



MINISTÉRIO DA EDUCAÇÃO
INSTITUTO FEDERAL DE EDUCAÇÃO, CIÊNCIA E TECNOLOGIA DO RIO DE JANEIRO

ELISA BEATRIZ BRAGA DELL'ORTO VAN EYKEN
BEATRIZ CANTANHEDE CARRAPATOSO SOUZA

ACTIVITIES AND SOCIAL PARTICIPATION OF CHILDREN WITH ATYPICAL MOTOR DEVELOPMENT

Study Protocol and Statistical Analysis Plan

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METHODOLOGY

Study design: Cross-sectional, observational, and analytical study on the perception of those responsible for the execution of tasks and activities, the environments, and the social participation of children (up to 11 years of age and 11 months of age) with neuromotor disabilities in neurofunctional physiotherapeutic care.

Setting: School Clinic of the Realengo campus of the Federal Institute of Education, Science and Technology of Rio de Janeiro, between October 2022 and September 2023.

Participants: All legal guardians of the children in attendance in the proposed period will be invited to participate. Those responsible for children in care for other causes will be excluded. Those responsible will be informed about the research and those who agree and sign the free and informed consent form (ICF) will be included.

PROTOCOL

Participants will answer the questionnaires while their children are in physical therapy. Each of them will answer two of three questionnaires:

1. Measure of Participation and Environment - Children and Youth (PEM-CY) <https://canchild.ca/en/shop/2-pem-cy-participation-and-environment-measure-children-and-youth>. Those with a child aged 5 years or older, or
2. Measure of Participation and the environment - young children (YC-PEM), <https://canchild.ca/en/shop/23-yc-pem-young-children-s-participation-and-environment-measure>. Those with a child under 5 years old.

The PEM-CY and the YC-PEM assess, through the perception of parents/guardians of children and young people, the participation, and environmental factors in three sections: home, school, and community. Each section is divided into "participation" and "environment". In the part related to participation, the items evaluated consist of typical activities that children usually perform in that scenario (home, school, or community), while in the part related to the environment, the items concern the environmental characteristics (barriers or facilitators present in the house, school, or community) that influence participation. The questions are distributed as follows: 10 items about participation and 12 items about the environment in the home section; 5 items about participation and 17 items about the environment in the school section, and 10 items about participation and 16 items about the environment and 21 in the community section. For each environment, there is also a space for the guardian to list things that he or the family members do to help in the participation of the child. Each item about participation is evaluated in three dimensions: frequency (seven-point scale), involvement (five-point scale) and desire for change (scores from zero to 100%). The environment, in turn, is evaluated by its characteristics, as well as by the availability of services and resources (scores from zero to 100%). The PEM-CY allows the knowledge about what types of activities parents understand to be important for children and young people to participate, the identification of the types of factors that support or prevent the participation of a child in important life situations, as well as the evaluation of the frequency of participation of their children and the facilitators and environmental barriers that influence participation. (Bornbaum et al., 2015; Krieger et al., 2020)

3. Pediatric Evaluation of Disability Inventory (PEDI) – For all the participants.

The PEDI is an inventory based on the ICF that assesses, also through the perception of the parents/caregivers, the child's performance in daily activities, mobility, and the need for help from the caregiver and changes in the environment and in the child. The three parts of the PEDI are: Part I – on functionality in the home environment, addresses tasks of: self-care (73 items), mobility (59 items) and social function (65 items); Part II – concerns the amount of help needed from the caregiver, determining the independence to perform self-care (8 items), mobility (7 items) and social function (5 items); Part III – addresses the use of some modification in the environment and includes 4 categories of modification: none, child-centered, rehabilitation or extensive, which are architectural changes. The score of Part I is the sum of the items scored with 1, that is, items that represent the ability to perform



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the activity. In Part II, each item can be scored between 0 and 5 points. Receives 5 the item in which the child performs the task independently and 0 when it needs full assistance. Scores 4 (supervision), 3 (minimum assistance), 2 (moderate assistance) and 1 (maximum assistance) represent the amount of help the child receives in the activities. These points are also added. Part 3 is qualitative. (MANCINI et al. 2016)

STATISTICAL ANALYSIS

Participation will be described according to the PEM-CY and YC-PEM in relation to the frequency (%) of participation, the child's level of involvement in the task and the modifications desired by the person responsible for the child.

The frequency of participation, ranges from never (0%) to one or more times a day (100%). The level of involvement of the child varies among little involved, 'more or less involved', and very involved. the desire for change in the child's participation (no or yes) with five options for the type of change when desired. In addition, for the full support of each environment evaluated.

For the PEDI, by normative scores and scatter plots reported by the instrument.

Spearman's correlation will be used to assess the relationship between normative PEDI scores and the frequency of participation. In all analyses, the significance level will be 5% ($p < 0.05$).