

Training Program for Improving the Wellbeing of people with Cerebral Palsy

Mariken Tacke¹, Michela Canensi¹, Marta Perotti¹, Marco Marcelli², Rosa Fernández Valero³, Juan Navarro³, Lucía Fernández Molina⁴, José Alvarelhão⁵, Jorge Carvalho⁵, Saša Radić⁶, Ivana Ćuk Krajačić⁶, Ileana Hamburg⁷, Gabriela Lütgen⁷

¹ 'Il Cerchio' Società Cooperativa Sociale Consortile (Italy), ² ASL Viterbo (Italy), ³ AVAPACE Asociación Valenciana de Ayuda a la Parálisis Cerebral (Spain), ⁴ CUNAFF Fundació Lluís Alcanyís de la Universitat de València (Spain), ⁵ FAPPC Federação das Associações Portuguesas de Paralisia Cerebral (Portugal), ⁶ HURT Hrvatska Udruga Radnih Terapeuta (Croatia), ⁷ IAT Westfälische Hochschule Gelsenkirchen (Germany)

Background

Cerebral palsy (CP) is the most common cause of permanent but not unchanging motor disorder in childhood, often accompanied by sensory, communication, behavioral, cognitive and/or perceptual difficulties. It has a varied spectrum of clinical manifestations which may affect the subjective wellbeing and Quality of Life (QOL) of people with CP.

Major nutritional and eating difficulties can be associated with CP. A healthy diet, attractive food, specialized help with specific eating problems (e.g. dysphagia), autonomy in eating (adapted tools), participation and inclusion in mealtimes can help improve the Wellbeing and QOL of people with CP.

Due to the motor disorder, with a variety of severity levels, people with CP generally are less physically active in relation to persons without motor difficulties. This can result in a deterioration of health conditions, besides poor participation in daily (social) activities, which may reduce their wellbeing and QOL.

Often information and guidelines for differently-abled people are given just to professionals and family members without directly involving the differently-abled people in acquiring knowledge and participating actively in the decision making regarding their care.

Method

The CP-WELLBEING project started in September 2016 and will finish in August 2018. This period is used to develop the training program together with people with CP, their family members and professionals working with them.

The partners involved in the project come from 5 different European countries and have different professional backgrounds.

The project is divided in the following phases:

- 1) The partners of the project have collected and studied the background information in international literature regarding the topics of the project.
- 2) The partners have developed a first edition of the materials for 10 training activities (Teaching Guide, PowerPoint presentations, training activities, questionnaires/ surveys).
- 3) Subsequently they have presented these materials as trainers in an interactive way involving a total of 160 people with CP, their family members and professionals, in the different participating countries.
- 4) Based on observations of the trainers, verbal comments of the participants and satisfaction surveys filled in by both, the produced materials have been reviewed and changed during a central meeting of all the partners.
- 5) A virtual platform is now being developed to integrate with and support the training activities.
- 6) Between March and June 2018 the revised training activities, now 8, the other reviewed materials and the virtual platform will be proposed to a total of approximately 160 people (CP, family, professionals).
- 7) Then step 4) will be repeated and in July 2018 all the final materials will be ready.

All the materials of the training activities have been adapted for different cognitive and communication levels. Written text is supported by PECS, images and photo's.

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new.cpswell.eu – infancia@avapace.org

Aims

- To raise and increase awareness and motivate people with CP and the collective around them of the importance of inclusive eating and physical activity as a tool for improving Wellbeing and Quality of Life.
- To transfer knowledge, tools and guidelines to people with CP, their families and professionals working with them, to enable inclusion and (major) participation in eating, physical activity and sport of people with CP.
- To develop a innovative training program for people with CP with different levels of impairment and from different European countries, with their direct active involvement in the development of it.

Results

The results at the end of the project will be:

- ✓ 8 Training Activities
 - For people with CP, their family members and professionals working with them
 - With the topics: Wellbeing and Quality of Life, Inclusive Eating, Physical Activities and Sport
 - Consisting in: PowerPoint presentations, activities/games related to the topic of the training, sharing experiences, homework
- ✓ A Teaching Guide
 - With background information on the topics addressed in the training activities
 - With step by step explanations about how to set up the training activities
 - For professionals who would like to organize the training activities, as a trainer, for people with CP, their family members and other professionals
- ✓ A Virtual Platform (new.cpswell.eu)
 - In 6 European languages: English, Spanish, German, Italian, Portuguese and Croatian
 - Where all the produced materials of the CP-WELLBEING project will be freely available (Teaching Guide, PowerPoint presentations of the training activities, execution guides of the training activities, questionnaires/surveys, handouts)
 - With a private virtual workspace where trainers can upload materials for their specific training activities and their participants can read the uploaded materials, find links, play games, answer questionnaires, write a diary about the topics addressed in the training activities and get in contact with the trainer.

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