<tr>
<td>Repeats</td>
<td>Appreciates</td>
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<tr>
<td>Chooses</td>
<td>Likes</td>
</tr>
<tr>
<td>Classifies</td>
<td></td>
</tr>
</tbody>
</table>

**Checklist;** is a form used in the rough evaluation of the student. This form consist of the instructions, questions, result and explanations parts. The goals in curriculum are written in the instructions part. As the check lists can be formed for each academic lesson, these can also be prepared dedicated to self-care and daily life skills.

Afterwards, the checklist prepared in line with the curriculum is applied one-to-one to the student. The things that the student can do are indicated with “+” to the result column, where the things that the student cannot are indicated with “-“. If the student has a special situation, this is reflected in the explanations part. (for instance, “the writing problem derives from the weak hand muscles” etc.) At the end of the implementation, the things that the student can and cannot do are revealed.

The things that the student can do show us the performance of the student, while the things that the student cannot do shows us the needs.

- We examine characteristics of the special needed student related to the communication, social and academic behaviours that we want the student to show during the lessons.

  **Example:** Teacher Elif is studying with the students in the classroom the addition operation with carry. In the evaluation studies related to the mathematic lesson done with Ali, she observed that Ali couldn’t even do addition operation without carry now. For this reason teacher Elif has determined the addition operation without carry as the need of Ali.

- In addition to the academic lessons, the needs of the student is determined via the check lists prepared in the areas as the self-care and daily life skills of the student.

  **Example:** In the evaluation studies related to the self-care skills with Ali, Teacher Elif determined that Ali cannot wash his hands. For this reason, teacher Elif determined washing hands as the need of Ali.
At the same time, the interviews done with the parents and the student accompanied by the check lists enable us to know the significant needs of the student.

In these studies, many needs of the student can be determined. In such a case, one should determine the priority for the student. (Examples of checklist can be found in the supplementary material of the booklet)

**Activity 1**

Fill in the checklist below with the gains part for an academic lesson that you choose within the frame of the overall objectives determined for the students in your country or making use of any curriculum. Afterwards, hypothetically tick the result part for a student.

<table>
<thead>
<tr>
<th>No</th>
<th>Gains</th>
<th>Result</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
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<td>8</td>
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</tr>
</tbody>
</table>

**Step 2: Describing Performance Summaries**

The data obtained as a result of the educational evaluation studies done with the student are documented. The important issue in describing the performance summaries is to mention the strong points of the student in every field first and then to write the problematic areas.

Ali diagnosed with CP can sit in the classroom during the teaching period and can follow the lesson quietly. However, he can communicate with low level comprehensive sentences formed of at most two words. He needs the repetition of the instructions given to him”

(Examples of summary of performance can be found in the supplementary material of the booklet)
Activity 2

Describe the performance of the mentioned student according to the check list hypothetically marked in the activity 1.

Step 3: Development of Long Term Goal and Short Term Goal

a. Development of Long Term Goal (LTG)

The LTG is developed according to the needs of the student. It shows the success expected from the student within one year. However, we must not forget that the achievement of many goals might take more time than one year. IEP should be considered as a plan that aims the student to gain all the skills within one year. LTG could be written according to the development areas that the student needs. The LTG for the students who are having special needs in the academic field can be in the cognitive development area. Particularly, the goals developed in the areas of reading, mathematics, language and comprehension are included in the cognitive field.

Example;

- Respects the rules of the capital letters and punctuation marks in his homework.
  
  LTG for the students having difficulty in adaptive behaviour, social and emotional development can be emotional development field.

Example;

- Participates in group games.
  
  LTG for the students having shortcomings in motor skills as minor, major motor coordination, muscles control, reaction time and other physical activities can be psychomotor field.

Example;

- Eats food independently.
- Participates in physical activities that are done with the group.
Activity 3

Examining the LTG below, mark them as (T) for True and (F) for False.

1. ..... Participates in the games played with the group.
2. ..... Cuts a simple shape with the scissors.
3. ..... Writes a short text told to him/her.
4. ..... Takes bath independently.
5. ..... Shows the colour red independently among the mixed colours around.
6. ..... Shows the main colours independently.

b. Development of Short Term Goal (STG)

STG are the measurable mid steps between the current performance levels of the student and the LTG. STG is formed by dividing logically the main parts of the annual goals.

LTG is developed for one term, semester or year while STG shows the daily, weekly or monthly targets to reach. In short term goals, the mid steps starting from the capability level of the student until the level expected at the end of the year from the student are mentioned.

STG is prepared in a certain educational order to achieve the annual goals. Attention is given to each and every sub capability to follow a logical order and the analysis to be coherent with the teaching order.

For instance, in mathematics before teaching the addition and subtraction operations, multiplication cannot be taught. In skill learning, for a student who cannot put on his/her shoe, tying shoelace should not be set as a target.

<table>
<thead>
<tr>
<th>Mathematics Lesson</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LTG</strong></td>
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<tr>
<td>Adds a 2 digit number and another 2 digit number with carry.</td>
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<td></td>
</tr>
</tbody>
</table>
Activity 4

Examining the STG below, mark them as (T) for True and (F) for False.

1. ..... The student forms pattern from symbols.
2. ..... The student draws the basic lines.
3. ..... The student answers the questions asked to him/her.
4. ..... The student draws a line between the spaces in verse independently.

Activity 5

Develop LTG and STG for the student whom you wrote the performance hypothetically in Activity 2.

<table>
<thead>
<tr>
<th>Log Term Goal</th>
<th>Short Term Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>1.</td>
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<tr>
<td>2.</td>
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<tr>
<td>3.</td>
<td></td>
</tr>
</tbody>
</table>

Step 4: Determination of start-end dates of the IEP and the responsible persons

The development of a realistic timetable in IEP process is important in terms of realization of the goals in time, planning and review of the services. In the determination of these dates, we should know that different needs require various lesson time durations. For the realization of LTG; one term, or one year is needed while for the realization of STG a few weeks or months are required.

Although the class teacher is perceived as the person responsible for the IEP, there might be the need for some other responsible persons in the achievement of some certain goals. For this reason, the main responsible persons and the other should be indicated in the student’s IEP.

Suggested Readings


Chapter 5

The other components in IEP

Learning Outcomes

Trainees will be expected to;

1. Determine the support services
2. Determine the materials to be used
3. Make environmental adjustment
4. Determine the correct instructional methods

Chapter Contents

The student’s needs, student performance, LTG, STG, start-end dates and the responsible persons are the essential contents of the IEP.

Determination of support services, materials, environmental arrangements, teaching methods and techniques and IEP evaluation are the other components of IEP.

Determination of Support Services

One of the information to be included within the IEP is the support services provided for the student, if any. It should be indicated in IEP whether the child benefits from services as support education room, in-class support, language and speech therapy, physiotherapy, transportation, parental education and education at home.

Determination of Materials

Another issue that should not be neglected during the preparation of IEP is the determination of the materials to be used in the education. Efficient materials should be selected in order to obtain gains in IEP. For instance, in order to support the understanding and comprehension skill of a child having intellectual disability in addition to CP, it could be more effective to use real material. Furthermore, tearing of the notebook/papers the child uses due to unintentional spasms might create reluctance in the child. For this reason, instead of paper a thicker carton can be used or a computer and keyboard can be preferred.

Making Environmental Arrangements

The information of the individual differences renders the preparation of IEP mandatory. The learning type of each student is different. For instance, when
we prepare the IEP with the information telling us that the children with CP have difficulty in receiving education in noisy environments with loud and instant noises, the decision that the education will take place in a silent environment can be included in the IEP. In another example; while working with a student having attention deficit together with CP, the decision that there will be no other stimulus in the education environment except for the material used for learning the targeted behaviour can be included in IEP.

**Determination of Suitable Teaching Methods and Techniques**

In addition to the venue, duration, material and teaching activities that are delivered in the education process it is also important to determine the teaching methods and techniques in advance. The convenience of these methods and techniques determined to the student should also be questioned.

The best learned things are the ones that the individual makes and experiences by him/herself. The teacher should take this method as the basis for every activity. Attention should be drawn to use experience, dramatization and demonstration methods. In addition to the oral method in order to increase the efficiency of learning it would be suitable to use teaching methods as observation, experience, modelling, problem solving, question-answer, discussion and group work and so on.

**Evaluation of IEP**

The role of evaluation is significant in the successful implementation of the IEP. The results of the evaluation done will be effective for the preparation and implementation of the new IEP in the future. In this way, the evaluation gives us information whether the gains in IEP are achieved or not, whether these are suitable for the child, as well as what the future gains would be.

The person responsible for the implementation of the student’s IEP is also liable for continuously evaluating the success of the student in the proposed education environment. The individual development reports showing the individual progress of the student should be prepared at least once a year. The individual development reports could be prepared after the interim evaluations.

**Suggested Readings**

Chapter 6

Development of Individualized Instruction Plan

Learning Outcomes

Trainees will be expected to;
1. Define individualized instruction plan
2. Prepare the IIP
3. Evaluate by using IIP
4. Write instructional objectives

Chapter Contents

The Individualized Instruction Plan is the preparation of the things to be done in details for the behaviours that the student is expected to gain. The IIP is a guide for the teacher. The implementation of the goals in this program is only possible with the preparation of IIP. The IEP is prepared annually, while IIP is prepared as daily, weekly and monthly.

Detailed evaluation is required for the preparation of IIP. The detailed evaluation is done using Criterion Dependent Tests (CDT).

Criterion Dependent Tests (CDT)

CDT are the detailed evaluation tools consisting of the educational goals and the questions dedicated to them.

Short term goals enable us to achieve long term goals. Educational goals should be written in order to achieve STGs. Educational goals are developed analysing STG.

CDT contains notifications, instructions, criterion, results and explanation parts. In the notifications part, analysed sub goals of STG are written. In instructions part, the questions dedicated to these notifications should be inserted. Three questions should be asked for each notification. The evaluation criterion could be determined as 2/3 depending on the number of the questions. In the result part, (-) or (+) sign could be given depending on the fulfilment of the criterion by the student. For instance, if the student gives wrong answers to 2 questions among 3, and correct answer to 1 question, (-) sign is written in the result part.

The CDT prepared is applied to the student. The things that the student does form the initial step of him/her. According to the initial step, our educational goals are
determined. Afterwards, the experiences required by the goals, teaching materials and methods should be determined respectively. By creating experiences for the student using the method and the materials selected, the teacher is providing opportunities to achieve the educational goal. After the instruction, CDT are applied once again to the student and the evaluation is done. In this way, student’s development is determined.

**Activity 6**

Analysing one of the STGs you developed in Activity 5, develop the educational goals. Writing on the CDT table, prepare developments dedicated to the notification.

<table>
<thead>
<tr>
<th>Notifications</th>
<th>Instructions</th>
<th>Criterion</th>
<th>Result</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>1.</td>
<td>2/3</td>
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</table>

**Individualized Instruction Plan (IIP) Components**

The components to be included in IIP are as follows.

**IIP FORM**

Name / Sur name:
Class:

<table>
<thead>
<tr>
<th>Subject</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Student’s Performance Level</td>
<td></td>
</tr>
<tr>
<td>Long Term Goal</td>
<td></td>
</tr>
<tr>
<td>Short Term Goal</td>
<td></td>
</tr>
<tr>
<td>Learning Goal</td>
<td></td>
</tr>
<tr>
<td>Teaching Process</td>
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<td>Venue of teaching</td>
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<td>Tools and Equipment</td>
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<td>Methods/techniques to be used in teaching:</td>
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<tr>
<td>Duration</td>
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<tr>
<td>Delivery of the lesson</td>
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<tr>
<td>Evaluation</td>
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</table>
Subject: The name of the subject in line with the result of evaluation done dependent on the subject is going to be written here.

Student’s Performance Level: The performance level shown by the student is written here according to the result of the evaluation done dependent on the subject.

Long Term Goal: LTG existing in the IEP of the student related to the selected subject is written here.

Short Term Goal: STG determined according to the LTG in the IEP of the student is written here.

Learning Goal: The step(s) required for the realization of STG is/are written here. In the teaching of STG, the all educational goals are demonstrated on a single IIP and the education of these goals is performed.

Teaching Process:

a. Venue of teaching: The venue of teaching is written in this part.

b. Tools and Equipment: Every sort of material/tool-equipment to be used during teaching is written in this part.

c. Methods/techniques to be used in teaching: The methods/techniques to be used during the teaching are written in this part.

d. Duration: The duration to be used in the teaching is written in this part.

e. Delivery of the lesson: Starting from the preparation for the lesson, the manner of teaching (instructions, help, feedback and awards) are written step by step in this part.

f. Evaluation: The first evaluation done through criterion dependent measurement tool enables us to determine the initial level (IL) of the student. After the education, the criterion dependent measurement tool is re-applied and a new evaluation is done.

Issues to be considered in the implementation process of IEP

Attention should be drawn to the teaching of a targeted gain in IEP, particularly in levels of acquisition, fluency, consistency and generalization. For instance, the child learns a concept in the classroom during acquisition stage, in the fluency stage, student gives correct answers to a question related to that concept in the following minutes of the lesson, in the stage of consistency although the education is completed and a certain period of time has passed answers to the question related with this concept correctly. In generalization stage, the student provides correct answers to the questions related to that concept, asked at various times and in different environments. In order to accept the achievement of teaching, the stages mentioned above should be fulfilled. In addition, the best teaching route is from
Individualization to socialization, from concrete to abstract, from known to unknown and from close to far. It will be useful that the teachers accommodate the fields of knowledge to be presented to the student according to these educational principles.

The education should be continued in the environments outside the school as it is inside the school. For this reason, the goals mentioned in the IEP and the activities carried out should be notified to the parents regularly; and homework to support the activities carried out at home or in social environments should be given.

CHECKLIST FOR THE DEVELOPED IEP

<table>
<thead>
<tr>
<th>Getting prepared for IEP;</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview the student’s family and the student placed in the classroom</td>
<td></td>
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<tr>
<td>Determine the family needs</td>
<td></td>
</tr>
<tr>
<td>Cooperation with the all the persons and institutes related with the student/ gather information about the student</td>
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<tr>
<td>Perform educational evaluation.</td>
<td></td>
</tr>
<tr>
<td>Determine what the student can and cannot do.</td>
<td></td>
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<tr>
<td>Decide about the support services</td>
<td></td>
</tr>
<tr>
<td>Determine the dates of IEP meetings</td>
<td></td>
</tr>
</tbody>
</table>

During IEP process

| | |
| Write IEP through the information obtained in the preparation process | |
| Initialize and continue education process (IEP) | |
| Perform evaluations in the determined dates | |
| Guide IEP via the IEP meetings | |

At the end of IEP Process;

| | |
| Perform IEP evaluation | |
One of the most important problems that hinder the IEP implementation for the teachers is the behavioural problem of the student. We should efficiently use “Behaviour Modification Methods” in order to reduce the problematic behaviour of the students and increase their positive behaviours. The detailed information regarding the Behaviour Modification Methods is available in the supportive material within the scope of the project.

Suggested Readings


References

Rehabilitation Techniques, Training And Health Care Systems

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Miguel Santos

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TURKEY

This project has been funded with support from the European Commission. This publication [communication] reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein.
This training module was designed to provide knowledge about rehabilitation techniques, training and health care systems in a theoretical and in a practical basis. This chapter will present knowledge about important issues within rehabilitation techniques such as: (a) accompanying conditions of children with CP during the interaction with the child; (b) the concepts of intensity and repetition of rehabilitation approaches, the active participation of the child in those rehabilitation processes and its contribution to the development of the child; (c) training approaches for accompanying conditions such as cognitive, perceptual, speech, oral motor problems of children with CP; (d) the concepts of appropriate positioning during daily life in school, at home, etc., and behavioral changes related to positioning; (e) health care systems including knowledge about the facilities, supports of the health care system for their children and for themselves and about the health professional team and their roles in rehabilitation. The module is also expected to provide practical suggestions to be applied in daily life by parents and teachers of children with cerebral palsy (CP).
Chapter 1

Basic concepts of rehabilitation approaches

1-a: Accompanying conditions (low vision, hearing, speech and communication problems, intellectual or learning disability, perceptual difficulties, sensorial problems, epilepsy, gastro-esophageal reflux, constipation, nutritional difficulties, saliva control problems, recurrent chest infections)

Learning Outcomes

In the end of the session, parents and teacher will learn and increase their awareness about the accompanying conditions of children with CP during the interaction with the child.

Vision Problems

Half of all children with cerebral palsy have eye muscle imbalance or strabismus (cross eyes) and refractive errors (near-sightedness or farsightedness). You should give your child red-white or black-white toys to play with. You should place a mirror in your child’s room.

Hearing Impairment

You should suspect of hearing problems if your child seems oblivious to sound, does not respond to his or her name, or watches faces intently for the meaning of words. Whether or not your child shows any of these symptoms, you should have his hearing checked regularly beginning at four months of age. An audiologist can test your child’s hearing and diagnose problems affecting the transmission of sound. You should support your child development with visual and vestibular stimulations.

Speech Impairment and Communication Disorders

Children with CP often have speech impairments. This is because the muscle tone problems that make it difficult for children to control other body movements also make it difficult for them to control oral-motor movements, movements of the jaw, lips, tongue, and facial muscles used in speaking. Picture boards and computers can give your child the power to talk even when his or her muscles lag behind.
Intellectual or Learning Disability and Perceptual Difficulties

It must be stressed that there is a wide range of intellectual ability in children with cerebral palsy. Children with severe physical disabilities may have normal intelligence. Problems such as judging the size and shape of objects are termed perceptual difficulties, and may not be apparent until school age.

Sensory Impairment

The senses that children with cerebral palsy most often have trouble with are touch, position (proprioception), movement (vestibular), and balance. Frequently, children with sensory impairments have difficulty using their senses to help them plan their movements. The term for this problem is dyspraxia. For example, to put on her clothes, a child with dyspraxia has to do each movement involved separately, taking time between each movement to plan the next. This makes dressing very time-consuming and laborious.

Epilepsy

Epilepsy may develop in about one in three of all children with CP. If epileptic seizures are not controlled, this may affect especially cognitive development of the child. When the child suffers a seizure, you should be calm and put the child in side lying position.

Gastro-Esophageal Reflux

Food comes back up the esophagus (gullet) more commonly in children with CP. Although the medical issues of GER need to be addressed primarily, you should assist with positioning to minimize reflux and promote comfort.

Constipation

This is common in children with cerebral palsy. The cause is not always clear. Sometimes it relates to the lack of usual mobility, or it may be related to the difficulty eating a high fiber diet.

Nutritional Difficulties and Saliva Control Problems

Some children with severe cerebral palsy may have difficulties with chewing and coordinating their swallowing, causing prolonged or difficult meal times. Children often dribble in the early years of life. Dribbling can persist in children with cerebral palsy.
Recurrent Chest Infections

This is a problem in only a small group of children with cerebral palsy. Some of the food and drink may inadvertently pass in to the lungs causing the child to cough and wheeze. Those with cerebral palsy may occasionally develop a chest infection, pneumonia or asthma.

Bone Disease

Some children with cerebral palsy are not able to be as active as children without disabilities and have some degree of osteoporosis. Fractures can occur with very minor injuries and sometimes during normal activities such as napkin change or putting an arm through a sleeve. Occasionally children need special medication to promote bone mineralization.

Learning Outcomes

In the end of the session, parents and teachers will acquire knowledge about the concept of intensity and repetition of rehabilitation approaches as well as the importance of the active participation of the child in that rehabilitation and its contribution to the development of the child.

There is no consensus regarding the optimal dose of training. Physiotherapy intervention, its intensity and frequency should be tailored to meet the need of each individual infant and their parents.

Intensive physical training for children has been defined in several ways, e.g. five sessions a week over six months, five sessions a week over four weeks, or several daily sessions over five months.

The need for active participation is emphasized throughout treatment with the specific aim of the child initiating and controlling the activity for him/herself as soon as possible. The strategies learnt in the treatment should be carried over into everyday life activities; therefore, there is a strong emphasis on parent and caretakers participation. Everyday activities, such as playing and dressing are used to promote practice and provide the opportunity for the repetition needed for the acquisition of new skills. When planning the most appropriate activities to work towards, therapists draw on an in-depth knowledge of child development, recognizing the interdependence of different aspects of development, including the control of movement, perception,
cognition and the development of the musculoskeletal system. Early intervention has been advocated by physio- and occupational therapists working with this concept, with the aim of optimizing the development of the infant’s activity prior to the strong establishment of patterns of movement associated with abnormal tone.

1-c: Individual problem solving

Learning Outcomes

In the end of the session, parents and teachers will learn and increase their awareness about individual problems of the each child and the importance of receiving professional support.

The impact of having a child with any sort of difficulty on parents can never be underestimated. Parents may experience emotions such as anger, grief, a sense of disbelief and feelings of isolation. These emotions are often very intense at the time of diagnosis and may recur over time. Children with severe cerebral palsy may need a lot of assistance with daily living skills such as eating, bathing and dressing, placing enormous stress on the family. There are a large number of hidden financial costs. These include visits to doctors and other professionals, special equipment, maybe extra nappies and extra childcare. All parents will have their own individual needs. However, for most parents their needs will include (a) having their questions answered - it is sometimes helpful if parents write down the questions they want to have answered when they see someone to discuss their child’s needs - (b) support in understanding the nature of their child’s problems - this support will include the opportunity to share the feelings, hopes, and fears they have for their child, Support may be from other family members, friends, parents with similar experiences and professionals; (c) information about services and assistance in gaining access to them; (d) information and skills to help them assist their child in the best possible way; (e) having a break -time off from childcare is important for most parents and when the child’s daily needs place extra demands on time and energy this is even more important. A break enables families to have a rest and to spend time doing other things.
Learning Outcomes

In the end of this session, parents and teachers will learn and increase their awareness about who a “physiotherapist” is, the content and extent of physiotherapy and the referral of the child to physiotherapy?

The goal of physical therapy (PT) is to identify and treat problems with movement and posture, or body position. With special exercises, handling techniques, and constant encouragement, physical therapists can help children learn or become more proficient in a variety of movement skills, including rolling, sitting, crawling, and walking. For children with cerebral palsy whose movement problems are caused by brain injury, it is crucial that PT begin at an early age. This is because the central nervous system is most susceptible to change during the first five years of life. Physiotherapy begins in neonatal period and continue during lifelong period although it varies according to many factors such as the age, severity of child condition, level of activity and participation of the child and so on. The physical therapist is the professional who will evaluate and treat the child for the movement problems described above. He or she will probably be one of the most important people in your child’s early life, helping your child to develop her motor skills to the maximum extent possible. He or she will also help you understand how to foster good self-esteem in your child, which is the critical element in how far and hard a child is willing to push to gain new skills. Most likely, the physical therapist will be your primary teacher about your child’s disability and about problems with specific movements. The physical therapist your child sees may specialize in pediatrics and may further limit his or her practice to infants and children with developmental disabilities. Your child’s physical therapist may also have specialized training in specific techniques for children with disabilities.

The intensity and frequency of physiotherapy intervention should be tailored to meet the needs of each individual infant and their parents. The goals are established based on the parents’ and children’s priorities. Learning takes place in individually tailored interventions in the child's natural environment by repetitive practice of the everyday goal activities, in a motivated, challenging and playful way, and in
combination with impairment-focused interventions. The overall aim of the therapy is to improve everyday performance in activities and participation.

1-e: Occupational therapy- when, why, how?

**Learning Outcomes**

In the end of this session, parents and teachers will learn and increase their awareness of who an “occupational therapist” is, the content and extent of occupational therapy and the referral of the child to occupational therapy.

Researchers say "Change the Environment, Not the Child". Occupational therapy is a treatment that focuses on helping cerebral palsy patients achieve independence in all areas of their life. Occupational therapy for patients with cerebral palsy can provide them with positive, fun activities to enhance their cognitive, physical, and fine motor skills and increase their self-esteem and sense of accomplishment.

Occupational therapy for cerebral palsy can meet children’s needs by working on fine motor skills so that kids can grasp and release toys and develop good handwriting skills. Occupational therapists also address hand-eye coordination to improve play skills, such as hitting a target, batting a ball, or copying from a blackboard. They also help children with severe developmental learning delays in some basic tasks, such as bathing, getting dressed, brushing their teeth, and feeding themselves. Occupational therapists can help kids with behavioral disorders and with learning anger-management techniques. For example, instead of hitting others or acting out, the children would learn positive ways to deal with anger, such as writing about feelings or participating in a physical activity. Occupational therapists for patients with cerebral palsy allow them to be evaluated for specialized equipment, such as pushchairs, standing frames, walking frames, side lying boards, splints, bathing seats, or dressing devices that will help improve your child’s mobility, posture, and so on. Spoons or forks with large or heavy handles can make it easier for a child to self-feed, as well as cups with special handles and plates with higher lips to keep food from slipping off. A patient with speech difficulties or physical limitations can operate computers with touch-screens or voice-command much easier. Special computers have the capability to help people with cerebral palsy perform tasks that would normally be impossible for them. Computers can help them turn on a light with the blink of an eye or open a door with a simple nod of the head.

The goal of occupational therapy for patients with cerebral palsy is to help them live as independently as possible. Occupational therapy for patients with cerebral palsy
uses the individual’s personal strengths to help them overcome their disabilities. It also helps them to learn how to perform daily activities such as dressing, eating, and bathing themselves, all this creating a higher sense of independence and self-confidence.

It is also the job of an occupational therapist to help make your home and community accessible to your child. Many adaptations may need to be accommodated in order for your child to reach his or her maximum level of independence. For instance, because children with Cerebral Palsy often have problems with their posture and muscle tension, a chair may need to be adapted with creative use of foam for the child to sit comfortably. Things such as the Rifton Corner Seat aid in a child’s ability to sit on the floor while playing, without stressing the leg muscles and while keeping the child’s posture upright.

1-f: Medical And Surgical Treatment For Muscle Tone

Learning Outcomes

In the end of this session, parents and teachers will learn and increase their knowledge about the recent medical and surgical interventions for muscle tone of children with CP.

Abnormal muscle tone can lead to complications that make it seem as if a child’s cerebral palsy is getting worse. Continuing tightness or spasticity of muscles can not only cause reduced function in the muscles themselves, but can also cause problems with the skeleton system— with the framework of bones, joints, ligaments, and tendons that support the muscles. These problems with bones, joints or muscles are known as orthopedic problems. Common orthopedic complications that children with high tone may develop included contractures, dislocated hips, and scoliosis.

Dislocated Hips

Sometimes the strong pull of muscles around the hips can cause the femoral bone in the upper leg to partially slip out of the socket joint where it joints at the hip. Children with severe quadriplegia are especially prone to develop dislocated hips. Generally, if your child is 3 to 8 years of age, the surgeon will begin by operating on the soft tissues (muscles, nerves, tendons). After your child is 5, the orthopedic surgeon might consider an osteotomy—an operation to change the angle of the femoral bone and the hip joint.
Scoliosis

About 15 to 30 percent of children with cerebral palsy develop scoliosis, or an abnormal curvature of the spine. A unequal tension of the muscles along the spine can lead to this condition. Scoliosis can also develop as the result of faulty positioning or posture - for example, if a child habitually leans to one side in the wheelchair or has dislocated hips. If not treated properly, scoliosis can affect your child’s posture, stature, sitting balance, walking ability, and heart and lung function. Scoliosis may also put additional pressure on the skin over the buttocks or back and cause pressure sores. If your child has a significant curvature of the spine, he or she might require surgery.

Contractures

This shortening of muscles and other tissues, with or without joint misalignment, is called a contracture. In children with cerebral palsy, contractures may develop because of limited active muscle movement or strong spasticity. Generally, contractures further limit the movement of children with cerebral palsy. When they occur in the lower extremities, contractures can also affect your child’s gait and posture. Contractures in the upper extremities affect a child’s ability to reach for, grasp, release, and manipulate objects.

Prevention and Treatment of Complications

Many of the complications of spasticity described above can be prevented or minimized with physical therapy and occupational therapy. Therapists can use stretching exercises to improve joint movement and prevent contractures; handling and positioning techniques to improve tone; and strength-building exercises to improve movement. Besides the therapeutic methods that physical therapists and occupational therapists use, there are several medical means to prevent or treat complications of muscle tone problems.

Medications and Nerve Blocks

Although medications can sometimes reduce high tone, they are not routinely prescribed for children with cerebral palsy. Generally, drugs are reserved for children with painful spasms of severe spasticity and are used as only one small part of the treatment plan. Spasticity in specific muscle groups can sometimes be significantly reduced through use of a nerve block. The effects of the procedure can last up to four to six months. The procedure can be repeated, but the medication is expensive. The Botox treatments are especially useful for children who have a limited number of spastic muscle groups.
Surgery

There are seven surgical procedures that can improve movement, correct deformities or prevent further contractions in children with cerebral palsy. Once surgery is approved a orthopedic surgeon will coordinate with your child’s physical therapist and occupational therapist to make sure that pre- and post- operation therapy will maximize the benefits of surgery. The types of surgical procedures sometimes used to help children with cerebral palsy are described below.

Soft Tissue Procedures

Soft tissue procedures are operations on the muscles, tendons, or ligaments to correct deformities or improve movement. They are the type of surgery most often used with children under five. Examples of soft tissue procedures include: Tendon lengthening, tendon transfers, tenotomy, neurectomy, neurectomies, muscle releases on recession (lengthening), myotomy.

Bony procedures

Bony procedures are operations on the joints and bones to correct deformities such as osteotomy, arthrodesis.

Selective Posterior (Dorsal) Rhizotomy

This approach involves selective cutting of the nerves of the spine. This can reduce the spasticity of muscle groups in the upper or lower extremities or trunk. By reducing spastic tone, the procedure can improve a child’s control of voluntary movements and enable her to move more easily. Also make sure that the surgery will be closely coordinated with your child’s therapy program for postoperative therapy.

Suggested Readings

- http://www.cerebralpalsysource.com/Treatment_and_Therapy/
- http://cerebralpalsy.org/about-cerebral-palsy/therapies/
- http://www.treatmentofcerebralpalsy.com
Chapter 2

Training Approaches

2-a: Training approaches for speech and language, cognitive and perceptual, oral motor problems of children.

Learning Outcomes

In the end of the session, parents and teachers will learn and increase their awareness about training approaches for accompanying conditions such as cognitive, perceptual, speech, oral motor problems of children with CP.

WHAT IS SPEECH AND LANGUAGE THERAPY?

Speech and language problems therapy can help children improve muscle tone and other problems such as motor planning difficulties (dyspraxia) that impede clear, fluent speech. Children with dyspraxia have the muscular ability to produce the movement, but can’t always successfully transmit the message to the specific muscles necessary to initiate the movement. Speech and language therapy can also help in the treatment of problems with feeding, drooling, non-oral feeding, or other oral motor functions - that is, movements involving the muscles in and around the face and mouth. In addition, therapy can help children who are permanently or temporarily unable to master the physical aspects of speaking learn to communicate in other ways - for example, through sign language, photographs, Picture symbols, or Morse code. Usually, children with cerebral palsy can start speech and language therapy as infants, provided their medical condition is stable. Because communication problems often translate into delays in social, emotional and cognitive development, it is vital for children to begin speech and language therapy at an early age.

COGNITIVE AND PERCEPTUAL PROBLEMS

Children with cognitive and perceptual problems demonstrate an impaired ability to utilise advanced cognitive process, manage simultaneous or multiple demands and successfully organise complex information, which subsequently effects task performance as well as task mastery. Health professionals must be able to adapt
examination and intervention approaches to accommodate the impairment of deficient intellectual functioning. It is the task and the challenge of parents and teachers to assist child to maximise his or her potential for optimum functioning across environments.

**ORAL-MOTOR PROBLEMS**

**A. DROOLING:** If your child drools because of sensory feedback problems, you should massage your child’s face with a washcloth and fabrics with a variety of textures to increase her sensitivity to wetness. If your child drools because of motor problems, you should learn to position her with her head and trunk aligned so that her muscle tone is as normal as possible. You should learn how to stimulate more normal swallowing, which is the key to controlling drooling and how to help your child control her lips so she can keep them closed when she is at rest.

**B. FEEDING:** If your child has difficulty sucking, chewing or swallowing because of muscle tone or sensory integration problems in the face, you should learn how to do a face massage to make feeding easier for her, how much food your child should eat and how much time should be necessary to eat a specific amount of food, which temperatures and textures of foods will best stimulate your child’s muscles and how to offer the cup, spoon and finger foods to your child, and will recommend adaptations to your child’s cup or spoon to make feeding easier.

2-b: Increase of physical fitness and endurance

**Learning Outcomes**

In the end of this session parents and teachers will learn and increase their knowledge about the basic and supportive therapy technique approaches for supporting the neuromotor development of the child.

**STRENGTH-TRAINING PROGRAMMES**

Strength training, also known as resistive training for people with cerebral palsy, is a type of therapy that is often used in conjunction with other forms of exercise to increase muscle strength and flexibility. Strength training also prevents the atrophy of muscles that are rarely used, a common problem among children and adults with cerebral palsy. Strength training works to reduce the chances of developing contracture
by keeping the muscles strong and limber. Strength training is aimed at significantly improving gross motor skills such as standing, walking, and sitting.

PARTIAL BODY WEIGHT-SUPPORTED TREADMILL TRAINING (PBWSTT)

Treadmill training is a dynamic system approach for attainment of locomotor skills in children with CP. It provides therapeutic intervention at the activity level of walking, one of the most important milestones in a child’s development. The child is suspended over a treadmill in a harness which supports varying degrees of their body weight, reducing some of the effort required for walking. The treadmill assists in the production of steps and enables the speed to be maintained while the child is supported in a safe environment. There is considerable variability in how PBWSTT programmes are delivered. A recent study, which looked at the effects of PBWSTT on endurance, functional gait and balance, trained children for 30 min twice daily for 2 weeks, showed improvements in walking speed and energy efficiency. PBWSTT is an active, repetitive, task-specific approach used to facilitate attainment of stepping and locomotion and to achieve a more normalised gait pattern. Treadmill training is based on current theories of motor learning.

LOCOMAT

Robot-assisted walking therapy is a form of physical therapy that uses a robotic device to help a person improve his or her ability to walk. The patient is suspended in a harness over a treadmill, and an exoskeleton robotic frame, attached by straps to the outside of the legs, moves the legs in a natural walking pattern. A computer controls the pace of walking and measures the body’s response to the movement. The pediatric model also has an interactive gaming interface that, through cartoon characters and challenges, motivates children and provides them instruction.

ADELI SUIT

The AST technique uses an intensive exercise protocol paired with wearing a form-fitting garment that provides resistance to movement. The suit comprises a vest, shorts, knee pads, and specially designed shoes. Pieces of the suit are connected by hooks, rings, and elastic bands that can be adjusted to provide pressure and support to muscle groups and joints.
The bungee-like cords are adjusted by therapists to mimic normal flexor and extensor patterns of major muscle groups in an attempt to reposition limbs to correct abnormal muscle alignment. The theory is that once the body is in proper alignment, aggressive movement therapy can be performed that will re-educate the brain to recognize correct movement of the muscles. The therapy regimen begins with stretching and massage before donning the suit and performing therapy. With the suit on, patterning exercises are performed using suspended positioning against gravity and assisted movement during functional mobility tasks, with tasks chosen based on the child’s level of function. Suit treatment programs are lengthy; most are run 6 days per week, 5 to 6 hours per day, and last 3 to 4 weeks in duration.

**Constraint induced movement therapy**

Constraint induced movement therapy often abbreviated to ‘CIMT’ is a therapy for children with hemiplegic cerebral palsy that aims to increase the child’s use of their hemiplegic arm and hand. CIMT involves constraining a child’s unaffected hand and/or arm for a period of time, usually in a modified glove or mitt, while they are encouraged to use their affected hand and arm in play activities.

**Hippotherapy**

Hippotherapy is a physical therapy approach that utilizes equine movement as part of an integrated intervention program to achieve functional outcomes. The horse provides a dynamic base of support, making it an excellent tool for increasing trunk strength and control balance, building overall postural strength and endurance, addressing weight bearing, and motor planning. Equine movement offers well-modulated sensory input to vestibular, proprioceptive, tactile and visual channels. During gait transitions, the patient must perform subtle adjustments in the trunk to maintain a stable position.

In addition to all those approaches above, many children may benefit from aquatic (water) therapy, swimming, acupuncture, shiatsu, reflexology which are called alternative additional therapies in children with CP.

**GOAL DIRECTED THERAPY (GDT)**

The definition GDT was: a therapy that emphasises the learning of meaningful activities (expressed as goals) in child’s environment, wherein the activities are
regarded as important by the child, the parents and others in child’s environment. The intervention is directed towards (1) the child by supporting motor learning, towards (2) the everyday environment by facilitating activity and participation and toward (3) the task by adjustments in relation to child’s strength and difficulties. The parents, the preschool teachers and the multi-professional teams at the corresponding habilitation center delivered the therapy collaboratively.

HOME-BASED TRAINING PROGRAMME

Home based programs come in many varieties, but in all of them, parents play a crucial role. As a parent, you should expect to participate in the home-based education or therapy sessions your child receives. You should observe and ask questions about what the teacher or physiotherapist and occupational therapist is doing and how this will help your child progress. Especially with your child’s physical therapy, you should have “hands on” practice during the session and therapist should observe and instruct you as you work with your child. For your child to receive the most benefit from the exercises and positions the therapist shows you, it is important that you and other family members carry them out on a consistent, daily basis.

SCHOOL BASED TRAINING PROGRAMME

In some school systems, preschoolers are in classrooms in a regular school, in a wing where classrooms for children with special needs are located. These settings enable therapists to provide services and coordinate with teachers easily and efficiently. For example, the physical therapist or occupational therapist might help position a child in an adaptive chair for classroom circle time. Second, a classroom that serves many children with special motor needs is likely to have more therapy equipment available than is a school with only one or two children with cerebral palsy. Therapists and special education teachers who provide services to children in regular classroom settings are often itinerant that is, they move from school to school. If your child’s therapists or special teachers are not based at your child’s school, try to work out some regular means of communicating with them. You
may have your child carry a communication book and ask each of his special-therapists or teachers, as well as his regular classroom teacher, to regularly give you feedback about his program and suggestions for home activities. Remember, your input about your child’s life at home continues to be very important, so be sure to include your feedback in the book. And never hesitate to phone your child’s teacher or therapist, ask to observe a therapy session, or arrange a special meeting with school staff.

**VIRTUAL REALITY**

Virtual reality-based therapy is one of the most innovative and promising recent developments in rehabilitation technology. Virtual reality is a computer technology that simulates real life learning and allows for increased intensity of training while providing augmented three-dimensional and direct sensorial feedback. It is a novel technology that allows users to interact with a computer-generated scenario (a virtual world) making corrections while performing a task. Wii-Fit is considered as one of the virtual reality-based therapy.

**2-c:** Handling and positioning the child for a specific task, or position

**Learning Outcomes**

In the end of this session, parents and teachers will learn the concepts of appropriate positioning during daily life in school, at home, etc. and creating the behavioural changes related to positioning.

Children with cerebral palsy are unable to position their bodies as early or as competently as other children are. Not only is this highly frustrating for children with cerebral palsy, but it can also slow down their learning in many areas. For example, a child who does not crawl around and move his body over, under, through, and next to various pieces of furniture may have trouble learning spatial relationships. A child who cannot sit without using his hands for support will not be free to develop and practice fine motor skills because his or her hands are
tied up in supporting his body. For these reasons, you need to use positioning
techniques to help keep your child’s tone and posture as normal as possible.

Many of the principles involved in carrying your child correctly also apply to
positioning him. The main difference is that when you hold your child, you use your
own body to provide the support and control he needs. But when you position your
child, you use an inanimate object such as a pillow, sandbag, or hammock to provide
the support. Because inanimate objects cannot respond to your child’s needs as you
can, positioning often involves much trial and error and frequent adjustments.

POSITIONING METHODS

**Prone Position:** One of the first positions children use to
play in once they have developed some control is the
prone position. Depending on your child’s ability to
support his head, you should begin placing your child in
this position. If your child has difficulty maintaining this
position, you may want to place a rolled towel under his
shoulder area to keep his arms forward. If hip flexion
makes it hard for your child to lie prone, you can help him with firm downward
pressure on the buttocks from your hand. Yet another way to help children with
cerebral palsy achieve a good prone position is to use a wedge. Wedges can be
especially helpful for children who do not have adequate head control. One caution
about using the prone position: Until your child can roll out of the position his own,
always make sure someone is there to supervise him when he lying on his tummy.

**Supine Position:** You should put your child on the supine position. Playing while
on their backs helps children to develop lower body control. It also gives them an
opportunity to bring their hands together in the center of their body a good position
for manipulating and exploring objects. As in all positions, correct body alignment in
supine is especially important for children with cerebral palsy because it is the key to
efficient movement. If your child has mostly high tone, placing a small pillow or neck
roll under his neck can help to reduce muscle tone. Flexing one or both knees while
your child is lying on his or her back also helps to relax his body. Finally for children
with cerebral palsy who are totally extended and need more flexion in their muscles,
a hammock is often helpful in encouraging a good supine position.

**Side Lying:** Besides front and back lying, another good
position for many children with cerebral palsy is side
lying. It provides opportunities for developing fine
motor skills and eye-hand coordination. In addition,
children who cannot lift their heads to see what is going
on around them while in a prone position have better
opportunities to use their vision in a side-lying position.
Sitting: Once your child has some ability to keep his back extended and some head control (or a seating system that provides that control), you should begin working on sitting. It is from the seated position that children do most of their early play and exploration of objects, as well as learn self-help skills such as feeding, dressing, and bathing. Sometimes, you will need to add rolled towels, foam pieces, or stuffed toys to correct your child’s alignment.

CARRYING METHODS

If your child has low tone, you have probably already noticed that he enjoys fast movements and being bounced around and responds with some desired increase in tone. Still, you may need to hold and carry your child in ways that support his body and keep joints and muscles in proper alignment. If your child has high tone, he probably responds best to slow movement and firm touch. Because your child’s tone can easily increase with excitement and anticipation, it is best to keep interactions low key. In holding children with low or high tone, how your position the pelvis is of major importance. Because the position of the pelvis is the key to the rest of your child’s posture. If you hold your child so that his pelvic area is properly aligned, the rest of his body often responds positively, and you can hold and support his upper body in a way that is comfortable for you and your child. Children with high tone often extend and scissor their legs due to tight adductor muscles in the hips and inner upper thighs. Separating the legs and flexing the knees can control this. So a good way to carry these children is straddled on your hip, or for a small baby, in a “football” hold with your arms separating the legs. Sometimes in addition to problems in the pelvic area, tightness in the shoulders may make it difficult to hold a child with cerebral palsy. In this case, you may be able to carry your child more comfortably by bringing his arms up and forward over your shoulder. Sometimes a child may be tight but with predominance of flexor tone, that is tone that brings the body forward or into a folded position.

Don’t be discouraged if it takes a while to discover the best way to hold your child. Remember, too, that what was effective one day may not be as effective on another day; this is especially true for children with fluctuating tone. If one position doesn’t feel right, try another. When you finally find the right way to hold your child, you will
be able to tell by the feedback you receive from his body. Adaptive chairs, standing frames, wedges and orthotic equipments can be used for positioning equipments.

### Suggested Readings

- [http://www.treatmentofcerebralpalsy.com](http://www.treatmentofcerebralpalsy.com)
Chapter 3
Lifelong therapy

Learning Outcomes

In the end of the session, parents and teachers will learn and increase their awareness about lifelong living with CP.

Motivation in Lifelong Therapy

For a better understanding of your child during the maturation process, you may do the exercises on your body and may feel what it looks like and see the challenge that your child has to face in their daily life. Trying to feel the way that they fell can make you more empathic.

As your child matures, you will want her to develop an inner drive to go after the essential goals to her growth and happiness. You will want her to learn to decide for herself, which goals are important and pursue them without motivation. While your child is young, however, much of what she does will be to please the important people in her life, rather than herself. Your child will be more willing to tackle difficult tasks if she knows everyone wants her to succeed. All family members should express their mutual respect by listening to and encouraging one another.

Your child motivation will also be strengthened if she can see the positive aspects of trying to accomplish something new. For example, reaching a toy she wants makes the struggle to inch across the room worthwhile. As your child experiences success, she will begin to take pride in her accomplishment for themselves, as well as for the praise and attention the rest of the family gives her.

It is important not to undermine your child’s pride in her accomplishments with critism. Critism makes children feel that their ways of doing things are not respected, and often leads to anger and resentment. To keep your child’s motivation high, you should also try to avoid “taking over”. When you take over, you are implicitly criticizing your child and showing you don’t think she can do it right. If she is trying to get a shirt over her head and you take over and help, she may resent your interference before she is ready to ask for assistance.
Always stress the pride you feel in your child because she keeps on trying. “That was a great try; you almost did it.” “You did that much by yourself. Soon you will be able to do it all.” “We all make mistakes. That’s how we learn new things.”

ICF’s activity and social participation according to age

The revised version of the International Classification of Functioning, Disability and Health (ICF; World Health Organization 2001) incorporates biological and social perspectives of disablement to represent more fully the impact of health conditions on an individual’s life, including participation in society. ‘Disability’ is now used as the negative aspect of functioning. Environmental factors have been included in the model as they may influence the impact of a person’s impairment or activity limitation. For children with CP, the ICF can be a good framework in the formulation of problems from the different domains and might also be a bridge between professionals and families. Activities and participation domains are examined with nine parts in ICF. 1) Learning and applying knowledge 2) General tasks and demands 3) Communication 4) Mobility 5) Self-care 6) Domestic life 7) Interpersonal interactions and relationships 8) Major life areas-education and work 9) Community, social and civic life.

Leisure and sport activities

Having a child with cerebral palsy complicates many family activities. Depending on your child’s mobility and the special equipment she needs, certain activities may be difficult, if not impossible, to do together. And then there are the reactions of other people to deal with. There is no denying that whispers, stares and rude questions can spoil even the most enjoyable outing. If you are proud of your child and her accomplishments, though, the whispers and stares become less important. Bear in mind, too, that many people ask questions not of rudeness, but out of curiosity, ignorance, or even concern. Although it may sometimes seem simpler and less nerve-wracking not to do anything at all, remember: actions speak louder than words. If you truly want family members to believe that you are all big family, then you must act as a family. That means doing things together - and not just going to medical appointments, therapy sessions or evaluations - but doing things strictly for fun.

Many of the activities your family enjoys doing together will be at home. For example, you may enjoy playing a game all the children can manage, having popcorn while you watch a film or reading or doing puzzles with together. But it is also important to get out of the house and provide kinds of activities that children need to help them learn to handle the outside world. All children need opportunities to play in park, select books at the library, choose food at the supermarket, eat out at restaurants, watch sporting events, attend religious activities and go on picnics.
Outdoor activities such as walking, camping may need to be reconsidered and modified to fit new situations, for example, family camping in more accessible areas may be better alternative, at least for a while. If your child uses a wheelchair, renting a vacation cottage on a grassy lakeshore may be more practical than renting one on a sandy beach. Some amusement parks may not be as much fun if everyone can’t go on the rides together. Still, you can often get ideas for fun, accessible outings from other parents, teachers and therapists.

Of course, doing activities outside the home requires you to confront the issue of other people’s reactions head-on. Since many parents of children with obvious disabilities say that socialization is one of their biggest concerns, this will be probably not be easy for you. You may feel that your child’s appearance or behavior will upset other people, or you may hesitate to expose yourself and your child to reactions you expect might occur. If family members or friends have been avoiding your family since learning your child’s disability, you may feel even more justified in your concerns. Once you actually take your child out in public, though, you may find that other people’s reactions are related to your own attitude of acceptance toward your child. As you interact with your child in public, onlookers will take their cues from you. If you seem comfortable with your child, discuss with her in whatever communication method you use, attend to her responses, and calmly go about whatever you are doing, onlookers will generally relax and be less obtrusive in their staring and curiosity. Besides, if you are genuinely involved with your child, you and your child will be less likely to notice what by standers are doing.

Finding relevant sports for the children/ which sport is relevant for which child

Making sure your child is active is always important, and if your child has cerebral palsy, this need for activity is not only amplified, it may be more difficult to achieve. Sports teach youngsters hand-eye coordination, teamwork and cooperation, help to build self-esteem, as well as a bevy of other healthy benefits of exercise and sport activity. As a parent of a child with cerebral palsy, you may struggle to find outdoor activities that are suitable for your child. The following is a list of organizations dedicated to sports and recreational activities for people with cerebral palsy and other developmental or neurological disorders.

Riding a specially adapted tricycle can also be very exciting and provides excellent exercise. An outdoor activity that can benefit almost any child with cerebral palsy is swimming. Not only does swimming give children a freedom of movement they don’t have on land, but it can also help improve respiratory ability. It is important to note that cold water can increase muscle tone, but warm water often has relaxing effect and helps reduce muscle tone. This means you should look for a pool with a water temperature best suited to your child’s tone. Other activities you may want to
investigate one your child reaches school age include therapeutic horseback riding and Special Olympics.

**The adaptation of children with CP to parents, teachers, peers, siblings (acceptance, inclusion, social participation, sharing)**

How well your family adjusts to having a child with cerebral palsy depends on you, the parent. Children, other family members and friends all follow the parents’ cues. Because the way you view your child affects the way the whole family sees her right from the start, it is vital that you accept your child and her disability as early as possible.

What is acceptance? Acceptance means finding whatever pleasure you can caring for her day to day. It means looking at other child without always wishing that she were like them. It means looking at the situation not in terms of what she can do for you, but what you can do to enhance her potential. Acceptance means letting her progress at her own rate. It means being proud of her as your child and wanting others to know her. It means not deriving your own self-esteem from her developmental milestones. True acceptance means feeling that you can be a happy family as you once hoped.

Unfortunately, learning to accept your child’s cerebral palsy and to see her as a unique individual instead of someone with a disability is often a difficult and lengthy process. The excitement parents usually feel at having a beautiful, perfect baby is dimmed. Instead, feelings of disbelief, shock, helplessness and isolation may well up. These and other emotions can sometimes make it as hard to accept a child’s disability as it is to accept a loved one’s death. For many parents, paralysing doubt about their own abilities to care for a special-needs child may complicate acceptance even more.

**Suggested Readings**

- [http://www.treatmentofcerebralpalsy.com](http://www.treatmentofcerebralpalsy.com)
Chapter 4
Health Care System

Learning Outcomes

In the end of the session parents and teachers will learn and increase their awareness about the facilities and supports of the health care system for their children and for themselves as well as the health professional team and their roles in rehabilitation.

Training of how to cope with health care system: State of art

Management of onset

It is very important for families to have an established general medical care provider, either a pediatrician or family practice physician. Families must be encouraged to maintain regular follow-up with a primary care physician because very few orthopedists or other specialists have the training or time to provide the full general medical care needs of these children. Standard immunizations and childcare examinations are especially overlooked. However, most families see their child’s most apparent problem as the visible motor disability and will focus more medical attention on this disability at the risk of overlooking routine well childcare. The physician managing the motor disability should remind parents of the importance of well child care by inquiring if the child has had a routine physical examination and up-to-date immunizations. A physical or occupational therapist will provide most of the medical professional special care needs related to the CP. The specialty medical care needs are provided in a specialty clinic, usually associated with a children’s hospital.

Cerebral Palsy Clinic

Another way to organize the management of these well childcare needs is with a multidisciplinary clinic in which a primary care pediatrician is present. The needs of children with CP vary greatly. These needs range from a child with hemiplegia who is being monitored for a mild gastrocnemius contracture to a child who is ventilator dependent with severe osteoporosis, spasticity, seizures, and gastrointestinal problems. It is impossible to have all medical specialists available in a clinic setting, especially in today’s environment where everyone has to account for their time by doing productive work, described mainly as billable time. There are two models currently being used in most pediatric centers for the care of children with CP.
One model has a core group of clinicians who see the children, often including an orthopedist, pediatrician, or physiatrist, social worker, physical therapist, occupational therapist and orthotics. The second model consists of families making separate appointments for each required specialist. The advantage of the first model is that it helps families coordinate their child’s needs. The major disadvantage is that it is costly and not reimbursed by the fragmented healthcare system. The advantage of the second system is its efficiency to healthcare providers; however, there is often no communication between healthcare providers, and the responsibility of coordinating care from many different specialists thus falls to families.

**Family Care Provider and Professional Care Provider Relationship**

The specific organizational model for providing care is not as important as the fact that the medical care provided to the child with CP must always be provided to the family-child unit. This relationship may be somewhat different for educational professionals than for medical care professionals.

**Selecting a Pediatrician**

Finding a pediatrician who understands your child’s special needs is crucial to your child’s development and wellbeing. Even though your child will frequently see other medical and developmental specialists, the pediatrician will be your primary resource for help in dealing with medical concerns. Your first priority is to find a pediatrician who is very knowledgeable about children with cerebral palsy. The doctor should know how your child’s motor impairments may affect her health, behavior, and development - and he should share this information with you. For example, the pediatrician should inform you if your child’s stiff legs will make diapering and dressing more difficult, or if tight abdominal muscles could lead to problems with having bowel movements. He should also listen to your questions and concerns and answer them in clear, nontechnical language. Another factor to consider is the pediatrician’s familiarity with community resources and specialists. He should be able to refer your child to the right person or place whenever medical, neurological or developmental concerns arise. He should have regular contact with your child’s medical specialists, therapists, and educational programs so he can tell them how your child’s health will affect her education. Most importantly, the pediatrician needs to be a strong advocate for your child and take an active role in helping you find and secure appropriate treatment for your child. Finding a pediatrician with all these qualities can be a tall order. By asking around, however, you can generally get the names of pediatricians in your area who specialize in treating children with developmental disorders.
Multidisciplinary team for rehabilitation and their roles for the healthcare system

Audiologist

It is important, however, that children with cerebral palsy also have their hearing assessed by an audiologist, especially if they also have a visual impairment. An audiologist specializes in testing hearing impairment. Because hearing loss is so prevalent among people with cerebral palsy, hearing aids are quite common in the CP community. An audiologist is responsible for the maintenance, prescription and development of hearing aid devices.

Developmental pediatrician

A developmental pediatrician is a pediatrician that has special training in the evaluation and care of infants who are having difficulty doing what other children their age are able to do. They are trained to evaluate the level of functioning for each infant through a series of developmental tests. They will also help to locate resources within each community to provide therapies to help infants and children in meeting milestones. There might be overlap in what they do with neurologists. Developmental pediatricians work closely with nurse practitioners and/or occupational therapists/physical therapists to decide on the best therapies for each child. The developmental pediatrician, and sometimes the neurologist, is often the first to diagnose a developmental disability like cerebral palsy. While your child will have more than one pediatrician, the developmental pediatrician is for the most part only focused on your child’s development, as opposed to the entire body, as his or her general pediatrician will be.

Neurologists

Neurologists play a key role in the diagnoses and treatment of cerebral palsy, as it is a neurological condition. They are usually the ones to diagnose a condition such as cerebral palsy, and, along with the primary physician, neurologists are leaders in the interdisciplinary healthcare team established for each patient. If neurosurgery is to be considered, the patient’s neurologist will usually decide whether or not it is necessary, and they will be an integral part of the patient’s treatment both before and after surgery. Surgeries that may be considered for a cerebral palsied person are a dorsal rhizotomy or placing a brain shunt for hydrocephalus.

Nutritionists

People with special needs, such as a person with cerebral palsy, may not be able to eat as easily as a person without such a disability. A nutritionist’s opinion may be sought out in such a case to make sure the person is receiving adequate nutrients.
To do this, the nutritionist may monitor how a specific child compares to what is considered normal height and weight for a certain age. The nutritionist assesses feeding history, dietary intake, and blood tests that reflect nutritional status in order to determine whether the child has nutritional deficiencies. For a child with cerebral palsy, a nutritionist will advise the parents about methods and specific types of food that will provide proper nutrition and meet the daily requirements for caloric intake.

**Orthopedic Surgeons**

Orthopedic surgeons treat problems with bones, muscles, tendons, nerves or joints. Specific treatments for patients with cerebral palsy may consist of techniques such as physical therapy to decrease spasticity and improve function, orthopedic appliances such as braces to prevent deformity, and surgery to correct deformities.

**Behavioral Therapist**

Because the symptoms of cerebral palsy can cause behavioral and emotional problems, many children benefit from counseling or behavior therapy. Behavioral therapy utilizes psychological techniques to improve physical, mental, and communicative skills. The activities used vary greatly according to age and disability. Some techniques will be used to discourage destructive behavior, others to encourage self-sufficiency.

**Social workers**

Social workers support people with cerebral palsy and their families in many ways, including strengths-based counseling and mutual aid group work. Social workers from your local authority can advise on practical and financial problems, or tell you how to access local services. You can contact a social worker via your local social services department. Some areas will have special child and adult disability teams; in others you may not be assigned a named person and instead may have to speak to the duty social worker.

**Suggested Readings**

- http://www.cerebralpalsysource.com/Treatment_and_Therapy/
- http://cerebralpalsy.org/about-cerebral-palsy/therapies/
- http://www.treatmentofcerebralpalsy.com
References

- http://www.cerebralpalsysource.com/Treatment_and_Therapy/
- http://cerebralpalsy.org/about-cerebral-palsy/therapies/
- http://www.treatmentofcerebralpalsy.com
This project has been funded with support from the European Commission. This publication [communication] reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein.
This training module is produced in the scope of CP-PACK project and in accordance with the Need Analysis Report derived from the results of the focus group interviews and questionnaires among parents and teachers of children with cerebral palsy. This is a theoretical training module, which is based on the international legal instruments regulating disabled people rights and on the main legal framework available in partners’ countries. This training module should be used as a starting point on how to deal and understand applied law. This module is not and can not be understand as a legal counselling.
Chapter 1

Fundamentals of Assistive Technology

Learning Outcomes

Participants will acquire general knowledge about Assistive Technology (AT) and its different levels of classification, as well as awareness of the role of AT in several contexts and its connection to the Universal Design principles, especially in what concerns educational environments.

Chapter Contents

Assistive Technology and CP

We can no longer deny the importance of technology in our lives. We have become so dependent on technology and tech products that we find it hard to live even a single day without it. We use technology in different forms, but when we think of it, we have to look at technology from different angles and consider all the new advancements, how our behaviors and lives are being conditioned for good and for bad, but especially consider how that same technology has been revolutionary in changing the overall lifestyle of people with incapacities.

Cerebral Palsy is one of the conditions that has most profited from technological development. From communication to mobility and not forgetting all the precious devices that help in daily activities, there is a world of opportunities that rely on assistive equipment as a solution for social inclusion and quality of life. That is why all professionals that deal with CP children and especially parents and users themselves should be well aware of the existent devices for each solution.

Definition(s) of AT

Assistive technology (AT) is a concept that refers to products and services that can help compensate functional limitations, facilitate independent living and enable disabled people realize their potential. While a great variety of products fit this description (e.g. a car to overcome my functional impairment of not being able to transport myself fast), it is commonly understood that “assistive technology refers to products and services for those needs that are specific to three groups: disabled persons, elderly persons and chronically ill persons. AT enables these people to participate more fully in daily life and supports their independent living “.
Assistive Technology (AT) is supposed to make life activities accessible to as many people as possible, through the most appropriate set of information/access technologies. Its devices are tools used to enhance the independent functioning of people who have physical limitations or cognitive impairments. They range from low-tech devices like simple pen holders to high tech devices, such as portable computer based communication systems, digital home technologies, environmental controls. This equipment covers a wide range of areas including communication, mobility, seating and positioning, sensory impairments and also daily living technology.

There are many “official” definitions of Assistive Technology:

- “Any product, instrument, equipment or technical system used by a disabled person, especially produced or generally available, preventing, compensation, relieving or neutralizing the impairment, disability or handicap” (ISO 9999)
- “The term assistive technology device means any item, piece of equipment or product system, whether acquired commercially, off-the-shelf, modified or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities” (public law 100-407, the technical assistance to the States Act, USA)
- “Technology which can help compensate for functional limitation, facilitate independent living and which can enable disabled and older people to realize their potential.” (TIDE, Bride phase, synopses, 1994)
- “Assistive technology is the use of any device that will enable persons with disabilities to function to their maximum potential educationally, vocationally, socially and in daily living activities. This includes both low and high technology applications. Low technology refers to any apparatus that is either non-electronically based or simple battery operated items (e.g. adapted toys and tape recorders). High technology involves the use of sophisticated systems that are electronically-based (e.g. power wheelchairs and environmental control systems).” (Bristow & Pickering 1995)
- “Assistive technology is any piece of equipment or device that is used to increase the independence of individuals with disabilities. These items can be commercially available, modified or customized for the user” (North Carolina Assistive Technology Project)
- “Assistive technology – technology for more independent, productive and enjoyable living – can be simple or complex” (WATA)
- “Assistive technology, by definition, is any piece of equipment that is used to increase, maintain or improve the functional capabilities of a person with a disability.” (Pursuit )
- “An assistive product is any product (including devices, equipment, instruments, technology and software) especially produced or generally available, for
preventing, compensating, monitoring, relieving or neutralizing impairments, activity limitations and participation restrictions”.

**Technological Literacy**

Although there is a long history of efforts to help persons with disabilities by using either technologies available to the general population as well as technologies designed solely for use by people with disabilities (Blackhurst & Edyburn, 2000), the past 20 years have seen an unparalleled interest in the use of instructional and assistive technologies. This is mainly due to digital revolution and to the development of technological literacy that led to mass production of equipment.

ABLEDATA, for example, maintains a database that includes names and descriptions of thousands of devices intended to enhance the learning and/or life functioning of persons with disabilities. Nevertheless, along with a clear unprecedented growth in the development of high-tech devices over the past years, there has been also a renewed appreciation for low-tech aids and considerable refinement in procedures to assess students for technological needs. That has a lot to do with questions like price, availability, ease of use and lack of capacity to provide a good network of services to help children in post-acquisition periods. Besides there is always a real danger of getting sophisticated material that will be obsolete in a short period of time.

**Classification**

When it comes to inventorying, there is no end in listing all assistive devices. Catalogues and databases such as Handynet or Abledata, for example, may contain information on more than 25,000 products. Such a list is perhaps too much extensive for newcomers in the field of assistive technology, but can be of great help for parents, teachers or technicians that deal with CP children and need a reference.

Therefore, classification and grouping of the many products is necessary to reduce this amount of devices to broad categories and it help us understand the scope of functionality of each one of them. We are however faced with a myriad of alternative ways of grouping assistive technology. Most of these grouping frameworks are not exhaustive nor have mutually exclusive categories.

The most known and formal classification of assistive technology is the ISO9999 international classification or its European standard CEN29999.

The ISO 9999 is a three-level classification system that clusters AT products round “CLASSES” (e.g. mobility, communication, recreation, etc.), then round “SUBCLASSES” (e.g. within class “mobility”: powered wheelchairs, cars adaptations, etc.), eventually round “DIVISIONS” (e.g. within subclass “powered wheelchairs”: electric motor-driven wheelchair with manual steering, electric motor-driven wheelchair with powered steering, etc.). Each ISO 9999 classification item has a numerical code: for
instance, item “electric motor-driven wheelchair with powered steering” has the code 12.23.06, where the first two digits stand for Class 12 “mobility”, the following two digits stand for subclass 12.23 “powered wheelchairs” and the last two digits stand for this specific division.

But we can also classify assistive technology by broad categories of impairments: visual impairments, auditive impairments, cognitive, mobility, …. It all depends on the purposes we have in mind. Within each category, one could again classify AT in those increasing the remaining capacity, those replacing the lost capacity by another capacity and a rest category, for example. Such an approach is also suggested by the HEART line E studies (Azevedo et al. 1993, Azevedo et al. 1994a) and this is the one we have adopted in this course module for its simplicity and efficiency, considering the public we are addressing. It suggests to classify AT into four groups:

- Communication;
- Mobility;
- Manipulation;
- Orientation.

Although there is no single unique, optimal way of grouping AT, we should also not forget that from the end-users’ perspective, classifications are not so relevant. Users do not really bother to which group the AT they need belongs, as long as they get it and can use it. Hence, within our material, we should strike the right balance between an analytic, classifying approach and a user-oriented more holistic approach.

**Universal Design**

As we will see, AT aims to fill the gap between what the user is “capable of” and what the environment requires from him. We can therefore think that, instead of making a positive discrimination enhancing the capacity of the person, we could also work to build a barrier-free environment where everybody could access everything, on a universal design perspective.

“Universal design is the design of products and environments to be useable by all people to the greatest extent possible, without the need for adaptation or specialised design”

Inclusive Design or Universal Design is a set of concerns, knowledge, methodologies and practices aimed at the design of spaces, products and services, used with efficacy, safety and comfort for as many people as possible, regardless of their abilities. UD naturally tends to be inclusive and non-discriminatory, resulting in improved ergonomics for all and it doesn’t necessarily lead to additional costs for the benefit of a minority.
Even if sometimes, the costs of development and initial production can be higher, they will however, benefit not only a minority, but the entire population, increasing the productivity of all, preventing misuse and risks of prolonged discomfort, and avoid accidents. Consequently, in the medium and long term, in can turn out to be an increase in productivity and a better life for all.

**Suggested Readings**

- HEART classification - The Centre for Cerebral Palsy
- Center for Universal Design: [http://www.ncsu.edu/project/design-projects/udi/](http://www.ncsu.edu/project/design-projects/udi/)
Chapter 2

Human Components

Learning Outcomes

Participants will acknowledge concepts of disability, impairment and disadvantage, under social models and under the perspective of International Classification of Functionality and World Health Organization.

Participants will also be aware of the several factors that interfere in the choice of AT devices.

Chapter Contents

This chapter relates to the need of understanding the human being with and without disabilities, and adequately integrate the technical solutions provided by assistive technology with the needs the human beings have, when facing an “adverse” environment.

Disability issues

Considering the new paradigm of disability developed in the new ICF model launched by WHO 2001, disablement is a “situation” that affects an individual in case a gap exists between individual capabilities and environmental factors and this gap restricts the quality of life and hinders full exploitation of individuals potential in society.

According to the World Health Organization (1980) should be understood as (in health):

“Impairment” means any loss or alteration of a structure or function of a psychological, physiological or anatomical. These losses or changes may be temporary or permanent, representing the manifestation of a disease state, reflecting, in principle, disruption to organic.

“Disability” restriction or lack of ability to perform an activity within the framework and limits considered normal for humans. It is characterized by excesses or deficiencies in behavior or performance of an activity that is common or normal, usually deriving from a disability.

“Handicap” is a social condition of the injury suffered by a given individual, resulting from an impairment or a disability that limits or prevents the performance of an
activity considered normal for that individual, taking into account age, sex and the factors the same socio-cultural. It represents the social expression of a disability or incapacity, by reflecting the impact (cultural, social, economic and environmental) caused by them.

Assistive Technologies can bridge such gap as “environmental factors” that contribute to generate or overcome disablement. AT devices are, most of the time real “facilitators” towards activity and participation, either enhancing the functional level of the user, or reducing the demands from the environment.

But we must also take in consideration that, sometimes AT can also be a barrier instead of a facilitator. The prescription of sophisticated equipment can be useless if the user is not well informed about its characteristics and how it works. At the same time, even very useful devices can quickly get obsolete and bring new barriers. A good follow-up service and continuous support is essential to the success of any AT program.

Quality of Life, autonomy and empowerment

The paradigm change from a medical model to a social model brought new light to the role of the user himself when choosing technical aid. Autonomy is a key word and all efforts must be made to empower end-users to make conscious and informed choices about what he/she thinks is best. This is perhaps not a relevant point when we consider most of the situations of cerebral palsy is this project, but it still is an important issue to follow.
Autonomy does not mean you do not depend on others to help accomplish tasks or reach your goals. Having autonomy is not about being able to do stuff all by yourself but having the power to decide what happens next in your life. Or even more specifically, it’s about having the *perceived* power to do so, and that is called “empowerment”

**Contexts and Environmental variables**

As we have seen International Classification of Functionality puts the notions of ‘health’ and ‘disability’ in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity.

The ICF thus ‘mainstreams’ the experience of disability and recognizes it as a universal human experience and by shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability.

Furthermore ICF takes into account the social aspects of disability and does not see disability only as a ‘medical’ or ‘biological’ dysfunction. By including contextual factors, in which environmental factors are listed, ICF allows to records the impact of the environment on the person’s functioning.¹

This is important when it comes to analyzing needs and formulating goals for our kids: sometimes it can be easier to interfere with the environment, than with the child.

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Assessment and Selection Process

Prescribing an AT device may not be an easy task. If the child goes to school, Assistive Technology (AT) should be considered for every child who has an Individualized Education Plan (IEP). The need for assistive technology is based on the question “What IEP goals are the student having difficulty meeting that assistive technology might assist?” The more specific the team can be in answering that question, the better an evaluator can be prepared when conducting an assistive technology evaluation.

According to Zabala, Reed, & Korsten, (1999)\(^2\) when considering a student’s need for assistive technology these quality indicators are important:

- the IEP team has the knowledge and skills to make informed decisions;
- a continuum of AT devices and services is explored;
- IEP team uses good team process to make decisions;
- decisions are made based on IEP goals and objectives;
- team decisions are made in compliance with federal and state statutes;
- determination of need is based on data about student, environments, tasks and tools; and decisions and supporting data are documented.

In fact, the process of selecting AT is a complex one that must take into consideration several kinds of opinions from a multidisciplinary team. Assessment is always a team work and involves a collaborative interaction among four groups:

1. The user
2. The persons around him/her who support and interact with him/her on a daily bases, including families members, friends, educators, therapists, doctors, and employers,
3. The assistive technology specialists who have knowledge of many tools and who facilitates a collaborative decision making process and
4. The developers of assistive tools

Suggested Readings

- International Classification of Functioning, Disability and Health (ICF): http://www.who.int/classifications/icf/en/
- Classification and terminology of assistive products: http://cirrie.buffalo.edu/encyclopedia/en/article/265/
- Special Needs Technology Assessment Resource Support Team (START): http://www.nsnet.org/start/
- SETT Framework: http://www2.edc.org/ncip/workshops/sett/SETT_Framework.html

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Chapter 3

Technical Components

Learning Outcomes

Participants will evaluate the potential of several equipments in the field of communication and show some proficiency in incorporating them in a functional selection process for a CP child. They will learn several software adaptation strategies for usability and accessibility to the PC as well as free hardware and software solutions for physical accessibility to information and communication Technology and to help in reading and writing processes.

In the area of mobility it is expected that they recognize the most significant equipment for CP children and demonstrate proficiency in selecting the most adequate solution for different environments considering also the importance of architectural accessibility and some technical solutions available, as well as the main modalities and characteristics of adapted sports suitable for CP.

Participants will also recognize practical solutions for daily activity with CP children, available in the market, in areas like feeding, dressing, housekeeping, and domotic solutions and environmental control strategies. It is also expected that they can recognize the most suitable educational and recreational solutions for their children/pupils.

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The technical components sub module focus on a more instrumental area, in which parents and teachers are supposed to “build” together possible solutions to help compensate disabilities and contribute to inclusion. The framework adopted has been the one of HEART Line E which, as we have seen distributes functional competences by 4 areas.

AT for Communication

Communication is the ability to generate, emit, receive and understand messages, interacting with other individuals at presence or at a distance, in a particular social context. Communication skills play a critical role in the process of developing and maintaining social relationships, learning to live in community, and general satisfaction of almost all human needs.
Using alternative methods (AAC) and taking advantage of the (not so new) digital technology we can help CP children to overcome communication disabilities and open way to literacy.

We can define Alternative and Augmentative Communication (AAC) as an integrated set of techniques, aids, strategies and skills that a person with severe communicative incapacity uses to communicate as alternative methods to supplement or replace speech or writing.

These individuals with severe communication impairment, unable to use speech to communicate, develop, most of the times, their own strategies to interact with others but they often use specific techniques to fulfill their communication needs: pictures with words or symbols, systems with voice output, etc., being however noted that a help for communication is not in itself a communication system, but one component of that same system.

With children with severe neuromotor dysfunction and inability to use speech as their primary means of communication, the situation becomes even more complex, affecting the processes of teaching and learning. The frequent inability of children with severe neuromotor dysfunction to achieve similar experiences to those of other children the same age groups lead sometimes to very negative and frustrating experiences, and to the adoption of an attitude of passivity and withdrawal.

Intervention strategies that involve the use of systematic Augmentative Communication Support of Assistive Technology, allow these children active participation that will influence greatly the process of acquiring new knowledge and get meaningful experiences. This is the fundamental role of Assistive Technology which, when used early, will allow greater autonomy and participation in school activities that give access to any educational curriculum.

The Augmentative Communication emerges as a powerful tool in the development of literacy for this type of population, allowing it to an active participation in literacy events, not only communicating and interacting, but also writing, producing and interpreting written language.

In this module we will have a bird’s eye view on:

- Aided and unaided communication systems: SPC, PECS, Bliss, Makaton, etc
- Low-tech devices and high-tech dynamic communication boards
- Speech output: recorded and synthetic speech
- Selection techniques: direct, scanning, encoding
- Rate enhancement and prediction techniques
- Hearing aids and Voice amplifiers
Access to PC

Nowadays, assistive technology products are often chosen specifically to accommodate the disability, or multiple disabilities, so that an individual can effectively access a computer. PC operability is crucial as it is also critical that the assistive technology be compatible with the operating system and other software. AT can include products such as a different type of pointing devices to use instead of a mouse, or a system equipped with a Braille display and screen reader. Not all users with accessibility needs require assistive technology products but, in the case of CP, there are a number of technical solutions that have been proved to be efficient, which we have divided in the following areas:

- control interfaces (switches, joystick, track ball)
- alternative keyboards (expanded, reduced) and keyboard emulation
- mice and mouse emulation and eye-gaze solutions (Tobii, Camera Mouse, Head-Dev, Trekker, etc)
- Touch screens, head-pointers, mouth-sticks
- Tablets and smartphones (iPad)

Because assistive technology cannot be added to just any computer—it must be compatible with the computer’s operating system and additional software products—it is important that the school selects software that is accessible and compatible with assistive technology.

Virtual accessibility is also important and teachers and parents must be aware of the so many configuration options of the several operating systems existing in schools and at home, even when it comes to using open source software. Accessibility options for Windows Xp and 7 can be easily found on the web. Apple also includes assistive technology in its products as standard features — at no additional cost. For example, iPhone, iPad, iPod, and OS X include screen magnification and VoiceOver, a screen-access technology, for the blind and visually impaired. To assist those with cognitive and learning disabilities, every Mac includes an alternative, simplified user interface that rewards exploration and learning. And, for those who find it difficult to use a mouse, every Mac computer includes Mouse Keys, Slow Keys, and Sticky Keys, which adapt the computer to the user’s needs and capabilities.

Reading and Writing

Also related to communication processes, reading and writing has always played an important role in a CP child’s education. This is especially important for those children with severe multiple disabilities since literacy represents their best hope for participation in the broader society.
Participation requires communication and for the severely speech impaired, communication requires either written language or the use of communication devices that take the place of human speech, devices most frequently requiring a literate user (Blackstone & Cassatt-James, 1988; Koppenhaver, Coleman, Kalman, & Yoder, 1991). In this area we will be considering inexpensive, yet effective low tech solutions for writing like wrist splints, clip boards, positioning pads or velcro tabs used to keep them in place.

Also important can be separate applications for PC, like word prediction software, for example, that reduces the number of keystrokes an individual has to make. Ebooks, online reading, OCR, vice recognition and prediction and many other technical options will also be under the scope of this part of the module.

Suggested Readings

- Makaton - http://www.makaton.fr/
- Arasaac - http://www.catedu.es/araasaac/
- Pecs - http://www.pecs.org.uk/general/what.htm
- Proloquo2go - http://www.proloquo2go.com/
- Grid 2 - http://www.sensorysoftware.com/
- Brain Control http://www.youtube.com/watch?v=kXY50Ig773M&feature=player_embedded%20-%20%20!
- Muscle-Computer - http://www.youtube.com/watch?v=R1agrUM4KYs
- Boardmakershare -
- Dasher - http://www.inference.phy.cam.ac.uk/dasher/portuguese/
- Camera Mouse - http://cameramouse.org/

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4 A word prediction program displays a list of words based on the letters that have already been typed. The typist saves keystrokes by selecting the correct word rather than typing the remaining letters.
AT for Mobility

Mobility is an individual’s ability to execute distinctive activities associated with moving oneself within the environment. Mobility refers also to the possibility to use environment facilities like adequately adapted public and private transports.

Within this area we will be considering, among others, the following items: manual mobility that includes the use of manual wheelchairs, sticks, crutches, walkers, bicycles and tricycles, transport chairs and manual hoists and transfer aids. Powered mobility, including powered wheelchairs, scooters, carts, mopeds, powered aids for lifting and transfer, interfaces for wheelchair control, robotic arms for wheelchairs.

Attention will also be given to all aspects of private transportation (including special controls for driving, special seats, ramps and platforms) and public transportation (like adaptation of public vehicles, ramps, platforms and lifts) existing in most countries.

Accessibility

Outdoor and indoor access aids are also a vital area for social inclusion and adaptation of CP children and home adaptations can make a difference in their quality of life. Ambient Assisted Living catalogues can provide good solutions whenever we are to consider autonomy and empowerment of children with disabilities. Other aspects of accessibility and mobility are be considered, namely components of seating and positioning systems, cushions and pressure management, orthotics and prosthetics aids, etc.

Adapted Sports

Sporting activities have also been used for rehabilitation and recreation and are increasingly being used as treatment complementing the conventional methods of physiotherapy. They help to develop strength, coordination, and endurance, but
also to regain self-esteem, promoting the development of positive mental attitudes and achieve social reintegration. They are also a good opportunity to establish social contact and human interaction.

Sports like Boccia, Goalball, athletics, can be a good opportunity for personal and social development.

Suggested Readings

• Assistive Technology Devices for Kids | eHow.co.uk -
• http://www.ehow.co.uk/info_8315500_assistive-technology-devices-kids.html#ixzz1jpSPMteT
• Neatech Chair Models: http://www.neatech.it/index.php
• Apple - Empowering Disabled Apple Users: http://atmac.org/
• Home Solutions: http://www.escadafacil.pt/index.htm
• Handy - Occasion: http://mashable.com/2011/10/05/tech-disabled/
• iBot: http://www.youtube.com/watch?v=xK5uAeEV7tl

AT for Manipulation

Manipulation is the individual’s ability to control physical environment and as an output of the activities performed by persons with disabilities. This also refers to the ability to regulate control mechanisms using any tool, independently of the part of the body used.

Although this an area in the scope of occupational therapy, it is also important that teachers and parents know about the existence of many devices that can make their life easier, even if it means only an extra time for themselves. Therefore, and from point of view of assistive technology, the items under manipulation include activities of daily life like:

• self care (hygiene; incontinence; sexuality; clothing),
• Housekeeping (cooking; cleaning),
• Safety ( alarm and signalling devices, environmental control units ),
• User control interfaces (voice recognition, ultrasound, switches),
• Robotics (desktop robots, page turners, feeding robots...) etc.
• Recreation (aids for games, exercise, sports, photography, smoking, adapted toys)
• Musical instruments and handicraft tools for sport and recreation
AT for Orientation

Orientation is the individual’s ability to locate oneself in relation to the dimensions of time and space. It represents also the individual’s ability to receive stimulus coming from several sensorial inputs (sight, hearing, smell, touch), assimilate those inputs and provide the adequate answer (output).

Items within the orientation area are, for example orientation & navigation systems which include orientation and mobility aids, sonic guides.

But this area we also include cognitive orientation and cognition like aids for memory compensation, aids for supporting time and space notions or, in a broader sense all kinds of educational material and didactic software the help compensating cognitive disabilities.

Orientation & navigation systems

Orientation and mobility aids, sonic guides, adaptations of the environment

Cognition: Aids for memory compensation, aids for supporting time and space notions, Educational Software

Suggested Readings

• Trekker System : http://www.youtube.com/watch?v=gsTZqKGtkyl
• Animation: http://goanimate.com/
• Mindmapping: http://www.mindmapping.com/
• Podcasting : http://vocaroo.com/
• Wiki: http://www.wikispaces.com/
Chapter 4
Socio-Economic Components

Learning Outcomes

Participants will be able to search for information related to AT funding in their own country and demonstrate skills in defining their plan of acquisition, based on the information provided by national or international databases.

They will also be able to evaluate the state of art of assistive technology, market trends and evolution at a European level.

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Choice factors

Providing AT devices is a complex process that involves the child/user, but also family members, caregivers, friends and fellow students. The process of acquisition or funding is different from country to country, depending on national legislation but there is a European trend towards a common database coordinated by EASTIN.⁶

Professionals are aware of all the interaction needed with the social context, how the provision of an assistive device will affect the persons interacting with the child with CP. Assessing the utility of an assistive device should include training of the people who are helping the user with the assistive device. As a consequence, family members, friends, caregivers, fellow students, co-workers, etc., are a critical part of the user’s support. Peers acceptance is always an important source of encouragement for device use.

Professionals must be trained to be fully aware of these important aspects when developing or providing assistive devices. Under this area we will also include every item related with the knowledge of available resources to the user, that is knowledge of advantages and disadvantages of different service delivery models, knowledge of the role, constraints, and perspective of manufacturers, distributors and suppliers. Among others, we consider the following: Actors/Service Delivery - Standards/Testing - Legal/Economic

⁶ European Assistive Technology Information Network
Service delivery

It is important that all agents (and especially the parents) are well aware of all legislation related to the provision of AT and know where to consult it. Internet can be of great value and a good source of information.

This kind of information include all procedures for getting or funding AT, depending on the country. Welfare authorities are usually receptive to funding programs and it is very important that parents know where to find information.

Negotiating terms with AT providers and suppliers is also an important issue and sometimes the most difficult one. There is a myriad of similar equipment and the choice is not always easy.

Information resources

Information is power. The internet provides a wide range of resources on assistive technology, from introductory fact sheets and training materials to in-depth discussion of best practices and emerging research. Other information items may include:

- Databases on AT, officially approved and financed
- Catalogues, magazines and other publications regarding technical aspects of the devices
- Exhibitions and information events on the latest developments
- Information centres for choice help
- Professional supports for choice of AT
- Other sources of information related to evolution of AT policies at international level, cost analysis for AT, outcome analysis for AT or even market trends

Suggested Readings

- http://www.handicat.com/
- http://www.dlf-data.org.uk/
- http://www.hmi-basen.dk/r0x.asp?ldbid=1
- http://www.rehadat.de/eastin.htm
- http://portale.siva.it/
- Resna: http://resna.org/
- SNOW: http://snow.idrc.ocad.ca/
• WATI: http://www.wati.org/
• EASTIN: http://www.eastin.eu/en-GB/searches/products/index

**Bibliography**


• Bain & Leger (1997), Assistive technology: an interdisciplinary approach, written for “rehabilitation service providers who are not necessarily AT specialists” and as such has more of a practical applications bias.

• Church & Glennen - The handbook of assistive technology, focuses on the “practical application” of assistive technology and is intended to be used as a hand book and resource guide for professionals in their daily work.(1992),

• Fundamentals of assistive technology, RESNA (1999), is a resource manual designed to be used in conjunction with the RESNA Fundamentals in Assistive Technology Course. It contains twelve modules written by experts in the field along with other useful course materials.


• IMPACT consortium (1998). Increasing the IMPACT of assistive technology, WP2 deliverable, From dreams to realities.

• TELEMATE consortium (1998), Analysis of Assistive Technology (AT) training and User Needs. NOTE: this document is restricted to members of the TELEMATE consortium.

• http://www.eaccessibility.org/
• http://www.ataccess.org/
• http://atnetworkblog.blogspot.com/2010/04/so-what-is-atacp.html
• http://www.cited.org/index.aspx
• http://www.dinf.ne.jp/doc/english/index_e.html