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ACTIVITIES AND SOCIAL PARTICIPATION OF CHILDREN WITH ATYPICAL MOTOR DEVELOPMENT

Informed Consent Form

Rio de Janeiro

07/30/2023

Informed Consent Form

(According to the Norms of CNS Resolutions No. 466/12)

You are invited to participate in the research **ACTIVITIES AND SOCIAL PARTICIPATION OF CHILDREN WITH ATYPICAL MOTOR DEVELOPMENT**. You were selected to participate because you are a caregiver and legal representative of a child up to 11 years and 11 months of age in neurofunctional physiotherapy at the IFRJ School Clinic. We would like to know what her perception is about the day-to-day tasks she does, where she does it (home, school, and community) and how she does it (how often and her involvement in doing it). In addition, we want to know the possibilities, difficulties, and barriers for the child to perform these tasks. With this information, we will provide personalized guidance to help improve your child's well-being. This research aims to know the ability to perform tasks and social participation of children with atypical motor development and **among other activities we intend** that you answer two questionnaires. One of them is the Measure of Participation and Environment that assesses how you think your child engages in everyday life activities in three environments: home, school, and community. The other is the Pediatric Disability Assessment Inventory that assesses the child's performance in daily activities, their mobility, the amount of help they need for activities, and the changes in the environment and in the child to meet their needs. Your participation is not compulsory. If you agree to participate, you will be included in the research if the child under your responsibility and care has impairment of the nervous system, according to a clinical report or complementary examination, which causes changes in posture and / or movement (neuromotor disabilities). Your child will remain in neurofunctional physiotherapeutic care at the School Clinic until the goals of her treatment are achieved, regardless of the research, and, in addition, you will receive guidance on how to facilitate the execution of tasks and the participation of your child. At any time, you can withdraw from participating and withdraw your consent. Your refusal will not bring any harm in your relationship with the researcher or with any sector of this Institution. The risks related to your participation in this research are: invasion of your privacy; reveal undisclosed thoughts and feelings about your child; discrimination and stigmatization based on the content revealed; disclosure of confidential data (registered in the ICF) and take your time to respond to the questionnaires, and the following measures will be taken to avoid/minimize them: you will respond to the questionnaires in an enclosed space and reserved for this; you can skip questions that you consider invasive; no personal information or feelings revealed during the survey will be disclosed or commented on with others; the questionnaires will be numbered and will not have a name and/or address and/or other information that could identify you or your child; we guarantee confidentiality and privacy, and the non-violation of the completed questionnaires that will be available to the collaborators of the survey only during the period of execution of the survey (October 2022 to August 2023); the signed ICF will be kept separately from the questionnaires and will be under the responsibility of the responsible researcher who will destroy them after disclosure of the research result and submission of a report to the IFRJ CEP. As a benefit, it is expected that this research will help to understand the limitations in the activities, the restrictions for participation and the barriers imposed by the environments to the child so that solutions can be indicated to improve their well-being. The information obtained through this survey will be confidential and we ensure the confidentiality of your participation. Their collaboration is important for us to know the activities, participation, and environments of children with atypical motor development. The data will be disclosed in a way that does not allow its identification but may be disclosed in presentations or publications for scientific or educational purposes. You have the right to know and follow the results of this research. Participating in this survey will not entail any cost to you, and as a volunteer you will also not receive any cash value as compensation for participation. You will be reimbursed for any costs you incur related to the survey and will be compensated for any damages arising out of your participation in the survey. You will receive a copy signed by the researcher, which must be kept, with the contact e-mail of these researchers who will participate in the research and the Research Ethics Committee that approved it, for further clarification. If you have any considerations or questions about the ethics of the research, please contact the Research Ethics Committee (REC) of the Federal Institute of Rio de Janeiro, Buenos Aires Street, 256, Penthouse, Center, Rio de Janeiro- phone 3293-6034 from Monday to Friday, from 9 a.m. to 12 p.m., or by email: cep@ifrj.edu.br.

The Research Ethics Committee is a body that controls the ethical issues of research in the institution and has as one of its main functions to protect participants from any problem. This document has two copies, one of yours and the other of the responsible researcher.

Signature of the responsible researcher

Institution: Federal Institute of Education, Science and Technology of Rio de Janeiro – Realengo campus

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I declare that I understand the objectives, risks and benefits of the research, and my rights as a research participant and agree to participate.

Name of the Research Participant

Date _____ / _____ / _____

Signature of the Participant