

Reliability of FUNDES-Child-SE - measuring participation and independence of children and youths with disabilities

Jennifer Gothilander, Anna Ullenhag, Henrik Danielsson & Anna Karin Axelsson

To cite this article: Jennifer Gothilander, Anna Ullenhag, Henrik Danielsson & Anna Karin Axelsson (2023): Reliability of FUNDES-Child-SE - measuring participation and independence of children and youths with disabilities, Scandinavian Journal of Occupational Therapy, DOI: [10.1080/11038128.2023.2237214](https://doi.org/10.1080/11038128.2023.2237214)

To link to this article: <https://doi.org/10.1080/11038128.2023.2237214>



© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



[View supplementary material](#)



Published online: 08 Aug 2023.



[Submit your article to this journal](#)



Article views: 92



[View related articles](#)



[View Crossmark data](#)

Reliability of FUNDES-Child-SE - measuring participation and independence of children and youths with disabilities

Jennifer Gothilander^a , Anna Ullenhag^a, Henrik Danielsson^b  and Anna Karin Axelsson^c 

^aSchool of Health, Care and Social Welfare, Mälardalen University, Sweden; ^bDepartment of Behavioural Sciences and Learning, Linköping University, Sweden; ^cCHILD Research Group, School of Education and Communication, Jönköping University, Sweden

ABSTRACT

Background: There is a need for an instrument to measure participation and independence in children with disabilities. FUNDES-Child-SE has its origin in the participation questionnaire Child and Adolescent Scale of Participation.

Aims: Test the psychometric properties of internal consistency and test-retest reliability.

Material and methods: This cross-sectional study included caregivers of 163 children with disability aged 6–18 years, 59 of whom were also included in the test-retest study. Descriptive statistics were used to evaluate the proportions of valid ratings. Internal consistency and test-retest reliability were tested through Cronbach's alpha and the intra-class correlation coefficient.

Results: The amount of not relevant/not applicable ratings was substantial but varied between items and subdomains. Internal consistency was acceptable (0.8–0.95), and the test-retest was marginal to excellent (0.73–0.95).

Conclusions: The reliability together with the content validity support the use of the FUNDES-Child-SE to measure participation and independence in children with disabilities. However, results should be interpreted with caution due to the small sample size and possible selection bias. Modifications to reduce the not relevant/not applicable responses should be investigated together with the instrument's responsiveness.

Significance: FUNDES-Child-SE can be used to facilitate a discussion of participation and independence and to plan interventions in a habilitation setting.

ARTICLE HISTORY

Received 10 October 2022

Revised 16 June 2023

Accepted 12 July 2023

KEYWORDS

Habilitation; internal consistency; psychometric; rehabilitation; test-retest

Introduction



Participation in daily activities is known to be important for a child's physical and mental development towards independence and is an important goal in Swedish habilitation services for children and youths [1,2]. Therefore, reliable instruments to measure participation and independence are needed.

Several instruments for the measurement of participation in children with disabilities have been developed and used in research [3]. Commonly, instruments of participation such as the Child and Adolescent Scale of Participation (CASP), are built on the World Health Organization's International Classification of Functioning, Disability and Health (ICF) definition of participation as 'involvement in life situations' [4,5]. The framework Family of Participation-Related Constructs (fPRC) is intended to further define the construct and describes participation as consisting of both attendance and

involvement in an activity. Attendance is a prerequisite for participation, whereas involvement may include engagement, which is an internal state involving focus or effort [6]. Despite involvement being central to participation, few instruments of participation include the aspect of involvement or engagement [3].

How independently a child can participate in activities can influence both the child's attendance and involvement in the activities [6]. Independence is also affected by environmental factors such as the activity setting [7]. Planning interventions aimed at optimising the child's participation requires reliable information about attendance, engagement, and independence in different activities and settings [2].

When developing new instruments, it is preferable to make adaptations of existing measures of the same concept rather than create new ones [8]. FUNDES-Child-SE is a translated, cross-culturally adapted [9], and further developed version of the Taiwanese instrument, the

CONTACT Jennifer Gothilander  jennifer.gothilander@mdu.se  School of Health, Care and Social Welfare, Mälardalen University, Box 883, 721 23 Västerås, Sweden

 Supplemental data for this article is available online at <https://doi.org/10.1080/11038128.2023.2237214>.

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group
This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

Functioning Scale of the Disability Evaluation System-Child (FUNDES-Child 7.0). FUNDES-Child 7.0 includes general information, impairments, participation, and environmental factors. The participation section (Part II) of FUNDES-Child 7.0 is based on the Chinese version of the Child and Adolescent Scale of Participation (CASP-C). The development process and adaptations from CASP to FUNDES-Child-SE have previously been described by Axelsson et al. [10]. FUNDES-Child-SE only includes part II of FUNDES-Child 7.0 and a dimension of engagement as well as an open-ended question about barriers to independence have been added to each item. FUNDES-Child 7.0 is answered by caregivers through interviews with trained staff, and FUNDES-Child-SE has been responded to by caregivers through a web or paper survey.

Before an instrument can be used for research or in clinical practice, it must be tested for psychometric properties such as reliability, and several aspects of validity. Reliability is of utmost importance in establishing the clinical and scientific utility of an instrument [11]. The attainment of valid data serves as a fundamental requirement for ensuring the reliability of the instrument. Reliability, as defined, refers to the instrument's capacity to effectively discriminate among subjects [12] or the extent to which the measurement remains unaffected by measurement error [13]. Having a low proportion of missing data and a few items rated as not applicable indicates that the instrument can generate valid data [14]. The instrument must also show the stability of results in repeated measures when no change is expected [15].

The internal consistency of CASP has previously been reported by Cronbach's alpha 0.96 [16] and 0.98 [17] and test-retest intra-class correlation (ICC) of 0.86–0.96 [16–19]. Cronbach's alpha of CASP-C has been reported as 0.96 [20] and the test-retest ICC of FUNDES-Child 7.0 is 0.85–0.99 [21]. Considering the new context, cultural adaptations of items, changed rating process, and the added dimension of engagement in FUNDES-Child-SE, there is a need to test the instrument's reliability.

Aim

The aim was to evaluate the reliability of FUNDES-Child-SE. The research questions were:

- i. How high is the internal consistency of items within the subdomains and dimensions in FUNDES-Child-SE?
- ii. How high is the test-retest reliability of FUNDES-Child-SE?

Material and methods

Design

This study of FUNDES-Child-SE's psychometrical properties used a cross-sectional study design as a part of the longitudinal research project on participation and mental health in children and youths with disability (CHILD-PMH). The study was approved by the Swedish Ethical Review Authority (no. 2019-05028 and no. 2017/496-31) and the procedure complied with the Helsinki Declaration of Medical Research [22]. Reporting follows the Guidelines for Reporting Reliability and Agreement Studies (GRRAS) [12].

Participants

The participants were caregivers of children with disabilities in six regions in Sweden. The children were from their sixth year of age to the end of their 18th year of age and were registered at a habilitation centre, meaning they lived with one or more disabilities. For inclusion in the retest study, the retest had to have been answered within 5 to 36 days after the first survey.

Instrument

Demographic data were collected on the children's age, gender, intellectual and physical disability as well as the participants' gender, education, and whether they needed an interpreter when communicating with authorities and health care services.

The 10 Question Screen (TQSI) [23] contains ten binary questions about various physical and mental problems. Four questions from the TQSI were asked to identify the child's physical and intellectual disability;

- *Compared with other children, does or did your child have any serious delay in sitting, standing, or walking?*
- *Does your child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?*
- *When you tell your child to do something, does he/she seem to understand what you are saying?*
- *Compared with other children of the same age, does your child appear in any way mentally slow?*

FUNDES-Child-SE measures the two aspects of participation, frequency of attendance and

engagement, as well as independence, in children with disability aged six to 18 years. The 20 activity areas (items) are in line with CASP and FUNDES-Child 7.0 divided into four subdomains and in FUNDES-Child-SE called; *To participate at home* (six items), *To participate outside the home* (four items), *To participate at school* (five items), and *To participate in the home and society* (five items). Each item is rated in each of the three dimensions, Frequency of attendance, Engagement, and Independence using a four-rating scale or the response alternative not relevant/not applicable. The definition of the dimensions in FUNDES-Child-SE as well as their numeric ratings are presented in Table 1. The content validity of the cross-cultural adaptation from FUNDES-Child to FUNDES-Child-SE was tested by cognitive interviews with children, youth, and caregivers [10]. As a result of these interviews, no items were removed or added. Examples of activities representing the items have been partly modified in FUNDES-Child-SE, e.g. ‘singing in the choir’ has been added and ‘parades’ has been removed as a result of the content validity testing. Further, ‘Not applicable’ was changed to ‘Not relevant/not applicable’, based on the interviews.

Procedure

Invitations were sent during the year 2020 and in January 2021, through the habilitation centre where children with disabilities were registered. The four-year longitudinal research project CHILD-PMH invited 2891 children born in 2007–2009 and 2013–2015 and their caregivers, from five regions in central Sweden to participate. In the sixth region, invitations to participate in the cross-sectional study were sent to the caregivers of 410 children born in 2003–2006.

Those who had agreed to participate were contacted and given the option of receiving a web survey or a paper survey in Swedish, English, Somali, or Arabic. Surveys were distributed from December 2020 to April 2021. For the web survey, a reminder was sent three times within two weeks. For the paper survey, a reminder was sent within two to six weeks.

The retest survey was sent after an interval of 7 to 21 days after the participant had started answering the first web survey or had returned the paper survey. It was possible to pause the answering of the first web survey for up to three weeks after starting it. The interval between the test and retest was intended to minimise the risk of remembering the previous answers and that an actual change had occurred [24]. Retest surveys answered within 5–36 days after the first survey were included in the analyses. The same reminder procedure as for the first survey was used for the retest survey, and the participant used the same type of survey (web or paper) in both the test and retest.

Data analysis

Data analyses were performed using the RStudio program version 4.1.2 [25], the R program version 4.1.2 [26] and the R packages dplyr [27], summarytools [28], psych [29], and mice [30].

The proportion of valid data in FUNDES-Child-SE was analysed with descriptive statistics using the R package summarytools [14]. The proportion of missing data and not relevant/not applicable ratings per item was examined, and items with $\geq 10\%$ missing data or not relevant/not applicable ratings were reported.

As the rating not relevant/not applicable does not belong on the rating scale, the R package dplyr was used to transform not relevant/not applicable to rating 3 (Never do it, Not at all engaged) in the dimensions of Frequency of attendance and Engagement. It

Table 1. Dimensions and rating scales in FUNDES-Child-SE.

Dimension	Rated as	Rating scale	
Frequency of attendance	How often the child/youth participate in different activities compared to children/young people without disabilities (with or without aids or other equipment)	0	The same as or more than what is expected for the age
		1	A bit less than what is expected for the age
		2	Much less than what is expected for the age
		3	Never do it
		9	Not relevant/not applicable
Engagement	How engaged/involved you perceive the child/youth to be in activities without comparing with other children/young people	0	Very engaged
		1	Rather engaged
		2	Little/somewhat engaged
		3	Not at all engaged
		9	Not relevant/not applicable
Independence	How independent the child/youth is in activities (regardless of whether he/she uses technical aids or not)	0	Independent, does not need any guidance or assistance
		1	Need guidance or little assistance
		2	Medium assistance
		3	Total assistance
		9	Not relevant/not applicable

was assumed that these response options have the same meaning, i.e. if something is not relevant or applicable it is not done or engaged with. In the dimension of Independence, the rating not relevant/not applicable was treated as missing data, as it cannot be assumed to have the same meaning as any of the rating scale alternatives. The R package mice and the mice function were used to perform imputation by multiple imputations of chained equations [30]. After treatment of not relevant/not applicable ratings, surveys with $\geq 50\%$ missing data within the three dimensions Frequency of attendance, Engagement, and Independence separately were excluded [31]. The R package psych was used to analyse the internal consistency within items in each subdomain and dimension, using the alpha function for Cronbach's alpha. Cronbach's alpha was also examined using the test-retest sample to compare imputed values to non-imputed, as this is recommended after imputation [32]. An alpha coefficient of 0.75–0.95 was considered acceptable, and an alpha >0.95 indicated redundancy [13].

The R package psych was also used to analyse test-retest reliability on the index of each subdomain and dimension. The intra-class correlation coefficient (ICC) and the 95% confidence intervals were examined using the ICC function, based on a single-rating, absolute-agreement, two-way mixed-effects model [11]. The index of subdomains and dimensions was calculated by the sum score of all applicable items (excluding missing data and not relevant/not applicable) in the subdomain and dimension, divided by 3 (the maximum possible score per item) and multiplied by 100 to get an index with a possible range of 0–100. An ICC between the test and retest of less than 0.5 was considered poor, 0.5–0.75 marginal, 0.75–0.9 good, and >0.9 excellent reliability [11].

Result

Of the 341 who agreed to participate, 200 returned the survey. Of these, 163 remained after exclusion criteria had been applied (child's age reported outside the 6–18 years range [$n=8$], 100% missing data in one or more dimensions [$n=29$]). For retest, 85 surveys were returned. Of these, 59 remained after exclusion criteria had been applied (response date not within 5–36 days [$n=20$], 100% missing data in one or more dimensions [$n=6$]). The test sample and retest sample had similar descriptive characteristics, see Table 2 for details.

In the subdomains *To participate at school* and *To participate in the home and society*, all items had $\geq 10\%$ not relevant/not applicable ratings. The subdomain *To*

participate in the home and society had the highest amount of not relevant/not applicable ratings (12.3–42.3%). Two items, *Using pedagogical materials and equipment that are also available for other students or that are adapted for you/your child* and *Communicating with other students and adults at the school* had missing ratings of $\geq 10\%$ in all dimensions. The items *Using transportation in order to move around in society* and *Work and responsibilities* had $<60\%$ valid ratings in all dimensions. In Table 3, items with a proportion of $\geq 10\%$ missing or not relevant/not applicable ratings are presented, together with the proportion of the items' valid ratings (a rating of 0–3).

Internal consistency

The number of surveys included in the analysis of internal consistency was 154 (Frequency of attendance), 152 (Engagement), and 139 (Independence). The proportion of missing data was 2.6% in Frequency of attendance, 3.7% in Engagement, and 4.1% in Independence. After the transformation, the proportion of missing data in Independence was 15.6%.

Items had acceptable internal consistency within the subdomains (alpha 0.8–0.92) and within the dimensions (alpha 0.94–0.96) (Table 4). The lowest alpha correlation coefficients (0.8–0.87) were found in the subdomain *To participate in the home and society* and the highest (0.91–0.92) in the subdomain *To participate at school*. Internal consistency was stable (differences of 0.00–0.07) when comparing the retest sample to the full sample (Table 4).

Test-retest reliability

Intra-class correlation coefficients (ICCs) of test-retest ranged from 0.73–0.9 within the subdomains and 0.85–0.95 in the dimensions. ICCs of test-retest are shown in Table 4.

Discussion

This study aimed to evaluate the reliability of FUNDES-Child-SE. The main findings are that the FUNDES-Child-SE has shown a high ($>10\%$) proportion of missing and not relevant/not applicable ratings for items in two of four subdomains, an acceptable internal consistency (alpha 0.8–0.96), and a good to excellent test-retest reliability (ICC 0.73–0.95).

The high proportion of missing and not applicable ratings, especially in the subdomains *To participate at*

Table 2. Demographic data of children and participants.

	Population (n = 163)	Retest population (n = 59)
Children		
Age		
Age in years (m, (sd))	10.7 (3.83)	11.87 (3.91)
Cohort born 2013–2015	41.1%	30.5%
Cohort born 2007–2009	42.9%	44.1%
Cohort born 2003–2006	16.0%	25.4%
Gender		
Boy	63.8%	64.4%
Girl	35.0%	33.9%
Other	1.2%	1.7%
Physical disability		
Has serious delay in sitting, standing, or walking	36.2%	35.6%
Has difficulty walking or moving arms or is weak or rigid in arms or legs	19.6%	18.6%
Intellectual disability		
Comprehends when a parent asks the child to do something	80.1%	82.8%
Seems to have difficulties comprehending or is slow	68.3%	69.5%
Participants		
Gender		
Woman	68.1%	73.7%
Man	31.9%	26.3%
Participants' education		
9-year elementary school	8.0%	3.4%
Upper secondary school	26.4%	35.6%
University	46.0%	47.5%
Missing	19.6%	13.6%
Need an interpreter		
Yes	16.6%	3.4%
No	64.4%	66.1%
Missing	19.0%	30.5%
Survey language		
Swedish	90.2%	94.9%
English	4.9%	1.7%
Arabic	4.9%	3.4%
Somali	0%	0%
Type of survey		
Web	66.9%	79.7%
Paper	33.1%	20.3%

school and *To participate in the home and society*, could have several explanations. Unlike the instructions for CASP [33] and FUNDES-Child 7.0, FUNDES-Child-SE did not explain the intended use of the response alternative not applicable in the instructions. Instead, not relevant had been added to the response alternative, i.e. Not relevant/not applicable. Some items could be irrelevant due to the child's age, such as young children not being expected to do shopping or manage money. The impact of age on not relevant/not applicable items was confirmed in post hoc analyses (see [Supplementary Tables 1–3](#)). Also, items could be irrelevant due to e.g. lack of public transportation when living in the countryside. The low proportion of valid ratings for items in the subdimension *To participate in the home and society* (47.2–80.4%) and especially item 20, *Work and responsibilities* (50.3–55.8%), was also found in CASP [16]. In CASP, 35% of the younger children had applicable ratings for that item, and the other four items in the

subdimension were applicable to half their sample of 60 children aged 3–22 years with various disabilities. Item 20 was removed from the analysis of internal consistency in CASP-C due to the item being considered not applicable to most of the participants, although no data on not applicable ratings are presented [20]. Additionally, as the dimension Frequency of attendance had a lower proportion of missing and not relevant/not applicable ratings compared to Engagement and Independence. This could indicate that respondents consider a rating of Engagement and Independence as being dependent on a rating of 0–2 in the dimension Frequency of attendance (0= The same or more than what is expected for the age, 1=A bit less than what is expected for the age, and 2=Much less than what is expected for the age). If so, a rating of Never do it or a rating of not relevant/not applicable in the dimension Frequency of attendance excludes rating Engagement and Independence in that activity area since it is never done. Consequently, this could result in a missing or not relevant/not applicable rating in Engagement and Independence. Alternatively, the number of missing and not relevant/not applicable ratings could be due to a high cognitive burden on the respondents as FUNDES-Child-SE in the present study was answered along with other instruments. An interview method, as used in FUNDES-Child 7.0, could perhaps decrease the amount of missing data and not relevant/not applicable through elaboration with the interviewer. The cause of missing and not relevant/not applicable ratings will require further investigation outside the scope of this study.

The internal consistency of FUNDES-Child-SE indicates a risk of redundancy within the dimensions (alpha 0.94–0.97), but not in the subdomains (0.8–0.92). Bedell et al. replaced not applicable ratings with the 60 participants' mean scores and CASP then showed internal consistency for all 20 items of 0.95 [16]. Internal consistency of CASP-C had an alpha of 0.88–0.9 in the subdomains and 0.96 in the 19 items remaining after *Work and responsibilities* were excluded from the analysis [20]. However, it is important to put the indication of redundancy in relation to the items' clinical significance. Used as an instrument to identify activity areas or settings of interest for interventions in clinical practice, all items can be relevant despite a potential redundancy [10]. In research, data from subdomains or other factors can be analysed, depending on the research questions. The structural validity of FUNDES-Child 7.0 has been tested [21] and the structural validity of FUNDES-Child-SE should be tested in future studies.

The test-retest ICCs are marginal to good within the subdomains (0.73–0.9) and good to excellent

Table 3. The 13 items with >10% missing data or not relevant/not applicable in one or more dimensions and the proportion of these items' valid ratings, per dimension ($n=163$).

	Frequency of attendance			Engagement			Independence		
	Missing	Not relevant/ not applicable	Valid	Missing	Not Relevant/ not applicable	Valid	Missing	Not relevant/ not applicable	Valid
Subdomain to participate at home									
Social, play or leisure activities at home with friends	3.0%	6.8%	90.2%	4.3%	11.7%	84.0%	4.3%	11.0%	84.7%
Subdomain to participate outside the home									
Social, play, or leisure activities with friends outside the home	6.1%	8.0%	85.9%	7.4%	15.3%	77.3%	8.0%	17.8%	74.2%
Organized activities outside the home	6.7%	12.3%	81.0%	8.6%	15.3%	76.1%	7.4%	18.4%	74.2%
Subdomain to participate at school									
Instructional activities together with classmates	9.8%	17.2%	73.0%	12.3%	16.0%	71.8%	12.3%	16.0%	71.8%
Social, play or leisure activities with other students at school	8.6%	13.5%	77.9%	11.0%	12.3%	76.7%	12.3%	12.3%	75.5%
Moving around at school	9.2%	12.9%	77.9%	11.7%	12.9%	75.5%	10.4%	12.3%	77.3%
Using pedagogical materials and equipment that are also available for other students or that are adapted for you/your child	11.7%	14.7%	73.6%	14.7%	14.1%	71.2%	14.1%	14.7%	71.2%
Communicating with other students and adults at the school	11.0%	12.9%	76.1%	12.9%	11.7%	75.5%	13.5%	12.9%	73.6%
Subdomain to participate in the home and society									
Household activities	7.3%	12.3%	80.4%	9.2%	12.9%	77.9%	8.6%	17.8%	73.6%
Shopping and managing money	7.4%	25.1%	67.5%	9.8%	27.0%	63.2%	9.8%	28.2%	62.0%
Managing a daily schedule	8.0%	22.7%	69.3%	9.2%	23.9%	66.9%	8.6%	25.1%	66.3%
Using transportation in order to move around in society	8.6%	35.6%	55.8%	10.4%	42.3%	47.2%	9.8%	41.7%	48.5%
Work and responsibilities	9.8%	34.4%	55.8%	12.9%	36.8%	50.3%	12.3%	35.6%	52.1%

Table 4. Cronbach's alpha correlation coefficients in subdomains and dimensions using the full sample and retest sample, and test-retest intra-class correlation coefficient (ICC).

	Alpha correlation coefficient (95% confidence interval)	Alpha correlation coefficient (95% confidence interval) (Retest sample, $n=59$)	Test-retest ICC (95% confidence interval)
Frequency of attendance ($n=154$)			
Subdomain to participate at home	0.84 (0.79–0.87)	0.80 (0.70–0.87)	0.80 (0.71, 0.87)
Subdomain to participate outside the home	0.80 (0.75–0.85)	0.82 (0.73–0.88)	0.86 (0.80, 0.91)
Subdomain to participate at school	0.92 (0.89–0.93)	0.88 (0.83–0.92)	0.84 (0.75, 0.89)
Subdomain to participate in the home and society	0.89 (0.86–0.91)	0.91 (0.87–0.94)	0.83 (0.75, 0.89)
Dimension frequency of attendance	0.95 (0.93–0.96)	0.95 (0.93–0.97)	0.90 (0.85, 0.93)
Engagement ($n=152$)			
Subdomain to participate at home	0.84 (0.79–0.87)	0.81 (0.73–0.88)	0.79 (0.70, 0.86)
Subdomain to participate outside the home	0.81 (0.75–0.85)	0.80 (0.71–0.88)	0.82 (0.74, 0.88)
Subdomain to participate at school	0.91 (0.89–0.93)	0.89 (0.85–0.93)	0.73 (0.61, 0.82)
Subdomain to participate in the home and society	0.87 (0.83–0.90)	0.89 (0.85–0.93)	0.77 (0.67, 0.85)
Dimension engagement	0.94 (0.93–0.96)	0.94 (0.92–0.96)	0.85 (0.78, 0.90)
Independence ($n=139^*$)			
Subdomain to participate at home	0.90 (0.88–0.93)	0.93 (0.90–0.96)	0.89 (0.84, 0.93)
Subdomain to participate outside the home	0.87 (0.83–0.90)	0.94 (0.91–0.96)	0.83 (0.75, 0.89)
Subdomain to participate at school	0.90 (0.89–0.93)	0.92 (0.89–0.95)	0.86 (0.79, 0.91)
Subdomain to participate in the home and society	0.90 (0.88–0.93)	0.90 (0.85–0.94)	0.83 (0.75, 0.89)
Dimension independence	0.96 (0.96–0.97)	0.97 (0.96–0.98)	0.95 (0.92, 0.96)

*Include imputed data. ICC: intra-class correlation coefficient.

within the dimensions (0.85–0.95). This should be compared to test-retest ICC of 0.86–0.96 for CASP [16–19] and 0.85–0.99 for FUNDES-Child 7.0 [21]. Most of the subdomains have a lower 95% confidence interval above the threshold for good reliability. The dimension with the lowest ICC is Engagement,

especially engagement in the subdomain *To participate at school*. Engagement could be difficult to rate, as it is judged through observation of the child. To rate engagement in a setting where caregivers are not frequently present, could therefore be even more difficult. This dimension and subdomain also had a high

proportion of missing and not relevant/not applicable ratings (14.7–16%). Taking this, the wide scope of the items to be judged, and the test-retest period into consideration, the ICC of 0.73 and lower confidence interval of 0.61 are considered to represent an acceptable agreement between the test and retest.

Methodological limitations

This study has limitations. The high attrition rate and consequently small sample size, which does not include 9–11-year-olds, a high proportion of missing data and not relevant/not applicable ratings, as well as imputation of data are obvious threats to the validity of the results. The sample size was large enough to study test-retest reliability and internal consistency [34]. The decision to conduct transformations and imputations was considered the most suitable option considering the sample size. As shown in the analysis using the retest sample, in which transformation and imputation were not performed, the internal consistency does not appear to be affected by transformations and imputations. The ICC of test-retest could have been affected by the time between test and retest in which circumstances e.g. move from school time to holiday time, could have influenced the ratings. Finally, although the translations are done by professionals, the Arabic, Somali and English versions should be validated to ensure the Swedish cultural meaning of the items has been translated and interpreted correctly. In this study, the sample using non-Swedish versions was too small to conduct separate analyses. Still, it should not have had a substantial effect on the results as only 5–9% used a non-Swedish version.

Conclusions

The results of this study indicate that reliability together with the content validity support the use of the FUNDES-Child-SE to measure participation and independence in children with disabilities. FUNDES-Child-SE can be used to facilitate a discussion and to plan interventions to improve participation and independence in children with disabilities, as recommended by Anaby et al. [2] and caregivers [10]. However, before the instrument is used to evaluate interventions, it is important to also test FUNDES-Child-SE's responsiveness [13] and modifications to reduce the amount of not relevant/not applicable responses should be investigated. In a clinical setting, a dialogue on the ratings can possibly

decrease the amount of missing and not relevant/not applicable. Before suggesting data management or possible revisions in the questionnaire, the factor structure will be tested to further evaluate the instrument and understand the concept of participation. Finally, the results of this study should be interpreted with caution due to the high attrition rate and possible selection bias.

Acknowledgements

We thank the participants for their contribution. We also thank the Swedish Research Council, Sunnerdahls handikappfond and Futurum - the Academy for Healthcare, Region Jönköping County for funding.

Ethics approval

The study was approved by the Swedish Review Authority (no. 2019-05028 and no. 2017/496-31) and the procedure complied with the Helsinki Declaration of Medical Research.

Patient consent

All participants have signed written consents.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Data availability

The data that support the findings of this study are available from the corresponding author, JG, upon reasonable request. Permission to reproduce material from other sources: FUNDES-Child-SE has been developed with permission from authors of FUNDES-Child, and developers of FUNDES-Child-SE are authors of this manuscript and have given their consent.

Funding

This study was funded by the Swedish Research Council (grant number 2018-05824_VR), Sunnerdahls Handikappfond and Futurum - the Academy for Healthcare, Region Jönköping County.

ORCID

Jennifer Gothilander  <http://orcid.org/0000-0001-7886-7171>
Henrik Danielsson  <http://orcid.org/0000-0002-0446-0827>
Anna Karin Axelsson  <http://orcid.org/0000-0001-9546-2264>

References

- [1] Anaby D, Avery L, Gorter JW, et al. Improving body functions through participation in community activities among young people with physical disabilities. *Dev Med Child Neurol.* 2020;62:640–646. doi: [10.1111/dmcn.14382](https://doi.org/10.1111/dmcn.14382).
- [2] Anaby D, Khetani M, Piskur B, et al. Towards a paradigm shift in pediatric rehabilitation: accelerating the uptake of evidence on participation into routine clinical practice. *Disabil Rehabil.* 2021; 8:1–12.
- [3] Adair B, Ullenhag A, Rosenbaum P, et al. Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: a systematic review. *Dev Med Child Neurol.* 2018;60:1101–1116. doi: [10.1111/dmcn.13959](https://doi.org/10.1111/dmcn.13959).
- [4] Imms C, Adair B, Keen D, et al. Participation: a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Dev Med Child Neurol.* 2016;58:29–38. doi: [10.1111/dmcn.12932](https://doi.org/10.1111/dmcn.12932).
- [5] ICF Browser [internet]. World Health Organization; 2021 [cited 2021 Dec 21]. Available from: <https://apps.who.int/classifications/icfbrowser/>.
- [6] Imms C, Granlund M, Wilson PH, et al. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Dev Med Child Neurol.* 2017;59:16–25. doi: [10.1111/dmcn.13237](https://doi.org/10.1111/dmcn.13237).
- [7] Anaby D, Hand C, Bradley L, et al. The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disabil Rehabil.* 2013;35:1589–1598. doi: [10.3109/09638288.2012.748840](https://doi.org/10.3109/09638288.2012.748840).
- [8] Cook DA, Hatala R. Validation of educational assessments: a primer for simulation and beyond. *Adv Simul.* 2016;1:31. doi: [10.1186/s41077-016-0033-y](https://doi.org/10.1186/s41077-016-0033-y).
- [9] Beaton DE, Bombardier C, Guillemin F, et al. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine.* 2000;25:3186–3191. doi: [10.1097/00007632-200012150-00014](https://doi.org/10.1097/00007632-200012150-00014).
- [10] Axelsson AK, Ullenhag A, Odman P. A Swedish cultural adaptation of the participation questionnaire – functional scale of the disability evaluation System – child version. *Disabil Rehabil.* 2021; 3:1–8.
- [11] Koo TK, Li MY. A guideline of selecting and reporting intraclass correlation coefficients for reliability research. *J Chiropr Med.* 2016; 15:155–163. doi: [10.1016/j.jcm.2016.02.012](https://doi.org/10.1016/j.jcm.2016.02.012).
- [12] Kottner J, Audige L, Brorson S, et al. Guidelines for reporting reliability and agreement studies (GRRAS) were proposed. *J Clin Epidemiol.* 2011; 64:96–106. doi: [10.1016/j.jclinepi.2010.03.002](https://doi.org/10.1016/j.jclinepi.2010.03.002).
- [13] Prinsen CA, Vohra S, Rose MR, et al. How to select outcome measurement instruments for outcomes included in a "core outcome set" – a practical guideline. *Trials.* 2016;17:449. doi: [10.1186/s13063-016-1555-2](https://doi.org/10.1186/s13063-016-1555-2).
- [14] Ware JE, Jr, Gandek B. Methods for testing data quality, scaling assumptions, and reliability: the IQOLA project approach. *J Clin Epidemiol.* 1998;51:945–952. doi: [10.1016/s0895-4356\(98\)00085-7](https://doi.org/10.1016/s0895-4356(98)00085-7).
- [15] Lexell JE, Downham DY. How to assess the reliability of measurements in rehabilitation. *Am J Phys Med Rehabil.* 2005; 84:719–723. doi: [10.1097/01.phm.0000176452.17771.20](https://doi.org/10.1097/01.phm.0000176452.17771.20).
- [16] Bedell GM. Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. *NRE.* 2004;19:191–205. doi: [10.3233/NRE-2004-19303](https://doi.org/10.3233/NRE-2004-19303).
- [17] Bedell GM, Dumas HM. Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: a follow-up study. *Brain Inj.* 2004; 18:65–82. doi: [10.1080/0269905031000110517](https://doi.org/10.1080/0269905031000110517).
- [18] Bedell G. Further validation of the child and adolescent scale of participation (CASP). *Dev Neurorehabil.* 2009;12:342–351. doi: [10.3109/17518420903087277](https://doi.org/10.3109/17518420903087277).
- [19] De Bock F, Bosle C, Graef C, et al. Measuring social participation in children with chronic health conditions: validation and reference values of the child and adolescent scale of participation (CASP) in the German context. *BMC Pediatr.* 2019;19:125. doi: [10.1186/s12887-019-1495-6](https://doi.org/10.1186/s12887-019-1495-6).
- [20] Hwang AW, Liou TH, Bedell GM, et al. Psychometric properties of the child and adolescent scale of participation—traditional Chinese version. *Int J Rehabil Res.* 2013;36:211–220. doi: [10.1097/MRR.0b013e32835d0b27](https://doi.org/10.1097/MRR.0b013e32835d0b27).
- [21] Hwang AW, Yen CF, Liao HF, et al. Structural validity of an ICF-based measure of activity and participation for children in Taiwan's disability eligibility determination system. *Int J Environ Res Public Health.* 2020;17:1–16.
- [22] Declaration of Helsinki [internet]. World Medical Association; 2013. [cited 2021 Dec 01] Available from: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.
- [23] Durkin MS, Wang W, Shrout PE, et al. Evaluating a ten questions screen for childhood disability: reliability and internal structure in different cultures. *J Clin Epidemiol.* 1995;48:657–666. doi: [10.1016/0895-4356\(94\)00163-k](https://doi.org/10.1016/0895-4356(94)00163-k).
- [24] Streiner DL. A guide for the statistically perplexed. Toronto (ON): University of Toronto Press; 2012.
- [25] RStudio [internet]. RStudio; 2022 [cited 2022 Mar 03] Available from: <https://www.rstudio.com/products/rstudio/>.
- [26] R: A language and environment for statistical computing [Internet]. R-project: RCore Team; 2021 [cited 2022 Mar 03] Available from: <https://www.R-project.org/>.
- [27] Dplyr: A Grammar of Data Manipulation. R package version 1.0.8 [Internet]. R-project: Wickham H, François R, Henry L, et al; 2018 [cited 2022 Mar 03] Available from: <https://cran.r-project.org/web/packages/dplyr/index.html>.
- [28] Summarytools: Tools to Quickly and Neatly Summarize Data. R package version 1.0.0. [internet]. R-project: Comtois D; 2021 [cited 2022 Mar 03] Available from: <https://cran.r-project.org/package=summarytools>.
- [29] Psych: Procedures for Personality and Psychological Research [Internet]. R-project: Ravelle, W; 2021 [cited 2022 March 03] Available from: <https://CRAN.R-project.org/package=psych>.

- [30] Buuren S, Groothuis-Oudshoorn K. Mice: multivariate imputation by chained equations in R. *J Stat Soft.* 2011;45:1–67. doi: [10.18637/jss.v045.i03](https://doi.org/10.18637/jss.v045.i03).
- [31] Hair JF, Anderson RE, Tatham RL, et al. *Multivariate data analysis*. 5 ed. London: Prentice Hall International; 1998.
- [32] Westergren A, Jakobsson U. Count with the internal drop out. *Nurs Dev.* 2006;3:54–56. Swedish.
- [33] The Child and Adolescent Scale of Participation (CASP) Administration and Scoring Guidelines [Internet]. Bedell G; 2011 [cited 2021 Dec 21] Available from: <http://sites.tufts.edu/garybedell/measurement-tools/>.
- [34] McKenna SP. Measuring patient-reported outcomes: moving beyond misplaced common sense to hard science. *BMC Med.* 2011; 9:86. doi: [10.1186/1741-7015-9-86](https://doi.org/10.1186/1741-7015-9-86).