

Outcome measures for adults with Down Syndrome based on the International Classification of Functioning, Disability, and Health Model: A Systematic Review

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ABSTRACT

Introduction: Adults with Down syndrome (DS) have functional disabilities due to the extra presence of chromosome 21. **Objective:** To identify the functionality and disability assessment instruments used in research involving adults with DS and associate them with the components of the International Classification of Functioning (ICF). **Methods:** Two independent researchers analyzed articles from PubMed, Lilacs, SciELO, Science Direct, and Cochrane databases, including cross-sectional and clinical studies whose results involved functionality and disability for individuals with DS (≥ 18 years), with no publication date limit for the studies. The methodological quality of the studies was analyzed by the Downs & Black Checklist; descriptive analysis was used for the results. This review was registered in PROSPERO (CRD42021234012). **Results:** 15 articles were analyzed in which 48 instruments were identified for the assessment of adults with DS (36.42 ± 10.62 years); the quality of the articles was considered “good”. Of these 48 instruments, 41 were associated with bodily function, 5 instruments were associated with the activity component, one instrument was associated with social participation and one instrument was associated with the environment. **Conclusion:** Of the 48 instruments identified to assess adults with DS, most were for the Body Function and Structure component; only the 6MWT and CAMDEX-SD have been validated for this population. LIFE-H and MQE were used to assess Social Participation and the Environment, but they cannot be considered dependable, as they have not been confirmed for individuals with DS.

Keywords: Down syndrome; functionality; disability; outcome measures; biopsychosocial model.

INTRODUCTION

Down syndrome (DS), also known as trisomy 21, is a genetic alteration caused by an error in cell division during meiosis that leads to the extra presence of chromosome 21¹.

Due to advances in health care, DS individuals have seen an increase in their life expectancy, currently reaching 50-60 years of age². However, they show premature aging, with physiological deterioration, including strength and muscle mass, balance,

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coordination, and impairment of cardiovascular function, all of which affect their functionality and quality of life, thus making a complete evaluation of functionality necessary³.

Assessment measures are essential for understanding an individual's functional status and establishing the right goals and therapeutic planning⁴. To this end, in 2001, the World Health Organization (WHO) adopted the biopsychosocial model of the International Classification of Functioning, Disability, and Health (ICF), which is considered the integrative and guiding model for understanding states of disability and human functionality. The biopsychosocial model considers the body's structures and functions and activities individuals perform in daily life, as well as their social participation, considering these components' relationship with personal factors and with the physical, social, and attitudinal environment in which they are inserted⁵.

Therefore, according to the ICF, environmental, social, cultural, and political factors may be involved in situations of disability. It is, therefore, important that the assessment of DS individuals be based on the biopsychosocial model as this model assesses not only health conditions but also bodily, individual, and social conditions⁵. It, thus, gives an extensive and complete view showing that environmental, social, cultural, and political factors can influence an individual's functionality or disability.

Therefore, the objective of this review is to identify the functioning and disability assessment instruments for DS adults used in scientific research and to relate them to the ICF biopsychosocial model. By identifying functionality and disability assessment instruments, professionals who work with this population will have better knowledge of the validated instruments that are more adequate for assessing DS adults.

METHODS

This systematic review was prepared following the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and registered in PROSPERO (CRD42021234012).

Two researchers conducted the review independently, as follows: 1) a specific systematic search was conducted in databases; 2) articles were selected based on inclusion and exclusion criteria, and 3) the reported outcome measures and treatment outcomes were associated with the ICF's biopsychosocial model.

Search Strategy

The search of the literature for the present review was made from March 2020 to March 2022 by two independent researchers. There were used the following virtual databases: Medline/PubMed (Medical Literature Analysis and Retrieval System), Lilacs (Latin American and Caribbean in Health Sciences Literature), Scielo; Science Direct, and Cochrane, without language distinctions and publication date limit.

The following keywords were used to perform the search in Pubmed: (("Down Syndrome"[Mesh]) AND ("Adult"[Mesh]) OR ("International Classification of Functioning, Disability and Health"[Mesh]) AND ("Outcome Assessment, Health Care"[Mesh]) OR ("Health Impact Assessment"[Mesh]) OR (Outcome Measure) OR (Outcomes Assessment)). Lilacs: Down Syndrome AND Adult AND Outcome Measure; Cochrane: (Down Syndrome) AND (Adult) AND (International Classification of Functioning, Disability, and Health); Scielo: Down Syndrome AND Adult AND Outcome Measure and Science Direct: Down Syndrome AND Adult AND Outcome Measure.

Selection of Articles and Criteria for Inclusion and Exclusion

The abstracts were selected and later read in full, using the following inclusion criteria: 1) articles dealing with DS subjects over 18 years old; 2) articles using assessment instruments or measures related to the ICF biopsychosocial model; 3) articles from cross-sectional studies and clinical trials.

After reading them in full, articles were excluded according to the following exclusion criteria: articles that had individuals other than DS adults. Mendeley Desktop software was used to organize selected articles and control bibliographic references.

Data Extraction

The two independent reviewers systematically extracted data from each study and reached a consensus on all items. The information extracted included author and year of publication, sample (number of participants), instruments for measuring Functioning and Disability found in the review, and the frequency with which they appeared (Table 1). The measuring instruments were associated with the ICF's components, following the WHO manual⁵ (Table 2). Descriptive analysis was used to tabulate the results.

Quality of article methodology

To assess methodological quality, the Downs & Black Checklist⁶ was used (Table 2). This checklist is composed of 27 questions divided into five domains: study quality (ten items); external validity (three items); internal validity (seven items); confounding/ selection bias (six items), and sample power (one item). The maximum score achieved in this checklist is 32 points. Item 27 was modified from how it is used in other studies^{7,8}, in which the original score would be assigned from 0 to 5 points. This was modified to a score from 0 to 1 point. Thus, a score of 1 was used, if the article had a power calculation or a sample calculation and 0 if the article had none of these calculations. After this modification, the checklist had total scores ranging from 0 to 28 points. Each article received a rating of "excellent" (24-28 points), "good" (19-23), "fair" (14-18) or "poor" (<14 points).

Table 1: Outcome of the Instruments that Assess Functioning and Disability in Adults with Syndrome.

Instrument	Outcome	Frequency
Plate Tapping Test	Speed	13%
Hand Grip Test	Muscle strength	26%
Shuttle Run	Speed and agility	26%
Flamingo Balance Test	Balance	13%
Sit down and reach out	Lower limb flexibility	39%
Reach behind the back	Flexibility of upper limbs	13%
High heel standing	Explosive strength of lower limbs	13%
Sit down and stand up	Muscle strength	39%
Bent Arm Hang	Muscle strength	13%
Timed Up & Go Test	Functional mobility	26%
6-Minute walk test	Functional capacity	39%
Bruininks Test	Motor Proficiency	13%
8-foot get up and got a test	Functional Mobility	26%
Isometric Flexion	Upper limb muscle strength	26%
Finger-Nose Test	Motor coordination	13%
Abdominal	Muscle strength	26%
Standing with one-foot support	static balance	26%
Walk in a straight line on the floor	Dynamic balance	26%
Modified Dots Task / Cats and Frogs	Inhibitory control and working memory	13%
Index of Social Competence (ISC)	Communication, self-care, and community skills	13%
Neuropsychiatric Inventory (NPI)	Cognitive	13%
Cambridge Neuropsychological Test Automated Battery (CANTAB)	Cognitive	26%
The Rapid Assessment for Developmental Disabilities – Second Edition (RADD-2)	Cognitive	13%
DAMES- Clinical Global Impression of Change scale	Cognitive	13%
The Cognitive Drug Research (CDR)	Cognitive	13%
Wechsler Adult Intelligence Scale IV (WAIS-IV)	Cognitive	13%
The Vineland Adaptive Behavior Scales, Second Edition (VABS-II)	Cognitive	13%
Dementia Questionnaire for Mentally Retarded Persons (DMR)	Cognitive	13%
Severe Impairment Battery (SIB)	Cognitive	13%
Adaptive Behavior Scale (ABS)	Cognitive	13%
Vineland Adaptive Behavior Scales (VABS)	Cognitive	13%
Test of Problem Solving—TOPS	Cognitive	13%
Clinical Evaluation of Language Fundamentals-Revised / CELF-R	Cognitive	13%
CAMDEX-SD	Cognitive	26%
Kaufman Brief Intelligence Test 2 (KBIT-2)	Cognitive	13%
The Arizona Cognitive Test Battery (ACTB)	Cognitive	26%
Dementia questionnaire for people with Learning Disabilities (DLD)	Cognitive	13%
The Behavior Rating Inventory for Executive Function (BRIEF—Parent Form)	Cognitive	26%
NAID Object Memory, NAID Memory for Sentences, Tower of London	Cognitive	13%
Developmental Behavior Checklist – Adult Version (DBC-A).	Emotional and behavioral problems	13%
Life-H	Participation	13%
MQE	Participation	13%
Cambridge Examination for Mental Disorders of the Elderly (CAMDEX)	Cognitive	13%
Cambridge Cognitive Examination (CAMCOG)	Cognitive	13%
Rivermead Behavioral Memory Test (RBMT)	Cognitive	13%
Fuld Object Memory Evaluation (FOME)	Cognitive	13%
Cambridge Cognitive Examination for Older Adults with Down Syndrome (CAMCOG-DS)	Cognitive	13%
modified Cued Recall Test (mCRT)	Cognitive	13%

Table 2: Description of Assessment Measures in Adults with Down Syndrome and Correlation with ICF Components

Study	Objective	Sample	Type of Study	Body Function and Structure	Activities	Participation	Environmental Factors	Quality Score
Silva et al. 2017 ⁹	To analyze the effects of exercise programs using the Wii video game on physical fitness, functional mobility, and motor proficiency.	27 adults with Down syndrome.	Clinical Trial	Static arm strength test; Hand grip test; Static arm strength; Sit and Reach Test; Explosive jump test; 30 Chair Test; Bent Arm Hang; Standing high heel; Flamingo balance test; Six-minute walk test; Shuttle Test	Timed Up & Go; Plate Tapping Test;			19
Vis et al., 2009 ¹⁰	Validate the 6-minute walk test in individuals with Down's Syndrome to assess cardiac restriction.	29 individuals with Down's Syndrome with cardiac alterations and 52 individuals with Down's Syndrome without cardiac alterations.	Cross-sectional	6-minute walk test;				21
Hanney et al., 2012 ¹¹	Evaluate Memantine's Efficacy on Cognition and Function in Adults with Down Syndrome	173 individuals with Down syndrome	Clinical Trial	Clinical Global Impression of Change scale (DAMES); Adaptive behavior scale (ABS)				18
Rafii et al., 2018 ¹²	Evaluate the safety of the Scylla-inositol drug and determine its parameters and outcome measures and safety in exploratory efficacy in adults with DS.	22 individuals with Down syndrome	Clinical Trial	The Rapid Assessment for Developmental Disabilities – Second Edition (RADD-2); The Cognitive Drug Research (CDR); The Block Design subtest of the Wechsler Adult Intelligence Scale IV (WAIS-IV); The Vineland Adaptive Behavior Scales, Second Edition (VABS-II); Neuropsychiatric Inventory (NPI)				23
Lott et al., 2011 ¹³	Determine the feasibility, tolerability, safety, and effectiveness of using alpha-tocopherol, ascorbic acid, and alpha-lipoic acid to treat dementia in individuals with DS	53 adults with DS	Clinical Trial	The Dementia Questionnaire for Mentally Retarded Persons (DMR); The Severe Impairment Battery (SIB); Vineland Adaptive Behavior Scales (VABS)				20
Heller et al., 2003 ¹⁴	Evaluate the effect of donepezil hydrochloride in the treatment of language deficits in adults with DS.	6 individuals with Down syndrome	Open Trial	Test of Problem-Solving—TOPS; Clinical Evaluation of Language Fundamentals Revised—CELF-R				17
Sinai et al. 2016 ¹⁵	Validate The Arizona Cognitive Test Battery (ACTB) in elderly people with DS.	50 adults with Down syndrome	Cross-sectional	The Arizona Cognitive Test Battery (ACTB); CANTAB (Cambridge Neuropsychological Test Automated Battery); The K-BIT II; Dementia questionnaire for people with Learning Disabilities (DLD); The Behavior Rating Inventory for Executive Function (BRIEF—Parent Form); NAID Object Memory, NAID Memory for Sentences, Tower of London;	Finger-Nose Test. Timed Get Up;			18

Continue...

Table 2: Continuation.

Study	Objective	Sample	Type of Study	Components of the ICF	Quality Score
Boer & Moss 2016 ¹⁶	Evaluate-retest reliability and minimal detectable change were observed in a functional fitness test in adults with Down syndrome.	43 adults with Down syndrome	Cross-sectional	Sit and Reach Test; Reach behind your back; Sit down and get up from the chair; Handgrip; Abdominal; Shuttle-run modified test; Trunk lifting test; 6-minute walk test; Board; one-foot support static balance (standing on one leg for 10 seconds); Dynamic balance (step in a straight line);	19
Ternalanche & Boer 2013 ¹⁷	Establish the functional fitness capacity of adults with DS and analyze which physical attributes predict functional performance.	371 adults with Down syndrome	Cross-sectional	Reach behind your back; Sit and Reach Test; Abdominal; Board; Shuttle-run modified test; Sit down and get up from the chair; Manual pressure; one-foot support static balance (standing on one leg for 10 seconds); -Dynamic balance (step in a straight line).	19
Fonseca et al. 2019 ¹⁸	Validate CAMDEX-DS for adults with Down Syndrome in Brazil.	92 adult individuals with Down syndrome.	Cross-sectional	The Cambridge Examination for Mental Disorders of Older People with Down's Syndrome and Others with Intellectual Disabilities (CAMDEX-DS).	19
Ball et al. 2004 ¹⁹	Modify and validate the CAMDEX questionnaire for adults with Down syndrome	74 adults with Down syndrome	Cross-sectional	Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) Cambridge Cognitive Examination (CAMCOG)	17
Foley et al. 2014 ²⁰	Assess the influence of the Environment on the social participation of adults with Down Syndrome	166 adults with Down syndrome	Cross-sectional	Developmental Behavior Checklist – Adult Version (DBC-A).	18
Rosenbloom et al. 2020 ²¹	measure the safety and feasibility of fast intranasal bonding with Down syndrome.	12 adults with Down syndrome	Clinical Trials	Rivermead Behavioral Memory Test (RBMT) Fluid Object Memory Evaluation (FOME)	20
Bejanin et al. 2021 ²²	To investigate the association of the APOE ε4 allele with clinical and multimodal biomarkers of AD in adults with DS.	464 adults with Down syndrome	Clinical Trials	Cambridge Cognitive Examination for Older Adults with Down Syndrome (CAMCOG-DS) modified Cued Recall Test (mCRT)	20
Rosalyn et al. 2020 ²³	Validate a dementia staging model and identify the trajectory of cognitive decline in preclinical and prodromal stages of AD for each outcome measure,	132 adults with Down syndrome	Cohort study	Kaufmann Brief Intelligence Test [KBIT-2] CANTAB paired associates learning [PAL] CANTAB intra-extra dimensional shift task [IED] Behavior Rating Inventory of Executive Function [BRIEF]) CANTAB simple reaction time [SRT] task) finger-nose task NEPSY car and motorbike	21

RESULTS

A total of 741 articles were found in the databases, and three more were added that had not been found in the data search (they were found in the references of the selected articles), totaling 744 articles. After reading the title and abstract, 650 were excluded, leaving 91 to be read in full. After reading, 76 articles were excluded, as the research subjects were not exclusively DS adults' diagnoses. Therefore, 15 articles were considered for this review, as shown in the flowchart (Figure 1).

Among the components found in the articles, 85% are associated with Body Function, which was the most found component, followed by Activity with 11%; 2% referred to the Participation and Environment components. The mean age of the DS population in the selected articles was 36.42 ± 10.62 years old.

Table 1 shows the 48 assessment instruments for DS individuals associated with the ICF model and the frequency with which they appeared in the study.

It is observed in Table 1 that the most frequently used tests are associated with Body Function, namely, the 6-minute Walk Test (6MWT) used to assess cardiorespiratory and aerobic functional capacity, the Sit and Stand Test which evaluates muscle strength of the lower limbs, the Sit and Reach Test to assess the flexibility of the lower limbs, and the Shuttle Test that assesses cardiorespiratory capacity.

Tests less frequently associated with Body Function were the Hand Grip Test used to assess upper limb muscle strength, the

Sit and Reach Test which assesses the flexibility of upper limbs, Isometric flexion to assess upper limb muscle strength, standing with one-foot support and walking along a straight line on the floor, both to assess balance, and Timed Up and Go (TUG) and 8-Foot Up and Go, both to assess functional mobility associated with the Activities component. Table 2 shows the studies analyzed and their respective assessment instruments for DS adults and their respective links with IFC's components.

Table 2 shows the 48 functioning and disability assessment instruments used to assess DS adults in the 15 articles⁹⁻²³ analyzed that were related to the ICF assessment components.

Of these 48 instruments, forty-one were related to the Body Function component, five related to activity, one related to participation, and one instrument related to the Environmental component (Figure 2).

Of the 48 instruments that addressed body function, 26 instruments were intended to assess cognition. These were the Clinical Global Impression of Change Scale (DAMES)²⁴, Adaptive Behavior Scale (ABS)²⁵, the Cambridge Examination for Mental Disorders of Older People with Down's Syndrome and Others with Intellectual Disabilities (CAMDEX-DS)¹⁹, Cambridge Examination for Mental Disorders of the Elderly (CAMDEX)¹⁹, Cambridge Cognitive Examination (CAMCOG)¹⁹, Cambridge Cognitive Examination for Older Adults with Down Syndrome (CAMCOG-DS)¹⁹ the Rapid Assessment for Developmental Disabilities – Second Edition (RADD-2)²⁶, the Cognitive Drug

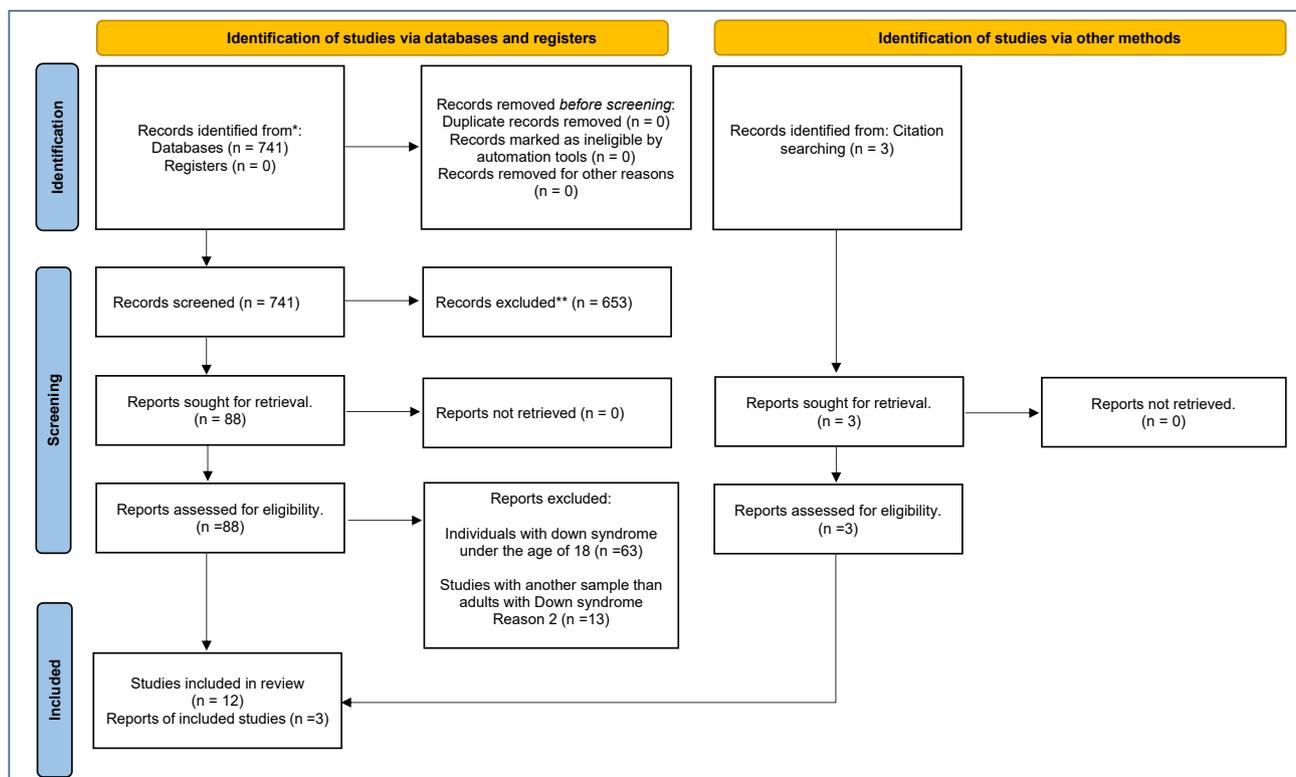


Figure 1: Prisma Flowchart

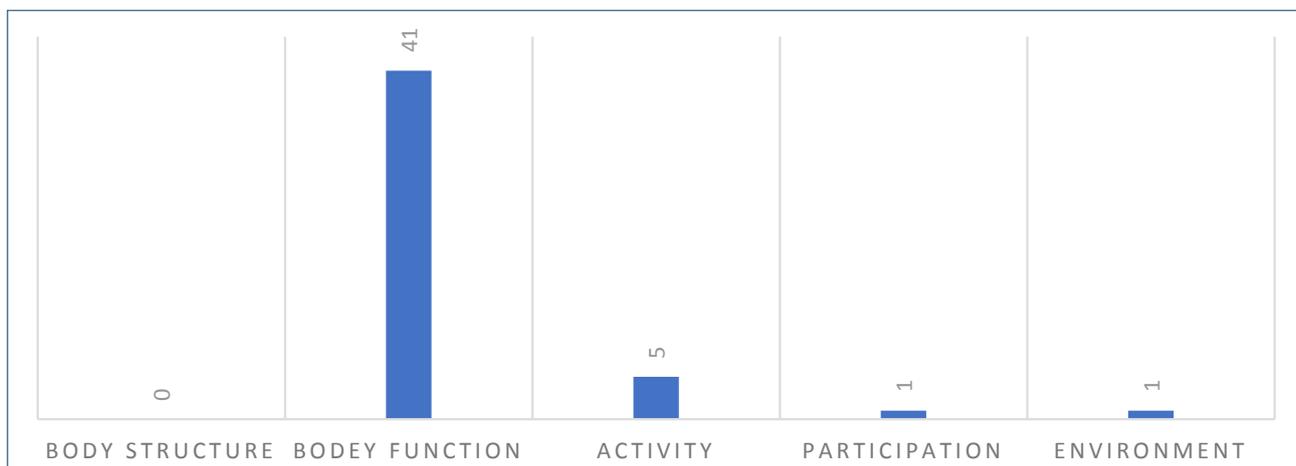


Figure 2: Frequency of instruments associated with ICF components.

Research (CDR)²⁷, the Vineland Adaptive Behavior Scales, Second Edition (VABS-II)²⁸, the Vineland Adaptive Behavior Scales, Second Edition (VABS-II)²⁹, Neuropsychiatric Inventory (NPI)³⁰, the Dementia Questionnaire for Mentally Retarded Persons (DMR)³¹, the Severe Impairment Battery (SIB)³², Test of Problem Solving (TOPS)³³, Clinical Evaluation of Language Fundamentals Revised (CELF-R)³⁴, the Arizona Cognitive Test Battery (ACTB)³⁵, NAID Object Memory, NAID Memory for Sentences³⁵, Cambridge Neuropsychological Test Automated Battery (CANTAB)³⁶, Modified Dots Task / Cats and Frogs³⁶, the K-BIT II³⁷, the Behavior Rating Inventory for Executive Function (BRIEF) Parent Form³⁸, Dementia Questionnaire for People with Learning Disabilities (DLD)³⁹, Rivermead Behavioral Memory Test (RBMT)²³, Fuld Object Memory Evaluation (FOME)⁴⁰, modified Cued Recall Test (mCRT)⁴¹, Block Design Subtest of the Wechsler Adult Intelligence Scale IV (WAIS-IV)⁴².

Six instruments were used to assess muscle strength, being the Hand Grip Test⁴³, Bent Arm Hang⁴⁴, Isometric Flexion⁴⁵, Abdominal⁴⁶, Sit-up Test from a chair⁴⁷, and Lower Limb Explosive Strength⁴⁸. Two instruments aimed to assess flexibility, are the Sit and Reach test for lower limbs⁴⁹ and the Reach behind the back for upper limbs⁵⁰. Similarly, both tests may be related to the Activities Component. An instrument was used to evaluate upper limb motor coordination via the Finger-Nose Test⁵¹ another for cardiorespiratory assessment, the Shuttle Test⁵², the 6MWT was used for aerobic and cardiorespiratory Functional Capacity⁵³, for Motor coordination, and the Developmental Behavior Checklist – Adult Version (DBC-A)⁵⁴ was used for measures emotional and behavioral problems and was developed specifically for use with adults with intellectual and/or developmental disability.

Three instruments were used to assess Balance, namely standing with single-legged support (10s)⁴⁹ walking along a straight line on the floor⁴⁹, and the Flamingo Balance Test⁴⁴. These tests can also be related to the Activities Component.

Of the five instruments that addressed the Activity component, two were used to assess Functional Mobility – the TUG⁴⁴ and 8-Foot Up and Go tests⁵⁰. The Bruininks–Oseretsky Test of Motor Proficiency First Edition⁴⁹ was used to assess motor proficiency; the Index of Social Competence (ISC)⁵² was used to measure domains of communication, self-care, and community skills; and the Plate Tapping test to evaluate the speed and reaction of the upper limbs⁴⁴.

To assess Social Participation, the Assessment of Life Habits (Life-H) questionnaire⁵³ was used, and as was the Measure of the Quality of the Environment (MQE) to assess the Environmental component⁵⁴ Figure 3.

DISCUSSION

The objective of this review was to identify the instruments to assess functionality and disability for DS used in scientific research and report them to the biopsychosocial model of the ICF.

We identified 48 instruments, and variables, to assess the functionality and disability of DS adults, however, we cannot say that these instruments are dependable for this population, since only two instruments, the CAMDEX-DS, and the 6MWT, have been validated for them.

Among the tests associated with Body Function and Structure, the Sit and Stand Test used in 3 studies^{9,16,17} was validated to assess the lower limb muscle strength of elderly people living in the community⁵¹. It was later validated for older people, showing the difference between genders, with an excellent reliability index (0.84) for men and (0.92) for women⁴⁵. In DS adults, it was used by Terblanche and Boer¹⁷, and reproducibility was evaluated later, achieving an excellent reliability¹⁶ index of 0.99.

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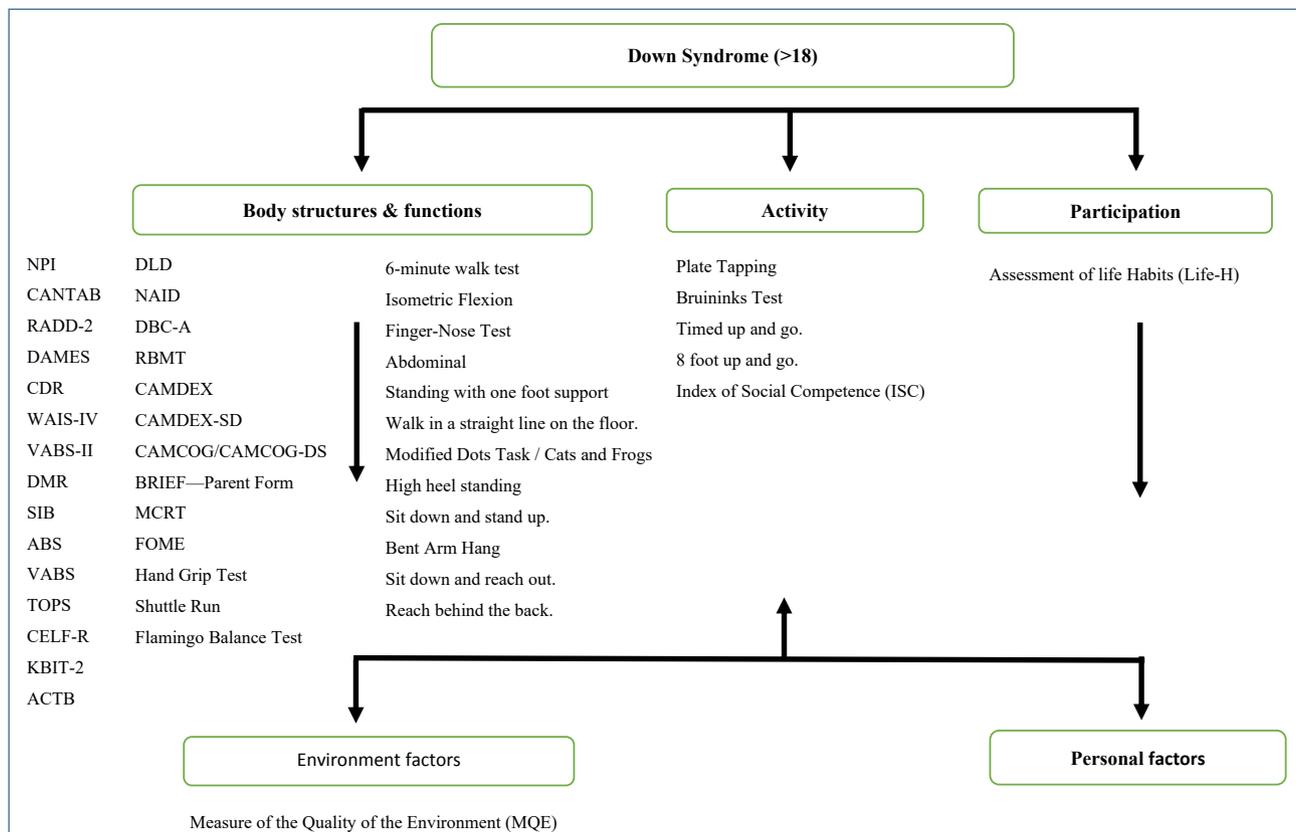


Figure 3: International Classification of Functioning, Disability and Health (ICF) framework. Clinical Global Impression of Change scale (DAMES); Adaptive behavior scale (ABS); The Cambridge Examination for Mental Disorders of Older People with Down’s syndrome and Others with Intellectual Disabilities (CAMDEX-DS); The Rapid Assessment for Developmental Disabilities – Second Edition (RADD-2); The Cognitive Drug Research (CDR); The Block Design subtest of the Wechsler Adult Intelligence Scale IV (WAIS-IV); Cambridge Cognitive Examination (CAMCOG); Rivermead Behavioral Memory Test (RBMT); Fuld Object Memory Evaluation (FOME); Cambridge Cognitive Examination for Older Adults with Down Syndrome (CAMCOG-DS) ; modified Cued Recall Test (mCRT); The Vineland Adaptive Behavior Scales, Second Edition (VABS-II); Neuropsychiatric Inventory (NPI); Vineland Adaptive Behavior Scales (VABS); The Dementia Questionnaire for Mentally Retarded Persons (DMR); The Severe Impairment Battery (SIB); Test of Problem Solving (TOPS); Clinical Evaluation of Language Fundamentals Revised (CELF-R); The Arizona Cognitive Test Battery (ACTB);Cambridge Neuropsychological Test Automated Battery (CANTAB);Dementia questionnaire for people with Learning Disabilities (DLD);The Behavior Rating Inventory for Executive Function (BRIEF-Parent Form);NAID Object Memory, NAID Memory for Sentences; Assessment of Life Habits (LIFE-H; Measure of the Quality of the Environment (MQE).

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The Handgrip Test, used in two studies, was validated to assess upper limb muscle strength for adults with intellectual disabilities⁵⁵, having an excellent reliability index (0.94). It was applied to older people in the community and had an excellent reliability index (0.99)⁴³. It was used for DS adults by Terblanche and Boer¹⁷, to assess physical fitness. Boer and Moss¹⁶ verified its reliability index, which was excellent (0.98).

Isometric Flexion was used in a study to assess upper-body muscle strength and has been validated for healthy adults⁴⁴. It was applied to adolescents with Intellectual Disabilities, with an excellent reliability index (0.98)⁵⁵. In DS adults, the test was used

by Terblanche and Boer¹⁷, and its reproducibility was evaluated, achieving an excellent reliability index (0.99).

The One Foot Support Balance was used in two studies and was validated for older people by Lin et al.⁵⁶. It was applied to adolescents with intellectual disabilities and achieved an excellent reliability index of 0.99⁴⁹. It was also used to assess the physical fitness of DS adults¹⁷ and later had its reproducibility tested¹⁶, having an excellent reliability index of 0.98 for the lower left limbs and 0.93 for the right lower limb.

The dynamic balance used in the two studies had an excellent reliability index (0.99) for individuals with intellectual disabilities⁵⁵. It was used by Terblanche and Boer¹⁷ in DS adults; reproducibility was evaluated later¹⁶, achieving an excellent reliability index (0.93).

The ICF defines balance as a component of body function in Chapter 2, “Sensory Functions and Pain”, specifically cited by code

b235, “Vestibular Function”, which includes “Inner ear sensory functions related to position, balance, and movement”⁵.

Chapter 1, Mental Functions of the ICF, broadly encompasses several possibilities for cognitive assessment in a more global manner ranging from orientation, awareness, intellectual, sleep, temperament, and personality to more specific functions such as memory, attention, and emotion⁵. Thus, there are several ways to assess an individual’s cognitive function, as seen in this review. Camdex-DS is a version of Camdex that was adapted for DS individuals in the United Kingdom¹⁹. It was also adapted and validated for the DS Brazilians¹⁸, being considered the first study to validate an instrument for detecting Alzheimer’s disease and the cognitive decline of DS individuals in Brazil. It is an important instrument as DS patients present aging, premature cognitive decline, and early diagnosis of Alzheimer’s Disease³. The Cambridge Cognitive Examination adapted for DS individuals (CAMCOG-DS) is a concise group of neuropsychological tests included in the CAMDEX-DS. It was also adapted and validated for the DS Brazilians¹⁸.

DAMES²⁴ is a questionnaire that assesses the cognition and function of Alzheimer’s disease. It was used in the study by Hanney et al.¹¹ to assess the cognitive function of DS adults, although it has not been validated for them.

RADD is a test battery that was created to assess the cognition of individuals with Intellectual Disabilities²⁷. It was used to assess cognition and dementia in DS adults living in California and was also used in the study by Hanney et al.¹¹ of DS adults.

The WAIS IV²⁸ was created to assess the intellectual capacity of individuals aged 16 years and older in general. It was validated for individuals who have suffered traumatic brain injury^{56,57} and was later validated for adolescents with Down Syndrome⁵⁸. Despite having been used in DS individuals, the test has not been validated for them.

The Neuropsychological Inventory (NPI)³⁰ is a questionnaire to assess neuropsychiatric symptoms in dementia. It has been validated in Brazilian Portuguese⁵⁹. Although it was used in the study¹² for DS adults, its validation and reproducibility have not been evaluated for this group.

The Arizona Cognitive Test Battery (ACTB)³⁵ was initially developed and validated for a neurocognitive assessment of DS in patients aged 7-38 years. It was later validated for older DS people over 45 years of age¹⁵. ACTB is a battery of tests that include several questionnaires that measure spatial associative memory, set-shifting, inhibitory control and working memory, cerebellar function, motor sequencing, visuomotor tracking, and hand coordination-eye.

The Eurofit Battery was found in only one study and the tests used are found in the Body Function component, being the Flamingo Balance Test, which is in Chapter 2 cited by code b235, “Vestibular Functions” related to balance and movement;

Bent Arm test, which belongs to Chapter 7, cited by code b740, “Functions Related to Muscular Endurance”; the Plate Tapping Test belongs to chapter 1, “Mental Functions”, code b1470, Psychomotor Control”, which controls the motor and psychological response time. These tests were taken from the Eurofit Test Battery created for healthy adults by Oja and Tuxworth⁴⁴ and were used in the study⁹ to assess DS adults. The Eurofit battery was used to assess the physical fitness of individuals with Intellectual Disabilities and has an excellent reliability⁶⁰ index (0.94).

Regarding the activity component, the most evaluated domain refers to mobility (chapter 4 of the activities and participation component). The ICF describes mobility as the movement that occurs when there is a change in the position or location of the body, that is, a change from one place to another when walking, running, or going up and down, and when using various forms of transport. Therefore, the ICF determines mobility as a component of Activities⁵. Standing out among the instruments identified for this purpose are the Reach Behind Back Test, TUD, and 8-Foot Up and Go.

The Reaching Behind the Back Test aims to assess flexibility and can be associated with both the Body Structure and Activity components. The test was validated for older people living in the community⁵¹ and for adolescents with intellectual disabilities⁵⁵. In DS adults, the test was applied by Terblanche and Boer¹⁷, and its reproducibility was later evaluated by Boer and Moss¹⁶ with an excellent reliability index of 0.99 for the left lower limb and 0.93 for the right lower limb.

The TUG and 8-foot Up and Go tests to assess mobility are cited in the ICF book by code D460 “Walking and Moving, Others Specified and Unspecified”. The test was validated for frail older adults⁵⁰. In DS adults, the test was applied by Terblanche and Boer¹⁷, and its reproducibility was evaluated later by Boer and Moss¹⁶, with an excellent reliability index (0.94).

The Bruininks–Oseretsky Test of Motor Proficiency, Second Edition⁶¹ an assessment of course and fine motor control, found in Chapter 4 of the Activities and Participation component, cited by code d440, “Fine Motor Skills of the Hand”. The test battery was initially designed to assess individuals from 4 to 21 years of age, which was revised between 2002-2005. The test was validated for children with Intellectual Disabilities⁴⁹, both with an excellent reliability index (0.99). Despite not having been validated for DS, it was used to assess the motor performance of both children with and without DS⁶².

The Participation Component is linked to Activities in the ICF book, which is defined as the individual’s involvement in a real-life situation⁵. The Assessment of Life Habits (Life-H) was created to be an instrument for measuring social participation³⁵. It is a questionnaire that encompasses all the chapters of the ICF’s Activity and Participation Component. LIFE-H was used in older people⁶³ with disabilities with an excellent reliability index (0.98). In SD individuals, it had a high-reliability²⁰ index (0.89).

The Measure of the Quality of the Environment (MQE) is a questionnaire that measures individuals' perception of their physical and social environment⁵⁴ and encompasses the entire Environmental Component of the ICF book⁵. In Stroke, it presented a good reliability⁶⁴ index (0.88). In individuals with DS, it presented an excellent reliability index (0.89)²⁰.

The study by Foley et al.²⁰ using the Life-H that assesses social participation and Measure of the Quality of the Environment (MQE) that assesses the Environment, representing the Participation components and Environment, respectively, was analyzed and entered into this review. Despite not meeting the inclusion criteria for presenting a sample of individuals aged 16 years and over, it was considered significant for this analysis as more than 75% of the sample of DS individuals in this study were over 21 years of age.

This review found that the most evaluated component was Body Function, specifically Mental Function since Intellectual Disability is one of the most common characteristics in DS¹⁹. However, this still shows that there is a great lack of assessment methods linked to the Participation and Environmental component, and this gap may be linked to the biomedical model that has only the diagnosis in mind, as it does not consider social factors⁵.

The ICF encompasses more than 1400 categories that are divided into four components⁵, thus making the classification system almost impossible to use in clinical practice. In this sense, there was a need to create Core Sets. These gather information beforehand and prioritize serving a specific population, thus making use of the ICF through Core Sets an applicable tool in clinical practice⁶⁵.

Currently, there are Core sets for several health conditions, such as lower back pain⁶⁵, ischemic heart disease⁶⁶, and depression⁶⁷, among others. However, there are still no Core Sets for individuals with DS; nevertheless, there are Core Sets focused on rehabilitation, which include individuals with limitations or restrictions related to health⁶⁸, that can be used for the DS population.

The methodological assessment of the quality of the twelve studies found two studies^{14,19} with the lowest score classified as "fair" and one¹² with the highest score being considered a "good" study. The quality criteria with the lowest scores were not describing the sample size or power calculation, not reporting if there were losses, and not reporting adverse events.

The importance of validating instruments for DS adults is highlighted, not only for use in the scientific environment but also for use in clinical practice, since they are extremely important instruments for conducting intervention programs and improving their quality of life.

Limitations of the review

The limitations seen in this review include the lack of homogeneity in the studies. Many were excluded for not evaluating only DS adults. Even though their characteristics persist into adulthood, the separation of this sample into children and adults is necessary since there are other clinical manifestations in the adult phase, different from the pediatric ones. This causes a lack of homogeneity in the studies, few selectable studies, and does not exclude studies with low methodological quality.

Conclusion

We found 48 instruments used to assess DS adults, however, only two of these were validated for this population, namely the 6MWT, which assesses functional capacity, and the CAMDEX-SD, which assesses cognition.

The 48 instruments are still used in the biomedical model, since there are many more instruments focused on the assessment of Body Function and Structure, with the main component for cognition. Only one instrument was used to assess the social environment, however, it has not been validated for this population, so we cannot guarantee that it is a reliable instrument for them.

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