

”IF I ONLY COULD...”

Empowerment of People with Cerebral Palsy

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INTRODUCTION

“We don’t want you in our school.”

“There is no meaning to study at the university if you have to communicate with other people, because you walk and talk so strangely.”

“How can you even dream of getting a job?”

“Would you really think that you will manage with a baby?”

“You can never be able to live an independent life.”

Many people with cerebral palsy (CP) are used to hear these kind of comments. (Järvinen 2012.) Unfortunately even medical specialists still equate physical condition with mental retardation – especially when it is talked about this congenital, permanent and non-progressive condition. It is often forgotten that CP is a term used to describe a group of disorders affecting body movement, posture and muscle co-ordination (Rosenbaum 2006). So every person with cerebral palsy is unique and should be treated as an individual with personal potential and strengths (see also Hotulainen et al. 2014).

This study is focused on experienced life and disability, searching answers to the following questions:

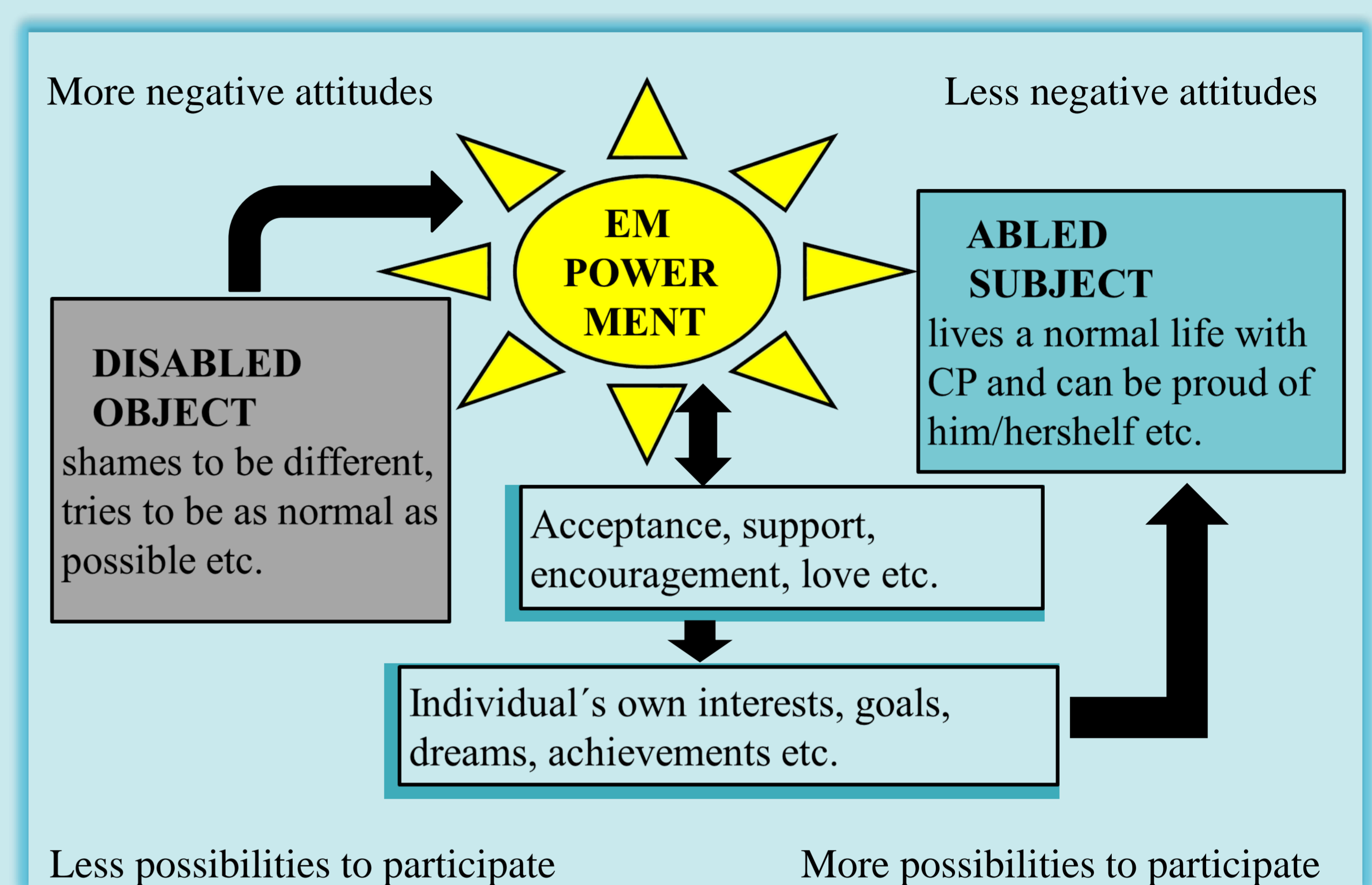
- Which factors promote and which prevent the acceptance of CP as a part of identity?
- Which things facilitate and which complicate the empowerment as an individual, subject-based and social process?

MATERIALS AND METHODS

The autobiographical life stories written by Finnish adults with CP have collected from different sources. “Nothing about us without us” has been a main principle in all stages of this narrative lifespan research. Chase (2005) argues that life stories will help us to understand different manifestations of the human life. Writing can also be an empowering experience itself.

In qualitative data-based content analysis, the main attention is at individual level. In addition some changes which have taken place in our society during last decades will also be under examination (e.g. segregation vs. inclusion and different models of disability).

EMPOWERMENT PROCESS IN DISABILITY CONTEXT



PRELIMINARY RESULTS AND DISCUSSION

Empowerment can be seen as becoming a subject in one’s own life – becoming powerful (Adams 1996; see also Siitonen 1999). For many people with CP this has been a long journey from shame to pride (see figure above).

The parents have a crucial role in this dynamic process. Every child should be seen primarily as a child, not as a living diagnosis. The life stories clearly show that with suitable education and encouraging examples it is easier to achieve a capable identity and have more opportunities to say: “Yes, I can!” A lot of *sisu* and creativity are however needed when overcoming all those visible and invisible barriers. Nevertheless almost everything is possible.

Be strong – the discrimination is wrong.

Keep on dreaming – the future will be shining.

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