Development of Functioning Assessment protocol for children and adolescents with Down Syndrome: The FADS protocol

Desenvolvimento de um Protocolo de Avaliação da Funcionalidade para Crianças e Adolescentes com Síndrome de Down: Protocolo FADS

Desarrollo de un Protocolo de Evaluación de la Funcionalidad para Niños y Adolescentes con Síndrome de Down: Protocolo FADS

RESUMO

Introdução: A avaliação da funcionalidade em crianças e adolescentes com síndrome de Down (SD) requer instrumentos padronizados e sensíveis, alinhados à Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF), e aplicados de forma contextualizada e individualizada. No entanto, há escassez de protocolos específicos para essa população. **Objetivo:** Propor um Protocolo de Avaliação da Funcionalidade (FADS) para crianças e adolescentes com SD, com idades entre 6 e 17 anos, fundamentado nos componentes da CIF. **Métodos:** Foram selecionados instrumentos padronizados, validados e adaptados para o português do Brasil, que contemplam os componentes da CIF e são apropriados para a faixa etária e população-alvo. **Resultados:** Os instrumentos selecionados avaliaram: Atividade: CHORES, Timed Up and Go, WeeFIM, PEDI-CAT, IPAQ-versão curta, Sobre a Minha Criança. Participação: Sobre a Minha Criança, PEM-CY, PEDI-CAT, Escala de Apoio Social. Fatores ambientais: Sobre a Minha Criança, PEM-CY, Escala de Apoio Social, Critério de Classificação Econômica Brasil (ABEP), questionário sociodemográfico inicial. Fatores pessoais: questionário sociodemográfico inicial. Estrutura e função do corpo: Sobre a Minha Criança, SDQ - versão em português. **Conclusão:** O protocolo FADS representa uma proposta padronizada para a avaliação funcional do desenvolvimento infantil, com ampla aplicabilidade. Sua utilização em crianças com SD demonstra potencial para identificação de fatores associados à funcionalidade e pode orientar intervenções e o desenvolvimento de políticas inclusivas.

DESCRITORES: avaliação, CIF, funcionalidade, síndrome de Down.

ABSTRACT

Introduction: The assessment of functioning in children and adolescents with Down syndrome (DS) requires standardized and sensitive instruments, aligned with the International Classification of Functioning, Disability and Health (ICF), and applied in a contextualized and individualized manner. However, there is a lack of specific protocols for this population. **Objective:** To propose a Functional Assessment Protocol (FADS) for children and adolescents with DS aged 6–17 years, based on the components of the ICF. **Methods:** Standardized instruments, validated and adapted for Brazilian Portuguese, were selected to reflect the components of the ICF and to be appropriate for the target age group and population. **Results:** Instruments were selected to assess the following: Activity: CHORES, Timed Up and Go, WeeFIM, PEDI-CAT, IPAQ-short version, About My Child. Participation: About My Child, PEM-CY, PEDI-CAT, Social Support Scale. Environmental factors: About My Child, PEM-CY, Social Support Scale, Brazilian Economic Classification Criteria (ABEP), initial sociodemographic questionnaire. Personal factors: initial sociodemographic questionnaire. Body structure and function: About My Child, SDQ-Portuguese version. **Conclusion:** The FADS protocol represents a standardized proposal for the functional assessment of child development with broad applicability. Its use in children with DS shows potential for identifying factors associated with functionality and may guide interventions and inclusive policy development.

DESCRIPTORS: assessment, ICF, functioning, Down syndrome.

RESUMEN

Introducción: La evaluación de la funcionalidad en niños y adolescentes con síndrome de Down (SD) requiere instrumentos estandarizados y sensibles, alineados con la Clasificación Internacional del Funcionamiento, la Discapacidad y la Salud (CIF), y aplicados de manera contextualizada e individualizada. Sin embargo, existe una

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falta de protocolos específicos para esta población. **Objetivo:** Proponer un Protocolo de Evaluación de la Funcionalidad (FADS) para niños y adolescentes con SD de 6 a 17 años, basado en los componentes de la CIF. **Métodos:** Se seleccionaron instrumentos estandarizados, validados y adaptados al portugués brasileño, con el fin de reflejar los componentes de la CIF y ser adecuados para el grupo etario y la población objetivo. **Resultados:** Se seleccionaron instrumentos para evaluar: Actividad: CHORES, Timed Up and Go, WeeFIM, PEDI-CAT, IPAQ versión corta, About My Child. Participación: About My Child, PEM-CY, PEDI-CAT, Escala de Apoyo Social. Factores ambientales: About My Child, PEM-CY, Escala de Apoyo Social, Criterio de Clasificación Económica Brasileña (ABEP), cuestionario sociodemográfico inicial. Factores personales: cuestionario sociodemográfico inicial. Estructura y función corporal: About My Child, SDQ versión en portugués. **Conclusión:** El protocolo FADS representa una propuesta estandarizada para la evaluación de la funcionalidad en el desarrollo infantil, con amplia aplicabilidad. Su uso en niños con SD muestra potencial para identificar factores asociados a la funcionalidad y puede orientar intervenciones y el desarrollo de políticas inclusivas.

DESCRIPTORES: evaluación, CIF, funcionalidad, síndrome de Down.

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INTRODUCTION

The way children and adolescents with disabilities are approached in clinical and research practice has changed since the publication of the International Classification of Functioning, Disability and Health (ICF) in 2001 by the World Health Organization[1]. Based on this model, the concepts of Functioning and Disability were established, which represent, respectively, the result of the interaction of the positive and negative aspects of Body Structures and Functions, limitation/constraint and performance in Activities and Participation, under the influence of environmental factors (facilitators or barriers) and interaction with the intrinsic personal factors of each human being[1]. Therefore, based on these concepts, it is encouraged that all components of Functioning should be evaluated in order to obtain a holistic overview of individuals. In other words, the focus is removed from assessments focused solely on body structures and functions, in the so-called biomedical model[2], to an approach in the biopsychosocial model[1].

Currently, in therapeutic and clinical assessments, it is recommended

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to focus on all components of Functioning, as well as to use assessment instruments that are suitable for the target group of their assessments, in an individualized manner[3], and that guarantee their reliability in assessments made by different evaluators (inter-evaluator) and in different periods of time (intra-evaluator)[4].

Based on this precept and knowing that Down syndrome (DS), also called Trisomy 21 (T21), is a health condition that affects Functioning, with a high incidence in Brazil (1 in every 700 live births, according to the National Health Council, 2014), and in the world totaling 5 to 8 million people worldwide[5], the importance of applying the biopsychosocial model in practice to evaluate this large population is highlighted. Thus, it will be possible to understand in a more comprehensive way particular aspects of the development of this population, thus generating scientific evidence that offers theoretical support for interventions also based on this model.

DS is the most prevalent chromosomal alteration in humans, which generates primary deficiency in several physiological systems, such as musculoskeletal, neuromotor, cognitive and sensory [6], with characteristics of muscle hypotonia,[7] ligamentous laxity[8], delays in reacting to sensory stimuli [9], slow cognitive processing [10], deficit in postural control and movement coordination [10]. These deficiencies can generate difficulties for children with DS to perform motor activities, such as running [11], transferring from sitting to standing posture [12], walking [13] and functional mobility [14]. Furthermore, limitations in cognitive activities [15], socials and participation [16,17]. We emphasize the equally important relevance of evaluating environmental factors, which can act as facilitators or barriers to functioning Thus, by identifying possible barriers, specific strategies can be developed to improve functioning.

To facilitate the approach proposed by the ICF, there are sets of categories that describe the functioning of individuals with a given health condition in a typical and significant way, called core sets. In other words, the core sets select ICF categories that function as a minimum standard for assessing functioning. For example, there are core sets for the assessment of children and adolescents with cerebral palsy for different age groups [18]. However, there is currently no core set for DS, so it is important that functioning assessment protocols exist to guide assessments of this population.

Therefore, based on the biopsychosocial model in health, and given the need for a guide for assessing the functioning of the population with DS, the objective of this study is to propose the Functioning Assessment in Down syndrome - FADS protocol, which represents a physiotherapeutic protocol for the biopsychosocial assessment of children and adolescents with DS, based on the ICF model. The ICF-based protocol can also serve as a basis for clinicians and researchers to conduct future studies on the specific needs of children and adolescents with DS, allowing comparisons with other conditions, associations/interactions between components of functioning and promoting the advancement of knowledge in the area.

METHOD

2.1 Study design

This study proposed an assessment protocol for children and adolescents with DS based on the biopsychosocial model proposed by the ICF, called the FADS protocol. The local ethics approved the research (CAAE: 31786920.8.1001.5504).

This assessment protocol is intended for children and adolescents with DS aged between 6 and 17 years, with or without comorbidities. Within this age range, all instruments that will be described can be used, as their individual psychometric properties are satisfactory.

2.2 Protocol development

A search was conducted for assessment instruments compatible with the age and population of interest. We selected instruments that addressed at least once all components of the ICF. For personal factors, we developed a questionnaire which will be described below.

2.3 FADS protocol: steps

In order to optimize professionals' time in the clinic and make it easier for caregivers to complete questionnaires, the FADS protocol is divided into in-person and remote modalities.

The FADS protocol consists of 3 stages (Figure 1):

Stage 1 - remote: the caregiver must complete the questionnaire remotely, through a link sent, either by WhatsApp or email, depending on the caregiver's preference. After completing the questionnaire, this stage allows the professional to access sociodemographic data and characteristics of the child/adolescent and their family.

Stage 2 - in-person: In this stage, the physiotherapist provides guidance on self-completion of some assessment questionnaires (About My Child, Social Support Scale, SDQ-POrt, CHORES, PEDI-CAT and ABEP). While the caregiver is filling it out, the therapist assesses functional mobility using the TUG test, balance (Berg Scale), and gross motor function using the Gross Motor Function test (GMFM-88 items) dimensions D and E.

Stage 3 - remote: the therapist schedules an interview with the caregiver, which can be done by telephone, to apply the IPAQ-short version, PEM-CY and WEEFIM. Figure 1 illustrates the steps of the FADS protocol.

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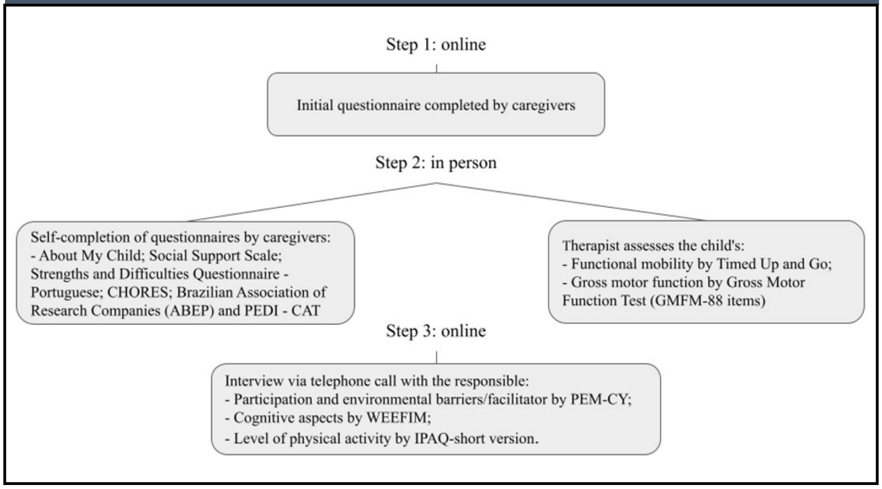
Figure 1. FADS protocol steps.



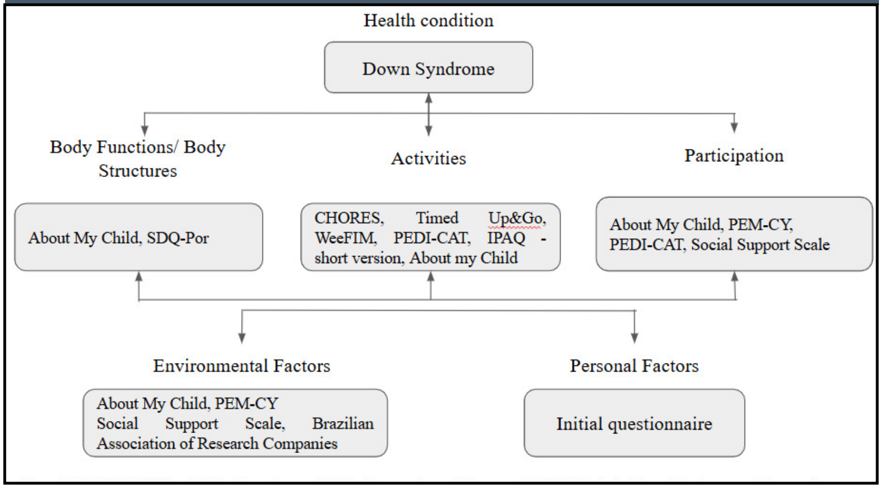
Legend: CHORES - Children Helping Out: Responsibilities, Expectations and Supports; PEDI - CAT - Pediatric Evaluation of Disability Inventory Computer Adaptive Test; PEM-CY - Participation and Environment Measure for Children and Youth; WEEFIM - Functional Independence Measure for Children; IPAQ - short version - International Physical Activity Questionnaire - Short version.

These procedures should ideally be restricted to a period of 15 calendar days, from start to finish. If the respondent has difficulty accessing the links, it can be done in person or by phone with the therapist. It is recommended that the therapist send a report on the patient's performance at the end of the evaluation, and that this evaluation takes place every 6 months.

The questionnaires used will be briefly described below.

Appendix 1 represents a summary of the characteristics of the questionnaires and their application.

Figure 2. FADS protocol and ICF components.



Legend: CHORES: Children Helping Out - Responsibilities, Expectations and Supports, PEM--CY: Participation and Environment. Measure for Children and Youth, SDQ-Por: Strengths and Difficulties Questionnaire - Portuguese, PEDI-CAT (Pediatric Evaluation of Disability Inventory Computer Adaptive Test), IPAQ - short version - International Physical Activity Questionnaire - Short version

2.4 Description of assessment instruments

a) Initial questionnaire

A questionnaire was developed to initiate the FADS protocol. This questionnaire includes questions from the child/adolescent as well as from his/her caregiver (Appendix 2).

b) About My Child

About My Child (AMC) is an instrument that measures, from the perspective of parents, aspects of children's lives based on biological, psychological, social and environmental aspects, from birth to 18 years [19]. Thus, it allows family members or caregivers to highlight conditions related to their child and the care provided to him/her. In addition, it identifies which aspects are important for each family individually. To do this, it uses a list of concerns that are common to parents (such as abilities related to feeding, bathroom, communication and participation in activities)[19]. The instrument is answered in 5 minutes and all of its items refer to aspects related to the ICF of Body Function and Activity and Participation, from the perspective of parents or caregivers [19]. The version translated and culturally adapted for Brazil by Brugnaro, de Campos & Rocha (2025, under review) will be used. More information can be found at <https://canchild.ca/en/resources/353-about-my-child>. It has 19 items with a similar structure composed of 2 parts: (1) "concern" and (2) "impact" perceived by each aspect questioned. (1) concern refers to the parents' perception of issues that affect the child's functioning and, if such concern exists, the impact (2) that, according to them, these issues have on the child/adolescent's ability to participate in daily activities is questioned. The interviewee must answer "yes" or "no" for each item questioned in the (1) concern part. For the items answered "yes", the

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interviewee must answer how much this impacts the ability to participate in daily activities, which therefore corresponds to the second part of the structure. If the interviewee answers “no”, he/she must skip to the next question. The first part of the score refers to the number of situations that concern the parents about their child, with 1 point being assigned for each “yes” answer, and zero points being assigned for each “no” answer. Thus, the raw score is calculated by adding the scores obtained and can range from 0 to 19 points. The second part of the score refers to the impact, with the respective scores and responses: 1 for “Nothing”, 2 for “A little”, 3 for “More or less”, 4 for “A lot”. Thus, this total raw impact score can range from 0 to 76. Higher concern scores indicate that the caregivers have more concerns related to their child, and higher impact scores indicate a greater negative impact on the child's day-to-day functioning.

c) Social Support Scale

The Social Support Scale is used to measure the social support provided to the primary caregiver of the participating child/adolescent. It is valid for the Brazilian population and has high internal consistency in all its domains [20]. The scale is composed of 19 items that assess, according to validation for the Brazilian population [20], three dimensions of social support: positive social interaction/affective support; emotional/informational support; and material support [20]. For each item, the interviewee responds, on a 5-point scale, to the extent to which he/she considers that he/she has that specific social support questioned, in the frequency of “never” (1); “rarely” (2); “sometimes” (3); “almost always” (4) and “always” (5)[20]. The final score is obtained by adding the points of all items, and this will be the value used in the statistical analysis. Thus, higher scores indicate that the interviewee has greater social support.

d) Strengths and Difficulties Questionnaire - SDQ-Port

The SDQ-Por was developed in 1997 by Robert Goodman, translated into Portuguese and validated by Fleitlich, Cartázar & Goodman in 2000. The data indicate that the SDQ-Por presents adequate psychometric properties measured for the Brazilian population [21]. It is widely used in the child and adolescent population[22], as it is short and simple to answer, very useful in clinical practice and has a Portuguese version available free of charge (http://www.sdqinfo.com). It is an instrument designed to detect personality traits, such as conduct disorders, hyperactivity, depression and some anxiety disorders, assessing both aspects of difficulties and aspects of capabilities[23]. There are versions that can be answered by the child/adolescent themselves or through interviews with caregivers or teachers. Initially designed for use in ages between 4 and 16 years [23,], in 2014, after psychometric studies, it was made available for use in ages between 4 and 17 years. It should be answered based on observation of the child/adolescent's behaviors in the last 6 months. The SDQ-Por has 25 items divided into five scales with five items in each: “Emotional Symptoms Scale” (items 3, 8, 13, 16 and 24), “Conduct Problems Scale” (items 5, 7, 12, 18 and 22), “Hyperactivity Scale” (items 2, 10, 15, 21 and 25), “Peer Relationship Problems Scales” (items 6, 11, 14, 19 and 23), “Prosocial Behavior Scale” (items 1, 4, 9, 17 and 20). Of the total items (25), 10 are about capabilities, 14 about difficulties and 1 is considered neutral. For each item, the answers are “False”, “More or less true” or “True”. A score of 1 is given for “more or less true”, while for “false” and “true” the score varies according to the item, as determined by the instrument manual, see link <https://www.sdqinfo.com/py/sdqinfo/c0.py>.

The final scores can be obtained by adding the scores of each scale, thus generating 5 scores that can vary between 0 and 10, and the “Difficulty” score can be obtained from the sum of all scales except the Prosocial Behavior Scale. This score can vary between 0 and 40, and the higher the score, the more personality change the child has, that is, the further away from what is expected. The analysis of the scores can be done based on the raw value obtained, as well as through the classification determined by the instrument manual, which considers the scores and classifies them as ‘normal’, ‘borderline’ or ‘abnormal’ behaviors, as determined by the instrument manual.

For the present study, the version completed by the parents will be used. The scores of each scale, as well as the difficulties score, are classified as ‘normal’, ‘borderline’ and ‘abnormal’ and will be used in descriptive analyses. Therefore, the higher the score obtained, the more changes in the personality characteristics of the child/adolescent.

e) Children Helping Out: Responsibilities, Expectations and Supports - CHORES

The CHORES scale was translated and validated to Brazilian Portuguese by Amaral et al. (2012) and consists of a questionnaire that provides information about children's involvement in household activities, as well as their respective changes over time. The instrument is validated for assessing children with and without disabilities and can be applied in an interview or self-completed format. In this study, the instrument was applied via an electronic form, with 34 items divided into two parts, the first being self-care (13 tasks) and the second family care (21 tasks), composed of activities related to the child's own needs,

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home environment and care for family members. The tasks are scored in two ways according to the child's daily performance in the task, one on a six-point Likert scale (6 = own initiative, 5 = with verbal suggestion, 4 = with supervision, 3 = with some help, 2 = with a lot of help, 1 = cannot perform the task, 0 = not expected to perform the task) and a dichotomous response (yes/no). Therefore, at the end of the instrument's use, data are obtained regarding the child's performance in self-care, family care, total performance and assistance scores required in the two subscales and total assistance [24,25]. A higher performance score in self-care, family care and total represents better performance. As for the assistance score in self-care, family care and total, the higher the score obtained, the greater the assistance required in the activities.

f) Brazilian Association of Research Companies - ABEP

ABEP is a socioeconomic measurement instrument based on characteristics of the home environment. It consists of questions about the number of items in the environment - variables (bathrooms, cars, refrigerator, etc.) and the level of education of the head of the family and access to public services. The answers given can be “does not have” or, otherwise, the number that is owned, ranging from 1, 2, 3 or +4. At the end of the questionnaire, a relationship is made between the values obtained at the end of the sum of the respective characteristics and scoring scores. In this way, the economic classification ranges are obtained A, B1, B2, C1, C2, D-E, with A being the highest class for the others (CCBE, 2019; see https://abep.org/).

g) Timed Up&Go test (TUG)

Timed Up&Go (TUG) was developed by Podsiadlo & Richardson in 1991 and assesses the functional mobility of individuals with motor alterations [26], and is considered a good parameter for functional measurement [26]. The TUG has been validated for use in individuals with DS[14], is a clinically relevant measure, and has a minimum detectable difference of 1.26 s for this population [27]. Lower time scores are indicative of greater functional mobility. In addition, it has a moderate negative correlation with motor performance, assessed by gross motor performance in dimension E (walking, running, and jumping) of the Gross Motor Function Measure (GMFM) scale[14].

To perform the TUG, the participant is instructed to stand up from a chair in which they are flexed at 90º of the hip, knee and ankle, measured by a goniometer, with a backrest and no armrests, walk 3 meters in a straight line, go around a small obstacle, and walk back to the starting point, finishing the test when they sit down on the chair again and lean against it[26,28]. The time, in seconds, that each participant takes to perform the test is evaluated, from the initial verbal command, until they lean against the chair again [26]. For this assessment, children and adolescents should wear comfortable clothing, preferably elastic, to facilitate the execution of the test procedures, and they should also wear their usual footwear. The child/adolescent will be explained how they should complete the test route, as well as instructions regarding walking speed: “walk as fast as possible, but keep walking” [26, 29] or “perform the task as quickly as possible” [28], but without running. An initial attempt will be made to demonstrate the procedure to the participant and clarify any doubts they may have, and then 2 valid attempts will be made, with the average of the times being considered as the final result. The average time in seconds to perform the test will be used in the statistical analysis. Shorter execution times indicate better functional mobility.

h) Pediatric Evaluation of Disability Inventory Computer Adaptive Test - PEDI-CAT

The PEDI-CAT [30] is an instrument that assesses functional skills, that is, functional abilities in a real-life context, for children and adolescents with different health conditions, aged 0-21 years. Its evaluation is done using the PEDI-CAT software (PEDI-CAT version 1.4.3, CREcare, LLC). The full version (PEDI-CAT) has translation, adaptation and good psychometric properties for the Brazilian population with excellent inter-examiner reliability indices (intraclass correlation coefficient-ICC=0.83-0.89) and test-retest (ICC=0.96-0.97) reliability, good internal consistency (0.99) and small standard error of measurement in all three age groups (0.12-0.17)[31]. The instrument contains 276 items of functional activities that are partially selected based on the age of the individual, and the responses that are given by the respondent, according to Item Response Theory (IRT). Its score is calculated from the sum of the scores obtained in each domain, constituting the continuous score. The PEDI-CAT assesses 3 domains of functional activity: (a) *Daily Activities*, (b) *Mobility*, (c) *Social/Cognitive* and one domain extra (d) *Responsibility*, measuring the management of complex tasks of daily life (Haley et al., 2011). We suggest using the Speedy version, which administers 10–15 items per domain. It presents 2 types of scores: (i) continuous score, which means the absolute amount of functional skills in each of the domains, and does not relate to the child's age; (ii) normative score (T-score), which represents the score obtained for each child in comparison with normative data from a population of the same age. This score has a mean for each age group of 50 and SD of 20. Thus, scores between 30 and 70

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(corresponding to mean +2 SD) are considered within the expected range for age[32]. For descriptive data, consider the T-score for below the expected value (<30) and within the expected mean value (30-70). Higher scores indicate better functional skills[33]. See link: <https://www.pedicat.com/about/>.

i) Participation and Environment Measure for Children and Youth - PEM-CY

The PEM-CY is an instrument that assesses the frequency and level of involvement in, and desire for change in, everyday activities that occur in the home, school, and community environments from the perspective of parents or caregivers [34]. It can be used with children and adolescents aged 5 to 17 years with TD or any type of disability, including physical, cognitive, or emotional, and must be answered by parents or caregivers, with a total application time of approximately 40 minutes[34]. It also verifies the extent to which those responsible for the child or adolescent believe that the particular characteristics of the environment in which they are inserted support or challenge the participation of their child or adolescent. For the present study, the instrument with translation and cultural adaptation for Brazil [61] and with ongoing validation by Longo, Cazeiro & de Campos will be used.

The instrument is composed of two parts: (a) participation, which involves frequency, involvement and desire for change and (b) environment, which involves characteristics of aids and barriers and the availability of services and resources.

For part (a) 'participation', the instrument has 10 items in the home section, 5 in the school section and 10 in the community section. In part (b) 'environment' there are 12 questions about particular aspects of the home environment, 17 of the school environment and 16 of the community environment, asking whether these help or hinder participation or whether or not they are available to support participation.

At the end of each session, the interviewee has the opportunity to list three strategies used to assist the child/adolescent in the participation of each of the environments.

The instrument does not verify the level of independence for carrying out the activity, that is, it does not take into account whether the child/adolescent needs help or adaptation, but only whether or not he/she performs the daily activity[35].

Thus, in part (a) 'participation', for each type of activity, the question is (1) How often the child/adolescent participated in certain situations over the last 4 months; (2) How involved the child/adolescent is when participating in 1 or 2 of the activities that he/she does most frequently; (3) Whether the person responsible for him/her would like the child/adolescent's participation to change or not, and if so, how he/she would like it to change. The frequency of participation (1) can be defined and scored from 0 (never) to 7. The total frequency score, for each environment, is defined by the sum of the scores obtained, with higher scores representing greater frequency of participation. For involvement in each activity (2), there are scores and options of 5, if "Very involved" when, in general, the child is engaged during the activity and shows a lot of initiative and/or interest and attention to what he or she and others are doing during the activity; 3, if "Somewhat involved", when the child/adolescent is engaged in the activity for some time and shows some initiative and/or interest and attention to what he or she and others are doing during the activity and 1, if "Minimally involved" when the child/adolescent is engaged for a small part of the time in the activity and shows little initiative and/or interest and attention to what he or she and others are doing during the activity. The total involvement score, for each environment, is defined by the sum of the scores obtained, with higher scores representing greater involvement in participation. To verify the caregiver's desire for changes in daily participation (3), the following are used: "I do not want change", "yes, to do it more often", "yes, to do it less often", "yes, to be more involved", "yes, to be less involved", "yes, to be involved in a greater variety of activities". These responses do not count towards the total score, but are important indicators for therapeutic goals. Thus, the percentages of occurrence of each of the possible responses will be calculated, to verify, in general, what type of main desire the caregiver has. The aspects of part (b) environment can be classified into two groups of four answer options, with respective scores of: 'not a problem' (4), 'usually helps' (3), 'sometimes helps/sometimes makes it difficult' (2), 'usually makes it more difficult' (1) as well as 'not necessary (4), usually yes (3), sometimes yes; sometimes no' (2) and 'usually no' (1). The first group refers to questions about aspects that can help or make it difficult to participate and the second group about aspects that are available or not. In this way, for each of the three environments, the sum of the scores obtained will be calculated, and the higher the score, the more the environment is considered to be a facilitator, in order to provide more support and more resources to support participation. At the end of the 'environment' part of the home, school and community, the guardian is asked to list 3 strategies that are used by the child or by a family member to help participation in each of the environments investigated (home, school and community).

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j) Functional Independence Measure for Children - WeeFIM

The WeeFIM measures the type and amount of assistance needed for a child with a disability to effectively perform basic activities of living. It has been translated and validated for Brazilians [36] and is one of the most widely used methods for pediatric functional assessment. It differs from the adult version (FIM) in its scoring, which considers the child's developmental stages. It is more suitable for children up to 7 years old and can be completed by caregivers or through observation of the child [37].

The WeeFIM assesses 6 subsets (self-care, sphincter control, transfers, locomotion, communication and social cognition) through 18 items that are scored on a scale from 1 (total need for assistance) to 7 (completely independent). In addition, the caregiver or family member indicates whether that item is related to the brain injury and can note observations. The minimum score is 18 points, indicating total dependence on the skills assessed, and the maximum score is 126 points, indicating total independence on the skills [38].

k) International Physical Activity Questionnaire - Short version - IPAQ- Versão Curta

The IPAQ assesses an individual's level of physical activity and inactivity. It was validated for Brazilians in studies with adolescents aged 12 to 18 [39] and adults [40]. The short version of the questionnaire (IPAQ-short version) consists of 8 open-ended questions that can be answered through an interview or self-administration. The information obtained allows us to estimate the frequency in days of the week and the duration in hours and minutes of physical activities (walking and moderate and vigorous intensity activities) performed by the individual and the time spent sitting (at work, at school or college, at home and during free time, except for the time spent sitting during transportation by bus, train, subway or car) considering the week prior to the date of the assessment. Finally, the final classification stratifies individuals into Inactive (sedentary), Insufficiently Active (A or B), Active and Very Active.

RESULTS AND DISCUSSION

This study aimed to present the FADS protocol, a pediatric assessment protocol for children and adolescents with Down syndrome aged between 6 and 17 years, based on the biopsychosocial perspective proposed by the ICF.

DS is a health condition with several clinical manifestations, reinforcing the need for a holistic global assessment of several components of functioning that may be impaired. Many health professionals, despite being familiar with several scales and tools, have difficulty applying them in a standardized manner, which makes it difficult to compare different periods of time for the same child or different children. The ICF proposes a biopsychosocial approach to health assessment, integrating not only biological aspects but also environmental and personal factors[1]. By adopting an assessment protocol with standardized instruments that assess the components and domains of the ICF, it is possible to go beyond the traditional view of the biomedical model. This type of assessment allows for a broader and more holistic view of the individual, enabling an understanding of their performance in everyday life situations, in addition to the factors that may influence their health. This allows professionals to understand not only the needs of the child, but also the family context. As a result, this information can help to personalize the care of children and adolescents with DS, according to the realities and needs of the child, whether at home, at school or in the community.

This study has the limitation of not performing feasibility studies from the perspective of families and children, which can be done in future studies. In addition, the FADS protocol is limited to the use of people who have knowledge about filling out Google Forms and access to the internet, which can be a barrier to access. As a strength, this study provides an evaluation protocol that can be performed and used by the transdisciplinary team, since it assesses biopsychosocial aspects of children with DS. In addition, it is an unprecedented protocol for evaluating this population freely, which is very prevalent in rehabilitation centers. Furthermore, the ICF-based protocol contributes to identifying the areas of the greatest need, such as mobility and social activities. Hence, it is able to prioritize which areas require an intervention, ensuring a more effective personalized health care.

CONCLUSION

This study allowed the development of a physiotherapeutic protocol for biopsychosocial assessment for children and adolescents with DS/T21. This protocol allows for the standardization of clinical and research assessments and suggests several tools to be used in a standardized manner. We hope that this protocol will enable the main components of the ICF to be assessed and that it will serve as an important trigger for further, more in-depth investigations if necessary.

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Appendix 1. Characteristics of the questionnaires and their application.

Measure	Translation and validation for Brazil	Age	ICF components	Domains assessed	Score (each item)	Interpretation	Application	Formal trainee needed	Cost
Participation and Environment Measure for Children and Youth - PEM-CY	Galvão et al. (2018)	5-17 years	Participation Environmental factors	Frequency and Involvement at home, school and community settings	Frequency= 0-7 Involvement = 1-5	Higher scores indicate greater frequency and involvement in each setting	Interview or self-completion	No	CAD $ 90 canadian dollars English/ Portuguese (https://canchild.ca/en/shop/2-pem-cy-participation-and-environment-measure-children-and-youth)
About My Child	Brugnaro et al. (under review)	0 - 18 years	Activity, participation, environmental factors, body structure and function	Some aspects of daily living which could concerns caregivers and how they aspects impact on participation	Concern = 1 - 0-1 (total 0-19) Impact = 1- 4	Higher score, greater concern for parents and greater impact on daily life	Interview or self-completion	No	CAD $ 150 canadian dolar English/ Portuguese (https://canchild.ca/en/shop/58-about-my-child)
Social Support Scale	Griep et al. (2005)	Child - adolescent (no age stablesed)	Participation, environment factors	Positive social interaction/ affective support, emotional/ informational support and material support	Range from 1 to 5	Higher score, more social support perceived by the caregiver	Interview or self-completion	No	Free English (https://cadc.ucsf.edu/sites/g/files/tkssra881/f/Description%20and%20Scoring%20Instructions%20MOS%20Social%20Support%20Survey.pdf?utm_source=chatgpt.com) Portuguese (https://www.academia.edu/15871485/ADAPTA%C3%87%C3%83O_CULTURAL_E_VALIDA%C3%87%C3%83O_DA_VERS%C3%83O_PORTUGUESA_Question%C3%A1rio_Medical_Outcomes_Study_Social_Support_Survey_MOS_SSS?utm_source=chatgpt.com)
Strenghts and difficulties questionnaire - SDQPort	Fleitlich, Cartázar & Goodman in (2000)	4 - 17 years	Body structure and function	Emotional symptoms scale, conduct problems scale, hyperactivity scale, peer relationship problems scales, prosocial behavior scale	0 or 1 for each item	Higher score the greater emotional difficulties the child has	Interview or self-completion	No	Free English/ Portuguese (https://www.sdqinfo.org/py/sdqinfo/b0.py)
Children Helping Out: Responsibilities, Expectations and Supports - CHORES	Amaral et al. (2012)	6 - 14 years	Activity	daily performance in the task	Range from 0 to 6	Higher score obtained greater performance, higher score for assistance greater dependence on the task	Interview or self-completion	No	Free English (https://eprovide.mapi-trust.org/instruments/children-helping-out-responsibilities-expectations-and-supports#need_this_questionnaire) Portuguese (http://www.eeffto.ufmg.br/eeffto/DATA/defesas/20151008162315.pdf)

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Brazilian Association of Research Companies - ABEP		No determined	Environment factors	Number of items in the environment, level of education and access to public services	A, B1, B2, C1, C2, D-E	Highest level: A	Interview or self-completion	No	Free English/ Portuguese (https://abep.org/criterio-brasil/)
Timed Up & Go test (TUG)	Nicolini-Panisson & Donadio (2014)	Older than 3 years	Activity	Transition between motor tasks, sitting to standing, walking around obstacle	Time in seconds	The shorter the time: the better the functional gait	Performed by the therapist.	No	Free English (https://www.sralab.org/rehabilitation-measures/timed-and-go) Portuguese (https://www.apfisio.pt/wp-content/uploads/2019/07/INSTRUMENTOS_MEDIDA_FISIOTERAPIA_CARDIORRESPIRATORIA.pdf)
PEDI-CAT	Mancini et al. (2016)	0 - 21 years	Activity andparticipation	Daily activities, mobility, social and cognitive, responsability	Continuous score, normative score	T-score for below the expected value (<30) and within the expected mean value (30-70)	Interview or self-completion	No	$2.10 (american dollar by form) English (https://www.pedicat.com/)
WEEFIM	Sarmento(2014)	Older than 7 years	Activity	Self-care, sphincter control, transfers, locomotion, communication and social cognition	Range from 1 to 7	Higher score means greater independence in tasks	Interview or self-completion	No	Free English (https://www.icare.nsw.gov.au/practitioners-and-providers/healthcare-and-service-providers/assessment-tools-and-resources) Portuguese (https://www.repositorio.ufal.br/bitstream/riufal/3864/1/Traducao%2C%20adaptacao%20cultural%20e%20confiabilidade%20da%20vers%C3%A3o%20Brasileira%20da%20medida%20de%20independencia%20funcional%20para%20crian%C3%A7as%20%28Wee%20Fim%29.pdf)
IPAQ	Guedes et al (2005)	12 - 18 years	Activity	Estimate the frequency in days of the week and the duration in hours and minutes of physical activities	Stratifies individuals into Inactive (sedentary), Insufficiently Active (A or B), Active or Very Active	Higher values indicate a higher level of physical activity	Interview or self-completion	No	Free English (https://youthrex.com/wp-content/uploads/2019/10/IPAQ-TM.pdf) Portuguese (https://rbafs.org.br/rbafs/article/view/931/1222)

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Appendix 2. Initial questionnaire

Questions about the caregiver	
Questions	Answer option
What is your full name? (name of the person responsible)	Open response
What is your WhatsApp number (with area code)	Open response
How old are you? (in full years)	Open response
Do you have other children? If so, how many and what their ages and genders are?	Open response
Your total family income is between: (in reais)	0 - 1,100.00 1,101.00 - 2,200.00 2,201.00 - 3,300.00 3,301.00 - 4,400.00 4,401.00 - 5,500.00 5,501.00 - 6,600.00 More than 6,601.00 More than 11,000.00
Questions about your child/teen:	
Full name of your child/teenager:	Open response
How old (in years) is your child/teenager?	Open response
What is your child/teenager's date of birth?	Open response
Your child/teenager was born:	Full-term (born at the correct/expected time) Premature (Pre-term/born before the correct/expected time) Post-term (born after the correct/expected time)
How many weeks or months into your pregnancy was your baby born?	Open response
How was your child born?	Cesarean
Did you have any problems during pregnancy? If so, please specify which ones.	Normal/Vaginal
Did you have any problems during delivery? If so, please specify what they were.	Open response
Did your child have any problems after birth and up to the age of 3? If so, please specify what they were.	Open response
Did you smoke during pregnancy?	Open response
Did you use any type of drug during pregnancy?	Yes No
Did you consume alcoholic beverages during pregnancy?	Yes No
Have you had gestational diabetes?	Yes No
How many kilos was your child born weighing? If you don't know, leave it blank.	Open response
Would you know what your child's Apgar score was at birth? These are two numbers that appear on the birth certificate, for the 1st and 5th minute of the baby's life. If you don't know, leave it blank.	Open response
Was your child/teenager born with any health problems? For example, heart, hearing or vision problems? Please specify	Open response
Has your child been diagnosed with any other condition, syndrome or disorder? Please specify.	Open response
Has your child/teenager undergone any surgical procedure? Please specify the type of surgery and the date.	Open response
Is your child currently undergoing any in-person therapy?	Open response
Is your child currently undergoing any remote therapy (via video call, for example)?	Open response
Your child/teen's school is:	Special Regular

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