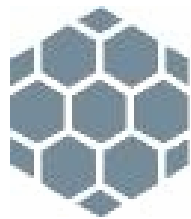


UN-PARALISING CULTURE

Cerebral Palsy, Stereotypes and Culture





APPC

associação portuguesa de paralisia cerebral

IPP PORTUGAL 2006

Project Name: "Un- PARALISING Culture"

Project Theme: Cerebral Palsy, Stereotypes and Culture

Dates: 8 to 29 of July, 2006

Delegations: of 3 participants

Countries: Portugal, Spain, Italy, France, Canada, USA, Tailand and Lebanon

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Abstract

CISV will work with Associação Portuguesa de Paralisia Cerebral (APPC), which is an association that works with Cerebral Palsy. The Association works alongside with the Centro de Reabilitação de Paralisia Cerebral Fundação Calouste Gulbenkian (Centre) which provides care and education for cognitive disabled individuals ranging from 16-35 years old.

Culture is a key component of the Association. Patients learn and do plenty of activities on various things, ranging from photography to poetry. This has a positive effect on all the users of the centre in terms of their personal and educational development. We have previously worked through Local Work activities with them in this area.

This IPP will be divided in three parts: (1) training and adjusting to special needs supervised by the Centre's technicians, this will take place in Lisbon; (2) national cerebral palsy individuals summer camp, where IPPers will work as facilitators, and (3) back in Lisbon, working with the users of the centre consolidating this we learned in the camp.

Working with people that have neurological disabilities is a challenge that we decided to face. This will be an opportunity to see that they have a culture of their own and how they overcome stereotypes.

Description of Partner Organisation

The Associação Portuguesa de Paralisa Cerebral (www.appc-sul.rcts.pt/) is an Association created in 1960 by parents and technical staff that felt difficulties helping the children and adults with Cerebral Palsy.

Cerebral Palsy is primarily a disorder of voluntary movement and co-ordination, due to a defect or lesion of the immature brain. It is an umbrella term covering a group of non-progressive, though not unchanging, motor impairment conditions, which range from multiple and profound to barely detectable. There are three main types:

- Spastic cerebral palsy refers to increased muscle tone or hypertonia.
- Ataxic cerebral palsy refers to disordered movements characterised by short and jerky movements. Often muscle tone is normal or decreased.
- Dyskinetic cerebral palsy usually comprises slow writhing movements where muscle tone fluctuates between increased and decreased tone.

Some years after the association felt the need to create a rehabilitation centre so the Centro de Reabilitação de Paralisia Cerebral Fundação Calouste Gulbenkian was created and is now part of the Portuguese Social Security. The Centre has 74 users, all of them older than sixteen years old and with Cerebral Palsy or other neurological problems. The Centre provides them external support in all aspects of their daily lives, such as education, professional training, and integration in the work market, transportation and all the special logistics needed.

In Portugal, two out of thousand children are born with cerebral palsy. Every year there are around 135 000 births in Portugal, so it is estimated that every year around 270 children are born with cerebral palsy.

Portugal is, at the moment, investing a lot in people with cerebral palsy, specially the ones that compete at the Paralympics.

The Association has several nucleuses all over the country and works closely with the Centre providing them contacts and facilitating beaurocracy.

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Themes from the CISV Education Circle

Development Education:

- Facing Prejudices:
 - Disability;
- Quality of Life;

Human Relations Education

- Group Life Interaction;
- Cooperation;
- Communication Skills;

Personal Development Education

- Individual Growth Through Experiences;

The Practical Project

For the first 2 days we would have the participants' presentations and group building activities.

Then, for the next 2 days we'll go to the association's where we will meet the partner organization staff, learn about the centre life and have some specific training about cerebral Palsy (theoretical – in terms of what is it? And how to prevent it? - and practical – how to deal with them), and begin to plan some activities along with sessions by some guest speakers that will come to talk about the theme.

The 3 days that follow we will work during the day with the users of the centre (CU), we will do cultural activities (something like national nights during the village program), present the IPPers and build some connection with the CU. This will give us some ideas to plan activities for the camping. The CU will teach the IPPers how to play Boccia (they are in the Paralympics team) and we can start a championship.

For the following 9 days we will go to a National Cultural Summer Camping of the Association that gathers about 40 people with brain Palsy from different parts of Portugal. This is a Cultural Camping so every day will there will be an “art of the day”. IPPers are supposed to help to prepare the CU, accompany the activities (specially the excursions) and plan some fun activities for the nights. Also IPPers can be asked to put up tents and help in the kitchen.

After the camping we'll spent 3 more days with the CU and play the finals of Boccia Championship, paint the gymnasium (this will be the IPP concrete legacy), and prepare the event for the local community, which will take place on the 4th day (after returning from the camping). This event will consist mainly in a fair where the CU will sell the arts & crafts. This event will link the CU with the society.

On the last 3 days we will evaluate and leave!!!! On the 1st (of this 3) the evaluation will be with the CU and the PO staff; on the 2nd day the evaluation will be with only the IPPers at our the camp site; on the 3rd day it's goodbye time!

The Educational Project

Participants (IPP'ers) will explore the theme in their own countries before the IPP and prepare presentations for the first week of the project.

- Find out what Cerebral Palsy is and try to know the living conditions of someone with Cerebral Palsy (CP) in their country
- Prepare an activity which shows the panorama of physical / mental and cognitive disabilities in their society;
- Prepare a culture presentation about your country and culture to show to the Centre Users;
- Collect as many activities as possible to do in the camping so that it can integrate all participants (IPPers + Centre Users + Technicians)

Guest speakers from the Partner Organisation and other specialists on the theme will be invited to guide us and give their input and knowledge to the project. Participants will have the opportunity to discuss and exchange ideas.

The IPP will also give participants a way to:

- become acquainted with people who have mental and/or physical disabilities;
- learn how to communicate with people with mental and/or physical disabilities;
- show their different cultures to the users of the Centre;
- learn, and teach the participants, through cultural activities;
- discuss ways that could improve the quality of life and acceptance of these people in society;
- maintain the MOSAIC project being developed by the chapter.

Goals and Objectives

1) To Demystify the Cerebral Palsy:

- i. A Doctor or a Nurse will come as a guest speaker to explain the causes of cerebral palsy and what can be done to prevent it, while the participants expose the research they did in their country
- ii. During the first week IPPers will walk in Lisbon with some of the CU's and find the difficulties there are for the people with physical disabilities;
- iii. Technical staff from the association will teach, through practical workshops how to take care of individuals with cerebral palsy, and participants will put in practice all that they learn during the camp;
- iv. With the help of the home staff (association and some of the local chapter staff that will have contact with the CU's during the year), every IPP'er will find a way to communicate with the CUs.

2) To show other cultures:

- i. IPP'ers will expose their own culture through a presentation, so that the CU's can learn about other traditions and cultures from all over the world;
- ii. In the camp there will be activities prepared by the IPP'ers where everyone will expose what they know about each other is cultures and present their way of seeing the world.
- iii. Painting the world. As the concrete mark of the procect, IPP'ers and CU's will paint, in a big placard, their vision of the world

3) To learn from each other

- i. IPP'ers will learn the daily life (all the problems and all the happinesses) of a person of their age with Cerebral Palsy by the interacting during all the project
- ii. IPP'ers will take (in daily routine, in special activities such as the "painting the world" and in the big farewell party) the CISV message of "peace and cross-cultural education" to special people who want to know the world;
- iii. To learn and experience new things through recreational activities (such as singing, dancing, theatre, poetry, photography, painting, among others); By preparing the activities and having to adjust to the special needs of the CU's; by the activity itself and the evaluations of each activity together with the CU's.

Participant Profile

A. Physical

- 19+ years old, and preferably not older than 35 .

The CU's are around 20 and the main aspect that led APPC to work with CISV was that they saw in CISV Portugal a group of people with the same age as the CU's, willing to work with them and to bring some dynamism and new ideas. For APPC the best about all the project is that the CU's will spend their summer with people of their age, making it "the best time of their lives"

- Energetic;
- Reasonably physically fit – to take care of disabled campers and participate in radical sports (because during the camp, CU's will do some radical sports in Serra da Estrela, where everything is prepared for it).

B. Educational

- Not necessary previous experience with people with disabilities (preferably no professionals in this areas)
- The ability to communicate in a Latin language, not obligatory, but an asset;
- Interest in working & communicating with people who may have multiple disabilities [may be unable to speak, may use wheelchairs, may need help being fed, etc];
- Interested in discussing issues affecting people with disabilities.

C. Personal Attitudes and Skills

- Funny, good spirit always in a good mood;
- Willing to try new situations;
- Lots of patience;
- Anxious to work with special people.

Preliminary Schedule

Saturday	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday
8	9	10	11	12	13	14
Arrive Introduction Ice-breakers Practicals		<ul style="list-style-type: none"> ▪ Introduction to Partner Organization Staff ▪ Learn about the centre ▪ Train IPPers about theme ▪ Share skills ▪ Begin to plan ▪ Guest speakers ▪ Learn how to deal with people with mental and/or physical disabilities 		Introduction to Centre Users (CU)		
	IPP	IPP & POS		IPP, POS & CU		
15	16	17	18	19	20	21
Practical Project Preparation						
Practical Project - Camping						
	IPP & POS	IPP, POS & CU				
22	23	24	25	26	27	28
Practical Project - Camping	Practical Project Wrap Up	Practical Project – Activities in the Centre			“Event” for local community	CU evaluation Farewell event for CU
IPP, POS & CU	IPP & POS	IPP, POS & CU				
29	30					
IPP evaluation	Leave					
IPP	IPP					

IPP = IPP participants & staff
 POS = Partner Organization Staff
 CU = Centre Users

Practicals

Accommodation: Participants and staff will be staying at a school in the city of Lisbon lent by the city hall. During camping participants will be hosted in tents, arranged by the staff, side by side with the partner organization in a camping park north of Lisbon (around 200km)

Transportation: participants will be transported either by a city hall shuttle, public transportation (Lisbon has an excellent subway system) or by car (driven by the staff). To the camping and back participants will either travel through a city hall bus, a private coach or a regular coach. A car will be available at all times in case of assistance need.

Food: it will be provided by the staff, through sponsoring both for the Lisbon and camping stays.

Health: there are no major concerns in Portugal relating to health. No special measures in terms of travellers' medication will have to be arranged.

Funding & Sponsors

Sponsoring: throughout the years, CISV Portugal has had contact with several sponsors. All sponsoring ethics have been respected and the IPP will be no exception.

We have assured several items of use for the IPP:

- Accommodation – a school will be provided for the IPP people to stay;
- Transportation – we are in contact to assure a shuttle for the IPP participants. Several transportation companies have sponsored us; especially in terms of public transportation (Lisbon's subway company has granted us a few hundred tickets);
- Food – we have granted throughout the years several alimentary items such as frozen meals, milk, yogurts, juices, butter and jam, cereals, pasta, chips, rice, canned food (tuna fish, beans...), bread, bottled water and snacks;
- Other items of interest:
 - Tents;
 - Sports material such as balls, arches;
 - Paint and painting materials;
 - Office items such as tape, paper, pens and ink for painting.

Preparation of the host country

We have already made a Local Work Activity with JB participants, and we are planning on doing others next year. Also we will plan the entire project with the Centre, from the inscriptions of all the participants, communication and marketing of the camping, logistics' etc. This will involve not only the home staff but also the entire chapter.

Staff

Marta Mendonça - Psychology Student

Leonor Pinto - Political Science Student

Manuel Soares - International Relations Student

Francisca Silva - History graduated

Joana Miranda - Journalist

Contact person

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Extras

More information on Cerebral Palsy can be found on the following websites:

- [http://www.scope.org.uk/;](http://www.scope.org.uk/)
- [http://www.ucp.org/;](http://www.ucp.org/)
- [http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm.](http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm)