



CP-PACK

Module 4

TRAINER GUIDE

Quality of Life

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Training Module for Parents “Quality of Life”

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 among parents and teachers of children with cerebral palsy. This Module provides theoretical knowledge and in ways practical instruction and methods which will be useful for parents with children with cerebral palsy, to get and to improve the quality in their family life. The module is divided into three chapters and includes an Activity Play Workshop. Each chapter is divided into sessions. Each session uses one or more teaching methodology and this is specified in the module.

Subject of training module	Quality of Life	
Target group(s)	Parents of children with Cerebral Palsy (CP) 3-18 years of age	
Goal(s)	Parents will learn ways and methods that will be useful to increase their family’s quality of life.	
Learning Outcome(s)	Parents will be expected to: <ul style="list-style-type: none"> - Learn ways to transform the Activities of Daily Life into easier tasks; - Learn how important playing with the child with CP is and learn ways to make it happen. It is also important to know how to promote the participation of the siblings in these activities; - Learn how parents can get free time for themselves; - Understand what the good cooperation with specialists can bring to their family. 	
Contents (General and/or Detailed)	Content	Time Needed
	<u>1) Family Life</u> 1.1 Activities of Daily Life 1.2 Playing with the child with CP and their siblings <ul style="list-style-type: none"> a) Child’s play b) Play value according to the child’s age or stages of social, intellectual and cognitive development and his/her needs c) Disability and play 1.3 Activity Play Workshop	3 hrs & 50 min

Chapter 1

Family Life

Session 1.1: Activities of Daily Life

Duration: 50 min

Learning Outcomes

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

Methodology

- Lecture about the meaning, the classification and the importance of training in “Activities of Daily Life”.
- Whole or small group discussion about some assistive devices for activities of daily life. After the presentation of some assistive devices the group should be divided in small groups and discuss among them about their use. Parents need to be encouraged to use assistive devices and to practice the Activities of Daily Life.
- Demonstration of good practices in Activities of Daily Life, supported by a video of children with CP in Activities of Daily Life.
- Answering questions, discussing with parents about their personal experiences and exchanging points of view (what they would need, what difficulties they face, what solutions they have found to their difficulties, proposals).

Supplementary Training Materials

- Devices for activities of daily life or their images
- Video-projector
- Laptop
- Dvd-player
- Papers and pens

Feedback on the Chapter

- Why is it important to train a child with CP in activities of daily life?

- Are the devices for activities of daily life helpful for the parents of a child with CP?
- How can specialists advice parents about the devices for activities of daily life?

Suggested Reading

- Trombly, C. (1995). Planning Guiding and documenting therapy. In C.
- Trombly, C. (Ed). Occupational Therapy for PHYSICAL Dysfunction, 4th ed. Baltimore: Wilkins & Williams.
- Krigger KW (2006). Cerebral Palsy: An Overview. American Family Physician; Jan 1, 2006; 73, 1; Health Modulepg. 91
- en.wikipedia.org/wiki/Activities_of_daily_living
- Sifaki M. (1998). Δραστηριότητες καθημερινής ζωής. .Τ.Ε.Ι. Αθηνών, Ελλάδα

Session 1.2: Play with children with CP and their siblings

Duration: 1hr

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.

Methodology

- Lecture and PowerPoint presentation about the benefits of play in general and in children with disability. The trainer must be flexible about the content, because it is very important to take into account the special characteristics of the group of trainees and their children with CP.

- Multimedia presentation of good practices. Children with CP participating in play activities, in order to get a better understanding about the plays that can be suggested according to the goal of the activity, the space and child's age.
- Whole group discussion. The trainer will discuss with parents issues raised during the presentation and other issues that concern them. The participants should be seated in a circle, where everyone can see each other. The participants will introduce themselves and will mention some information about their child with CP. Also they will present the ways they have been using until now to play with their child with CP. Later on the trainer will present a story and suggest discussing it. The purpose of this activity is to provide solutions to parents' difficulties and/or to give them guidelines.

Supplementary Training Materials

- Pen, pencils, notebooks
- Laptop with DVD player
- Screen
- DVD, projector

Feedback on the Chapter

- Which daily activity could be a new play activity for you and your child?
- Which activity could be a new play activity for the whole family?
- 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 Reading

- Garvey C. (1990) "Play" Cambridge MA Harvard University Press.
- Ginsburg K (.2006) Clinical Report doi:10.1542/peds.2006-2697 American Academy of Pediatrics (AAP) "The importance of play in promoting healthy child. Development and maintaining strong parent –child bonds."
- Piaget J. (1962)"Play, dreams and imitation in childhood", New York Norton.
- Piaget, J. (1928). The Child's Conception of the World. London: Routledge and Kegan Paul.
- 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
- Musselwhite, C. (1986). Adaptive play for special needs children: Strategies to enhance communication and learning. San Diego, CA: College-Hill Press
- Darbyshire, P. (1980). Play and profoundly handicapped children. *Nursing Times*, 76, 1538-1543.
- Li, A. (1983, December). Play therapy with mentally retarded children. *Association for Play Therapy Newsletter*, 2(4), 3-6
- Salomon, M. (1983). Play therapy with the physically handicapped. In C. Schaefer & K. O'Connor (Eds.), *Handbook of play therapy*. (pp. 455-456). New York: John Wiley & Sons Common Threads Publications Ltd. ISBN 1-904792-13-8.
- Auerbach S.(2004) *Dr. Toy's Smart Play Smart Toys (How To Raise A Child With a High PQ (Play Quotient))*. ISBN 0-97855-400-0.
- Auerbach S.(1999) *FAO Schwarz Toys For A Lifetime: Enhancing Childhood Through Play*. ISBN 0-7893-0355-8
- Shelly Newstead (2004). *The Buskers Guide to Playwork*. Common Threads Publications Ltd. ISBN 1-904792-13-8
- Erikson, E. H. (1950) "Childhood and society." New York: Norton (1950); Triad/ Paladin (1977), p. 242
- Bratton, S.C., Ray, D., Rhine, T., & Jones, L. (2005). "The efficacy of play therapy with children: A meta-analytic review of treatment outcomes". *Professional Psychology: Research and Practice*, 36, 376 – 390.
- Meyer, D. (1993) "Siblings of children with special health and developmental needs: Programs, services and considerations." *ARCH Factsheet*, 23, 1-4.
- Fromberg, D.P. (1990). Play issues in early childhood education. In Seedfeldt, C. (Ed.), *Continuing issues in early childhood education*, (pp. 223-243). Columbus, OH: Merrill.
- Dogra, A., and Veeraraghavan, V. (1994). A study of psychological intervention of children with aggressive conduct disorder. *Ind. Journal of Clinical Psychology*, n.21, p. 28-32.
- Paul Tough, "Can the right kinds of play teach self-control?", *New York Times*, 2009/09/27 (reviewing the "Tools of the Mind" curriculum based on Vygotsky's research).
- Rousseau J-J."Emile" (1979). Trans. Allan Bloom, New York Basic Books.
- Freud, S. (1909). Freud S. (1909b). Analyse der Phobie eines fünfjährigen Knaben ("Der kleine Hans") *Jb. psychoanal. psycho-pathol. Forsch*, I, 1-109; *GW*, VII, p. 241-377; *Analysis of a phobia in a five-year-old boy*. *SE*, 10: 1-149

Websites

<http://www.caringforcerebralpalsy.com>

<http://cerebralpalsytoysandplayaids.com>

<http://palsycerebral.org/paralysie-cerebrale-jouer>

<http://www.childdevelopmentinfo.com>

Session 1.3: Activity Play Workshop

Duration: 2 hrs

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.

Methodology

- Introduction of the workshop (lecture). The participants will be introduced to the main idea of this session and prepared to make practical use of the theoretical information they have received so far.
- Activity Play Workshop. The participants will be divided into three groups, according to children's age:
 - Group for parents with children 3 – 7 years old
 - Group for parents with children 8 – 14 years old
 - Group for parents with children 15 – 18 years old.

A week before the training, the participants have to complete a questionnaire, in order to provide the training team with information about their children with CP. This information is crucial for the design of a successful Activity Play Workshop that will meet the needs of the participants (for a suggestion see the Supporting Materials).

The trainers must design three different activities depending on the children's age.

- I. Group for parents with children 3-7 years old

This group will play in pairs or small group activities, through sensory stimulation, somatosensory and body contact.

II. Group for parents with children 8-14 years old

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

III. Group for parents with children 15-18 years old

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

- Discussion for evaluation of the workshop. At the end of the Activity Play Workshop there will be a discussion – evaluation of the workshop.

Supplementary Training Materials

- 3 meeting rooms,
- Supportive devices for the workshop as: a roll mat, exercise balls (different sizes), Boccia set of balls, assistive ramp, a head wand, wooden spoon, markers, rags of cotton and wool, scissors, knitting needles, glue, coat button.

Feedback on the Chapter

- What was most helpful or interesting for you in the training?
- Did the different workshops' snapshots give you ideas for spending more time with your child?
- Do you think that you can enhance a new activity with your child?
- Did your child's reaction during the workshop encourage you to play with him/her?

Suggested Reading

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Chapter 2

Social Life

Session 2.1: Support network

Duration: 45 min

Learning Outcomes

Trainees will be expected to know;

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

Methodology

- Lecture and PowerPoint presentation. The trainer should explain to the trainees the informal and formal ways that the supports can be provided to the individual/family. It is very important to present ways of using support networks and the influence that a support network can have in improving conditions for people with CP and their families.
- 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 we present later are part of the themes to be developed.

Supplementary Training Materials

- Video projector,
- Papers and pens

Feedback on the Chapter

The result of the group exercise will provide the feedback on the session.

Suggested Reading

- Stephen Murgatroyd and Ray Woolfe (1982): “Coping with Crisis” Harper and Row Publishers, London.
- Robert M. Moroney (1976): “The Family and the State” Longman Group Limited, London.
- 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

Duration: 45 min

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.

Methodology

- Lecture and PowerPoint presentation. The trainer has to explain which are the everyday family social activities. The participation of the child with CP in family’s social activities is very important because it is helpful for the development of social relations and the contacts with the community.
- Lecture and PowerPoint presentation. The meaning of social activities for the family relationships.
- Lecture and PowerPoint presentation. The cooperation with the specialists is helpful in the promotion of the child’s participation in social activities. In this part the trainer should discuss with the trainees or use the technique of case-studies analyses.
- Questions and answers, according to the trainees’ needs or the session contents.

Supplementary Training Materials

Video projector

Feedback on the Chapter

- Which is the favorite social activity for your child with CP and why?
- Which are the advantages of participating in social activities?

Suggested Reading

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Session 2.3: Leisure time for parents

Duration: 50 min

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.

Methodology

- PowerPoint presentation and lecture about the importance and the value of leisure time for parents of children with CP and for their family relationships and also about ways to manage parent's leisure time..
- Group discussion – Counselling. Parents will be divided into two groups with one trainer in each group and have a group discussion – parents counselling. The trainers present some issues to the trainees and they will encourage the trainees to present their own ideas. In the end there will be questions and answers and finally discussion (some examples of these issues are included in the Supporting Materials).
- Demonstration of good practices, videos, photos or presentation of programs which promote or support the leisure time of parents of children with CP.

Supplementary Training Materials

- Laptop,
- Notebooks, pens, pencils
- Colored markers,
- Two round tables

Feedback on the Chapter

The exchange of ideas in the 20 minutes group discussion/counseling, described in the Training Booklet, could be used as the feedback of the session.

Suggested Reading

- Croustalakis G., (2000). “Children with special needs”, Athens, Psychopedagogiki Paremvasi
- Minuchin, S., (2009). “Families and Family Therapy, Athens, Greek Letters, 61-62.
- Toti Gianni, 1982, “Leisure Time”, Athens, Memory
- Cerebral Palsy Greece – Research Dep. (2004), “My brother and I: The siblings of people with cerebral palsy look to the future”, Athens, Cerebral Palsy Greece

Session 2.4: Recreation and leisure time for children with CP

Duration: 50 min

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.

Methodology

- PowerPoint presentation and lecture by the trainers about the importance of the leisure time for children with CP and the categories of the activities and also

about the importance of family cooperation with Companion/Assistant on payroll and general criteria for the selection of an Assistant/Companion.

- Demonstration of good practices. It will be useful to watch a video where a parent and a child with CP cooperate with an assistant. It will also be useful to have an assistant presenting his or her opinion about recreation and leisure time for children with CP.

Supplementary Training Materials

- Paper, pens
- Video-projector
- DVD player,
- Laptop

Feedback on the Chapter

- Have you ever cooperated with a companion/assistant for your child?
- In which activities could your child participate with a companion/assistant?

Suggested Reading

Dr Feluka Vasiliki, “People with motor disabilities and their free time”, article

Chapter 3

Cooperation With Interdisciplinary Team

Session 3.1: Cooperation with an interdisciplinary team

Duration: 50 min

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.

Methodology

- Lecture and presentation about interdisciplinary teams and the interactions that should exist between the team and the family.
- Discussion, questions and answers

Supplementary Training Materials

- Video-projector
- Laptop

Feedback on the Chapter

The discussion between the trainer and the trainees will be used as feedback of the session.

Suggested Reading

- White Book on Physical and Rehabilitation Medicine in Europe
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- UN Standard Rules to provide persons with disability full participation and equality. New York: United Nations; 1994.

- 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