

Adolescents with cerebral palsy sharing their participation experiences: Everything about us with us!

Aim: to let adolescents with CP share their personal experiences using a participatory research project, with a focus on participation at school, at sports, and in healthcare

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School, sports, and healthcare are important participation areas for adolescents with CP. To be able to truly understand and optimize their participation, it is necessary to switch our perspective. Let the adolescent with CP be the starting point. This perspective implies qualitative research with a focus on their experiences. But that is not all: it also implies research in which adolescents themselves play an active role in determining the design and outcomes.

Participation of CP ambassadors in the project

Initiate/decision making

- Start a facebook page for the project
- Provide input that helps us to analyze the interviews
- Decide on the interview style

Co-research/co-produce

- Communicate in BOSK magazine
- Write texts about meetings
- Photography during meeting

Give advise

- Deliver input for introductionletter to participants

Are consulted

- Provide questions and keywords for interviews

Are informed

- Information sent via whatsapp on several topics

Participatory research:

- 10 ambassadors with CP
- as experts and as faces of the study
- are actively involved in research
- which is executed not only for them but with them
- in all phases of the project: from design to outcomes

Design:

- a 10-year follow-up of PERRIN
- 30 - 40 adolescents (12-17 years) with CP
- open interviews
- focus on participation
- qualitative analyses

Expected outcomes:

- experiential knowledge and practical recommendations, about participation at school, at sports and in healthcare
- insights in the process of executing participatory research with adolescents with CP

"What I really like about this project is, our opinion is truly valued, as this leads to new insights."
(Lauren, 14 yr)

"Ik vind het heel goed dat dit project veel aandacht besteedt aan onze mening want dit leidt weer tot nieuwe inzichten."

