



How youth with cerebral palsy perceive participation in everyday life after participating in intensive rehabilitation based on adapted physical activity

Anna Ullenhag^{a b}, Reidun Jahnsen^{b,c,d}, Nina Klove^c, Solveig Smedvig^b, Anita Hoberg^b

^a Mälardalens University, School of Health, Care and Social Welfare, Sweden

^b Beitostølen healthsports center, Department of Research, Beitostølen, Norway

^c Oslo University Hospital, Department of Neurosciences for Children, Norway

^d University of Oslo, Institute of Health and Society, CHARM, Norway

Intensive rehabilitation for children with cerebral palsy



Cerebral palsy (CP) is one of the most common childhood disabilities with a prevalence of 2.1 per 1000 residents (Hollung et al 2021)

In Norway, 18% of young people with CP have participated in intensive rehabilitation (2020, www.norcp.no)

There is a lack of evidence and consensus about the design and content of intensive rehabilitation aiming to improve participation (Størvold et al. 2020; Adair et al. 2015)

Understanding of the experiences of youth with CP is critical, to identify the optimal content and organisation of interventions

The objective



To explore how youth with CP experience and describe their participation in everyday life after an intensive rehabilitation programme, the Buskerud Intensive Programme (BIP)





Method and analysis

- A qualitative design; semi-structured interviews with 14 youths with CP (mean age = 17 years)
- Inclusive criteria: CP diagnosis, participation in the BIP, able to understand and communicate in Norwegian.
- A content analysis with inductive thematic coding associated with the participants' experiences of participation



Buskeruds Intensive Programme (BIP)



The BIP is a goal-directed, systematic and periodic intensive rehabilitation programme for children with CP from the ages of 1.5 to 15 years.

The BIP's main goal is to promote participation in everyday activities in a natural environment.

The BIP consists of four parts, three take place before the child starts school (I–III); and the last part (IV) takes place during the school years.

Buskerud Intensive programme part I-III at the habilitation centre

Part I-III	Age(year)	Focus of content
I I will and I can	1,5-3	<ul style="list-style-type: none">• Information about CP• Hand function• Communication• Strengthen the competence of parents and professionals in promoting participation• Learn to set goals in everyday life• Practice participation in daily activities
III- Reunion	3-5	<ul style="list-style-type: none">• Ensure that goals are in line with the child's capacity and opportunities for learning• Strengthen social bonds between parents and children• Introduce adapted physical activity• Strengthen collaboration with municipal service providers and health professionals
IV-On my way to school	5-6	<ul style="list-style-type: none">• Knowledge transfer and collaboration between the school, municipal service providers and habilitation• Knowledge of factors promoting activity and social participation in school



Buskerud Intensive programme part IV at Beitostolen health sport centre

Part IV	Age	Focus of content
Active leisure time	7-10	Adapted physical activities Participation in summer and winter leisure activities Strengthen social networks Adequate activity equipment and devices
Active social life and sports	12-15	Specialization in summer and winter activities Social network



Youths with CP's experiences of participation in everyday life

“Everyday life – to get the pieces of your life to fit together”.

- *“I focus almost exclusively on schoolwork and struggle with it from morning to night. Sometimes I can hang out with friends in the evening”.*(Mats)

“Participation means inclusion and belonging – the meaning of life”

- *“That I can be part of the community, and contribute, to help others, that I can contribute with my resources and my knowledge.... I should say that participation is the meaning of life”.* (Lena)

“Individual and environmental factors influencing participation “

- *“I use 50% more energy than others, so I get more tired in a way, and I get really exhausted every day at school and when I come home, I fall asleep”* (Mats)
- *I would not have these functions today if Mom and Dad had not trained with me every day when I was little. (Sonya)*

Experiences of participating in the periodical intensive rehabilitation programme (the BIP)



“Enjoyable activities away from home together with like-minded people increased function, independence and self-esteem”

“I could recognise myself in others with similar problems. Parents and doctors can never understand you in the same way”. (Sonya)

“You have been allowed to try different activities, challenge yourself a little, and try to learn something new”. (Hans)

“To be continued locally”

“It does not always turn out as planned. Surgeries and more schoolwork mean that you re-prioritise your time, are less physically active when you get home”. (Lena)

The youths' aspirations for the future



“The future is unknown, but anything can happen – visions for the future”

“I'm afraid that I'm still not going to have many friends, maybe”. (Milo)

“My dream is to build ‘nano-technology bones’ through an electronic spine. It is a very advanced and very unlikely dream, but not impossible. Or to become a lawyer then”. (Noah)

“I hope to find the balance between activity and rest, which means that I can be happy with the life I live, move and live by myself, and get the opportunity to be active without my parents”. (Lena)



hope & fear



Conclusions and implications

- Young people with CP describe participation as the meaning of life and state that it is essential for inclusion and being able to contribute to society
- A periodical intensive rehabilitation, including adapted physical activities in groups, is recommended to provide peer learning and mastery experiences in young people with CP
- To build the courage to push individual boundaries in new activities, intensive rehabilitation together with peers is preferable
- Young people with CP seem to have the same hopes for the future as their typically developed peers