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Scandinavian Journal of Occupational Therapy

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/iocc20

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To cite this article: Anna Karin Axelsson, Magnus Ivarsson, Henrik Danielsson & Anna Ullenhag (2024) Contributing factors for participation and independence in children and youths with disabilities, Scandinavian Journal of Occupational Therapy, 31:1, 2432332, DOI: 10.1080/11038128.2024.2432332

To link to this article: https://doi.org/10.1080/11038128.2024.2432332

Published online: 02 Dec 2024.

SCANDINAVIAN JOURNAL OF OCCUPATIONAL THERAPY
2024, VOL. 31, NO. 1, 2432332
https://doi.org/10.1080/11038128.2024.2432332

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RESEARCH ARTICLE

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Contributing factors for participation and independence in children and youths with disabilities

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ABSTRACT

Background: Disabilities can hinder children's and youths' participation (frequency of attendance and engagement) and independence in everyday life.

Aims: To identify factors that predict levels of participation and independence in everyday activities in Swedish children and youths with disabilities.

Material and methods: This cross-sectional study, including 131 participants, utilised instruments about child and environmental factors. LASSO regression analyses were conducted to identify predictors of participation and independence.

Results: An item screening for comprehension difficulties was the strongest predictor of attendance, engagement, and independence in daily activities. Other influential child factors included the presence of seizures, speech abilities, age, pain levels, and motor functions. None of the studied environmental factors were retained as predictors in the models.

Conclusions: Difficulties in intellectual functioning need to be evaluated and considered in planning interventions to improve participation and independence. Likewise, multifaceted nature of challenges found in this study underscores the need for diversity of interventions tailored for individual needs.

Significance: The result underscores the critical role of comprehension and intellectual functioning in predicting and enhancing participation and independence in children and youths with disabilities, advocating for comprehensive assessments and sustained support.

ARTICLE HISTORY
Received 29 April 2024
Revised 5 November 2024
Accepted 16 November 2024

KEYWORDS
Participation; independence; children and youths; disabilities; everyday life; bio-psycho-social perspective

Introduction

In today's inclusive society, ensuring the active participation of all individuals, regardless of their abilities, is paramount. However, up to 20% of children and youths in Sweden have some type of disability, which can hinder their full participation and independence in everyday activities. While these individuals are protected by conventions and laws that guarantee their right to participate in activities as independent as possible, they often encounter challenges that limit their physical and social interactions [1]. These challenges have long-term implications, such as poorer opportunities for participation in physical and social activities [2], and increased risk of psychopathology [3]. Consequently, increasing participation [4] as well as independence in daily activities is often a main goal for youths with disabilities, their families, and therapists at habilitation centres in Sweden, where multi-disciplinary interventions are provided for children with disabilities. Therefore, this study seeks to identify the factors that predict levels of participation (defined as attendance and engagement) and independence in everyday activities for children and youths with disabilities in Sweden.

Participation is a multidimensional phenomenon defined as a person's involvement in life situations and can be seen as a result of the interaction between a person and the environment [5]. Through participation in daily activities, children and youths are likely

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to experience higher levels of well-being, learn new skills and competencies, obtain experience of how society works, and have increased opportunities to build friendships [6]. The Family of Participation-Related Construct (fPRC) framework describes participation as a construct with two dimensions: attendance and involvement. Attendance is defined as 'being there' and referred to as frequency and diversity, whereas involvement is the 'experience of participation while attending' and includes elements of emotional characteristics, such as motivation, engagement, persistence, and social connection [7].

Elements that affect participation include individual factors (such as age, activity preferences, motor and cognitive skills, and sense of self); they also extend to the activity task itself and environmental factors [7–8]. These factors interact reciprocally, impacting both participation as well as independence. Independence is closely related, yet distinct, to participation and can be described as having adequate competence or being able to do things for yourself and make your own decisions, without help or influence from other people [7]. In addition, environmental factors, such as accessibility, availability, and attitudes can either facilitate or hinder participation [8,9]. Knowledge about barriers and facilitators can be used to understand the children's patterns of participation and to inform and develop strategies for increased participation and independence [10]. Primary caregivers who are familiar with the youth's patterns of participation can provide valuable information about the youth's experiences of participation and independence considering their capacity and available resources, social and physical environment. This information can guide service providers and policymakers in implementing effective practice and system changes.

Aim

The aim of this study was to identify factors that predict levels of participation and independence in everyday activities in children and youths with disabilities.

Materials and methods

This study has a cross-sectional design and is carried out in collaboration with the research program Child – Participation Mental Health (Child-PMH). The study has been approved by the Swedish Ethical Review Authority (Dnr. 2017/496-31 and Dnr. 2019-05028) and the procedure complied with the Helsinki Declaration of Medical Research [11]. The recruitment of participants for the Child-PMH was guided by power analyses calculated for the main longitudinal analyses planned for the research program. Thus, no separate power analysis was done for the present study.

Participants

Convenience sampling was used. Data from caregivers representing 131 children and youths with disabilities registered at habilitation centres in six different regions in Sweden were included in the study during the year 2020 and in January 2021. The children were from their 6th year of age to the end of their 18th year of age (the recruitment procedure is described in Figure 1). Informed consent for participation and permission for the publication of results were obtained from the caregivers of the participating children. In addition to Swedish, the questionnaires were also offered in English, Arabic, and Somali.

Instruments and variables

Background data

The collected background data regarding child factors included questions about the child's gender (boy, girl, other) and age (birthdate). The children were divided into three different age groups: 5–6 years of age (Cohort 1, born 2014–2015), 11–12 years of age (Cohort 2, born 2007–2009), and 13–18 years of age, i.e. teenagers, (Cohort 3, born 2003–2006). Children aged 7–10 years were not included due to the longitudinal design of the overall research program. This study only utilises data from the first wave of data collection, with the ages 7–10 years covered later waves as the participants age, meaning that data representing these specific ages are not included in this study. Data regarding parental and family factors included questions about the mother's country of birth, caregivers' employment status, highest education (elementary school, senior high school, or university), and the family's house residence (countryside, smaller society, or city). The following questionnaires were used to measure the child's level of participation, independence, health-related quality of life and functional ability:

FUNDES-Child-SE

FUNDES-Child-SE is a questionnaire measuring child attendance, engagement, and independence in 20 different everyday activities in four areas (the home, outside of the home, in school, and the home and

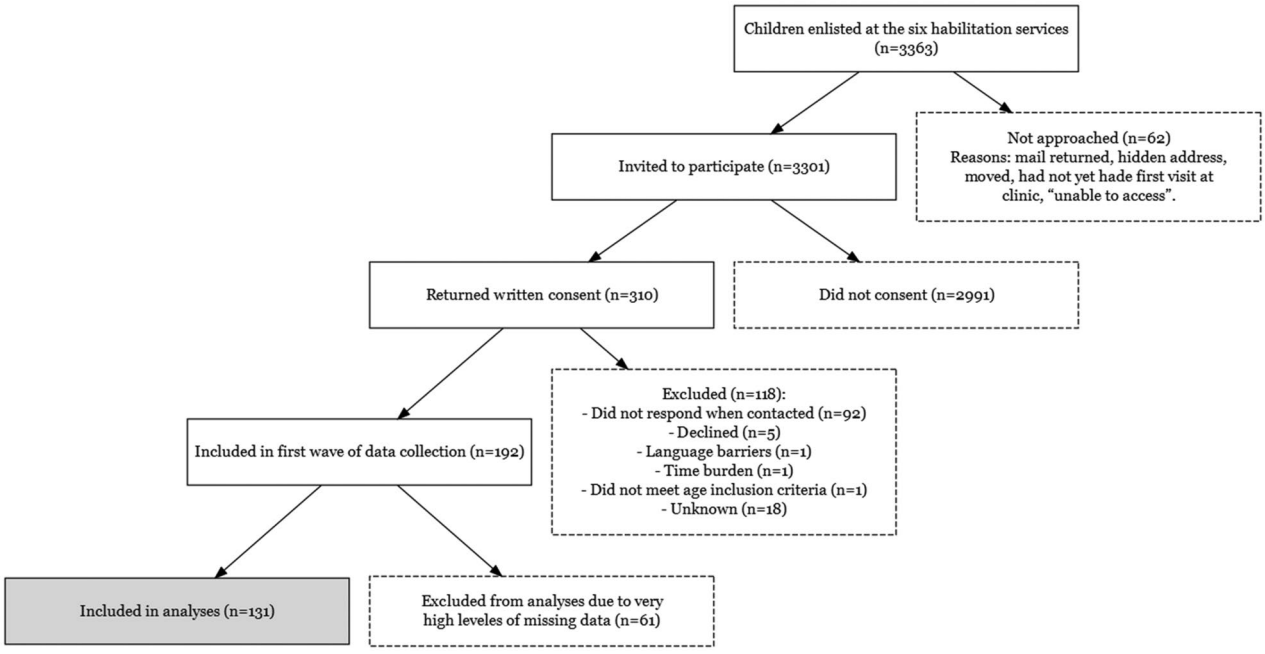

Figure 1. Recruitment procedure.

Table 1. Participant characteristics.

	Cohort		
	1	2	3
N	51	56	24
Girls	15	18	12
Age			
M	6.65	12.42	16.56
SD	0.80	0.86	1.30
Mother born in another country (than Sweden)	36.17	30.19	4.35
Parents employed			
Both	52.17	65.85	90.48
One	32.61	26.83	9.52
None	15.22	7.32	0.00
Parents highest education			
Nine years elementary school	6.67	2.00	0.00
Upper secondary school	26.67	32.00	37.50
Upper secondary special school	0.00	2.00	0.00
University	66.67	64.00	62.50
Residence			
City	52.00	62.50	45.83
Smaller town	36.00	26.79	33.33
In the countryside	12.00	10.71	20.83

Note. Values represent proportions (%) if nothing else is stated.

society) developed for use in children aged 6–18 years. For each activity, the caregiver is to rate how often the child attends compared to other children in the child's age, how engaged the child is, and the level of guidance or assistance needed (i.e. independence) regardless of the use of assistive devices or not, on ordinal scales numbered 0–3 where a lower number indicates less difficulties (Table 1). For each of the 20 activities, there is also an open-ended question about barriers to independence. The FUNDES-Child-SE has been developed from the Child and Adolescent Scale of Participation (CASP) [12,13], and the subsequent Taiwanese version FUNDES-Child, part II [14]. The FUNDES-Child-SE has been culturally validated [15] and has demonstrated acceptable internal consistency and marginal to excellent test-retest ICC [16].

EQ-5D-Y

EQ-5D-Y is an international, widely used questionnaire measuring young people's health-related quality of life (HRQOL) [17]. It comprises the five dimensions; mobility, looking after oneself, doing usual activities, having pain or discomfort, and feeling worried, sad, or unhappy, all to be answered on a three-level ordinal scale including 'None', 'A little', and 'A lot'. There is also a question about self-perceived health, which could be answered on a visual analog scale. A multinational study of the EQ-5D-Y, which included participants with and without self-reported chronic conditions in Sweden, demonstrates that the instrument is feasible, reliable, and valid [18]. In the present study, the items about pain or discomfort, and feeling worried, sad, or unhappy, were included.

Ten Questions Screening Instrument (TQSI)

The TQSI was developed for international use to identify children with disabilities, originally between 2 and 9 years.[19]. It comprises ten binary questions ('No, no difficulty'/'Yes, some difficulty') about the child's ability compared to typically developing peers in the areas of motor/physical functioning, vision, hearing, comprehension/cognition, and speech in addition to a question on the presence of seizures. Even though studies have shown that the TQSI is a

reliable questionnaire that could be used across populations that differ in culture and level of socioeconomic development [19], a need for improving cut-offs to determine disability prevalence has been found [20]. In the present study, an indication of a disability relating to intellectual functioning (i.e. positive response to the 10th question, called Level of comprehension difficulties), led to an additional question where the level of these difficulties was rated ('Mild', 'Moderate', 'Severe', or 'Very severe'). This 10th question was worded: 'Compared with other children of the same age, does your child in any way seem to have difficulties in understanding or to be slow?'

Gross Motor Function Classification System (GMFCS)

The GMFCS was developed for children with cerebral palsy aged 6–12 years [21], and 12–18 years [22]. It is a classification of self-initiated movements with five levels which in brief include (I) walks in different settings without the use of a hand-held mobility device, (II) experiences difficulties when walking longer distances and uneven terrain, (III) walks indoors using a hand-held mobility device, (IV) requires physical assistance or powered mobility in most settings, and (V) transported in a manual wheelchair in all settings. The GMFCS is widely used and is a valid and reliable classification system [23]. In this project, a caregiver proxy version was used.

Statistical analysis

The total scores of the FUNDES-Child-SE dimensions of frequency of attendance, level of engagement, and independence were the primary outcomes and were used as the dependent variables. The studied child factors including gender, age, the two EQ-5D-Y questions, 10 separate indicators of impairment (TQSI), and GMFCS level were used as predictors together with parental and family factors such as occupation and residence. The analyses were conducted in R (R Core Team, 2022) [24].

The missing data (26.27%) within the FUNDES-Child-SE items and the predictors (6.88%) were dealt with in several steps. For the predictors, the level of missingness decreased to 5.40% after removing participants who failed to respond to any of the questions. For the FUNDES items, participants who responded to less than 20% of the items were dropped from further analysis, resulting in a missingness rate of 5.64%. The remaining missing data was assumed to be missing at random and replaced through multivariate imputation by chained equations (MICE) with the mice R package [25]. Missing data among the predictors were predicted by the non-missing predictors, and missing FUNDES data was predicted by the non-missing FUNDES items.

Correlation coefficients for the 22 included child and environmental variables were determined with the mixedCor()-function from the psych R package [26]. This function identifies the appropriate correlation coefficients based on patterns in the data. Thereafter three Least Absolute Shrinkage Selector Operator (LASSO) regression analyses were conducted with the glmnet R package [27], to investigate which of the independent variables contributed to the prediction of the dependent variables. The independent variables were the same for all three models. The tuning parameter λ was set following the one standard error rule, i.e. one standard error under the λ that gives the best prediction accuracy. This approach fosters models' parsimony by allowing somewhat higher bias in the models. All variables were standardised (z-scores) to allow for comparisons of predictor weights. Before performing the analyses, regression assumptions were checked, and no violations were identified.

For items in the FUNDES-Child-SE frequency and engagement subscales, the response option 'Not relevant/Not applicable' was treated as equivalent to 'Never does' and 'Not engaged at all' respectively (i.e. '9:s' were transformed to '3:s'). Further, the level of engagement was automatically set to 'Not engaged at all' ('3') for activities that the child never attended, regardless of how the parent had rated the engagement in that activity (since it is theoretically impossible to be engaged in activities that one never attend).

Results

Table 1 shows the characteristics of the 131 participants and the results across the scales are found in Table 2. The correlation coefficients for all variables that were included in the models are displayed in Table 3. The strong correlations ($r = 0.81$–0.91) between the dependent variables indicate that the respondents rated attendance, engagement, and independence similarly. Six of the candidate predictor variables correlated >0.3 to all dependent variables: (1) serious delay sitting, standing, or walking, (2) does not understand what is said when asked to do something, (3) has seizures, rigidity, or loss of consciousness, (4) has not learned to do same things as peers, (5) does not speak at all, and (6) level of comprehension difficulties. To investigate the unique contributions of these, and the other, candidate predictor

Table 2. Results across the different scales.

	Cohort		
	1	2	3
Total frequency of attendance (FUNDES)			
M	34.17	21.83	23.96
SD	13.96	14.15	13.72
Total level of engagement (FUNDES)			
M	35.17	25.02	28.78
SD	14.07	15.41	14.94
Total level of independence (FUNDES)			
M	28.50	15.70	9.00
SD	19.60	10.72	9.72
Pain, discomfort (EQ-5D-Y)			
None	64.00	62.96	75.00
A little	30.00	31.48	20.83
A lot	6.00	5.56	4.17
Worried, sad, or unhappy (EQ-5D-Y)			
Not	70.00	58.18	33.33
A little	24.00	30.91	54.17
Very	6.00	10.91	12.50
Ten Questions Screen Instrument (TQSI)			
Serious delay in sitting/standing/ walking	45.10	21.43	50.00
Difficulties seeing	21.57	10.71	20.83
Difficulties hearing	13.73	8.93	4.17
Does not understand what is said when asked to do something	22.00	10.91	29.17
Difficulties walking or moving arms	19.61	19.64	12.50
Has seizures/become rigid/lose conscience	20.00	16.07	12.50
Has not learned the same things as peers	50.98	48.08	41.67
Does not speak at all	29.41	10.91	8.33
Does not mention one thing	21.57	8.93	8.33
Level of comprehension difficulties			
None	23.53	43.40	29.17
Mild	17.65	33.96	33.33
Moderate	27.45	13.21	25.00
Severe	17.65	7.55	8.33
Very severe	13.73	1.89	4.17
GMFCS			
I	68.00	83.02	78.26
II	24.00	11.32	8.70
III	4.00	0.00	4.35
IV	2.00	1.89	8.70
V	2.00	3.77	0.00

Note. Values represent proportions (%) if nothing else is stated.
For FUNDES, higher values represent lower levels of attendance, engagement, and independence. For each activity, respondents choose one of the following responses per outcome: (1) Frequency; 0=The same 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, (2) Engagement; 0=Very engaged; 1=Rather engaged; 2=Little/somewhat engaged; 3=Not at all engaged; 9=Not relevant/Not applicable, (3) Independence; 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.
For TQSI items, the questions are as follow: (1) 'Compared with other children, does or did your child have any serious delay in sitting, standing, or walking?', (2) 'Compared with other children, does your child have difficulty seeing, either in the daytime or at night?', (3) 'Does your child appear to have difficulty hearing? [Uses hearing aid, hears with difficulty, completely deaf?]'), (4) 'When you tell your child to do something, does he/she seem to understand what you are saying?', (5) '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?', (6) 'Does your child sometimes have fits, become rigid, or lose consciousness?', (7) 'Does your child learn to do things like other children his/her age?', (8) 'Does your child speak at all [can he/she make him or herself understood in words; can say any recognisable words]?', (9) 'Can your child name at least one object [for example, an animal, a toy, a cup, a spoon]?', (10) 'Compared with other children of the same age, does your child in anyway appear having difficulties or being slow in understanding (here called Comprehension difficulties).

variables to the prediction of the dependent variables, LASSO regression analyses were conducted.

The LASSO models identified three variables predicting the frequency of attendance in activities, one predicting the level of engagement, and seven the level of independence. In all three models, the level of comprehension difficulties (item 10 in TSQI) was the strongest predictor. It was also the only predictor to be selected across the three models. Larger comprehension difficulties predicted lower levels of attendance, engagement, and independence in everyday activities. As for the other retained predictors, an absence of verbal communication (item 8 in the TQSI) and the presence of seizures (item 6 in the TQSI) predicted lower levels of frequency and independence, while younger age, the presence of pain, difficulties in sitting, standing, or walking (item 1 in the TQSI), and a failure to learn the same things as peers (item 7 in the TQSI) were related to lower levels of independence (Table 4). Figures 2–4 depict the predictors emerging at different λ, with a vertical line at the level identified as the optimum λ for the present analyses.

Discussion

Participation in meaningful activity enables the practice and learning of new skills, building of competence, and increased independence [6]. The present study sought to investigate which child traits and environmental factors can be of use in the prediction of participation (in terms of attendance and engagement) and independence in everyday activities in children with disabilities. The results demonstrate that the level of comprehension difficulties was the strongest predictor across outcomes. Based on the wording of the corresponding item (the 10th question of the TQSI questionnaire), which includes aspects of comprehension difficulties and slowness in comparison with children of the same age, this question was considered to incorporate critical cognitive aspects. This in turn may indicate the importance of assessing the level of difficulties in intellectual functioning. The level of comprehension difficulties (as rated by a parent) was not only the strongest predictor but also the only variable involved in predicting all three outcomes. According to the American Association of Intellectual and Developmental Disabilities (AAIDD) [28], intellectual functioning includes abilities such as planning, understanding complex ideas, problem-solving, and learning from experience. Such abilities affect a person's ability to be independent in daily activities. However, AAIDD stresses that not only intellectual and adaptive

Table 3. Correlations coefficients between the variables later used in the LASSO regressions.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
1 Child sex	1.00																					
2 Cohort	−0.12	1.00																				
3 Mother born in other country	−0.07	0.75**	1.00																			
4 Parent employment	−0.02	0.38**	−0.02	1.00																		
5 Parent highest education	−0.04	0.04	−0.09	0.20	1.00																	
6 Residence	0.02	0.06	0.04	0.40**	−0.03	1.00																
7 Frequency of attendance in activities	−0.01	−0.33**	−0.06	−0.13	0.06	0.06	1.00															
8 Level of engagement when attending	0.11	−0.22*	0.02	−0.14	0.01	0.04	0.91**	1.00														
9 Level of independence in activities	−0.07	−0.37**	−0.11	−0.13	0.16	0.10	0.89**	0.81**	1.00													
10 Pain, discomfort	−0.02	−0.12	−0.11	−0.02	−0.06	0.27*	0.27	0.23	0.27*	1.00												
11 Worried, sad, or unhappy	0.11	0.29**	0.19	0.04	0.02	0.16	0.00	0.08	−0.04	0.60**	1.00											
12 Serious delay sitting, standing, or walking[a]	−0.14	−0.05	0.19	0.22	0.08	0.28*	0.43**	0.33**	0.53**	0.15	−0.04	1.00										
13 Difficulties seeing[a]	−0.06	−0.07	0.15	−0.13	−0.14	0.03	0.18	0.12	0.14	0.11	0.19	0.46**	1.00									
14 Difficulties hearing[a]	0.38*	−0.23	0.01	−0.15	−0.09	−0.09	0.01	−0.02	−0.02	0.13	0.03	−0.08	0.27	1.00								
15 Does not understand what is said[a]	−0.22	0.03	0.21	0.32*	0.05	0.05	0.42**	0.39**	0.42**	0.12	0.16	0.11	0.21	−0.07	1.00							
16 Difficulty walking, moving arms[a]	−0.09	−0.09	−0.14	0.11	0.17	0.19	0.04	−0.05	0.16	0.47**	0.18	0.45**	0.21	−0.27	0.16	1.00						
17 Seizures, rigidity, or loses consciousness[a]	−0.06	−0.12	0.21	−0.23	−0.22	0.18	0.58**	0.51**	0.56**	0.34*	0.05	0.46**	0.25	−0.03	0.21	0.21	1.00					
18 Has not learned to do same things as peers[a]	−0.21	−0.09	0.03	−0.31*	−0.06	−0.22	0.50**	0.51**	0.56**	−0.14	−0.25*	0.42**	0.11	−0.03	0.53**	0.03	0.33*	1.00				
19 Does not speak at all[a]	−0.25	−0.39**	−0.04	−0.27	−0.05	0.08	0.63**	0.56**	0.68**	0.26	−0.04	0.14	−0.25	−0.05	0.65**	0.28	0.23	0.65**	1.00			
20 Does not mention one thing[a]	−0.18	−0.29	0.01	−0.34	−0.18	−0.03	0.23	0.19	0.31	0.24	−0.07	−0.04	−0.34	0.04	0.49**	0.20	0.44**	0.55**	0.88**	1.00		
21 Level of comprehension difficulties[a]	−0.06	−0.24*	0.08	−0.29*	0.12	0.05	0.68**	0.64**	0.79**	0.11	−0.09	0.49**	0.18	0.14	0.41**	0.10	0.50**	0.62**	0.62**	0.29	1.00	
22 GMFCS	0.09	0.15	0.09	−0.11	−0.06	−0.29*	−0.34**	−0.26**	−0.40**	−0.56**	−0.15	−0.72**	−0.40**	0.08	−0.14	−0.87**	−0.36**	−0.28*	−0.32*	−0.19	−0.30*	1.00

[a]Item included in the Ten Question Screening Instrument (in this table nb 12–21).

Note. The *p*-values for the correlations are based on Spearman correlations to make them comparable.

*$p < 0.05$.

**$p < 0.01$.

functioning needs to be considered when assessing intellectual disability, but that the community context, ability to communicate, behavioural factors etcetera also need to be considered. The AAIDD [28] describes that appropriate support, e.g. assistive technology and personal assistance, over a sustained period should be expected to improve the life functioning of a person with intellectual functioning.

Maciver et al. [29] identified that the frequency of participation is associated with the child's competence. FUNDES-Child-SE contains everyday activities of varying complexity that take place in different contexts such as home, school, and the municipality. A child's ability to perform daily activities such as following rules and routines, and their understanding of and ability to meet responsibilities is dependent on their level of cognitive functions and skills. When needed, this implies the importance of optimal, personalised cognitive support for children with disabilities in their everyday lives including the effort it takes to achieve this support.

The results suggest that child factors are associated with participation and independence. Surprisingly, no support for the need to include environmental factors in models predicting the level of frequency, engagement, or independence in everyday activities was found in the present study. In previous studies, socioeconomic factors, such as the caregivers' educational level, employment, and house residence, have been important determinants of participation, especially in active physical and skill-based activities in children with disabilities [1,30]. Children living in families with limited financial resources, in remote or rural communities, may not have the same opportunities to participate in a diversity of activities because of limitations to the supply of activities and problems with transportation. A possible explanation for the lack of significance of these environmental factors in this study may be that Sweden has a well-educated population (46% of people aged 25–64 have a post-secondary education) [31] and that the families in the sample were mainly living in urban areas. Further, Sweden is known to have good health insurance coverage. In October 2020, 75,800 people had at least one municipally enforced intervention according to the Act on Support and Services for certain disabled persons (LSS), with the opportunity for children with disabilities to receive grants for transport, devices, and assistants [32].

Overall, it is important to measure the frequency of attendance, engagement as well as independence as they represent distinct but correlated aspects of a child's relation to everyday activities. No single aspect controls participation outcomes and it is essential to consider the simultaneous contributions of interrelated factors [10,29]. Individual factors interact with environmental factors and there may be differential influences of individual versus environmental determinants on different facets of participation. Environment and individual factors should therefore always be considered together [10,29,33]. An additional aspect to consider and further study is that factors associated with participation and independence in everyday activities may also be strengthened through participation.

Limitations

In this study, caregiver reports were used as proxies for child reports. Direct report is advocated not least in participation research. Even though the caregivers were asked to answer the FUNDES-Child-SE through a common discussion with the child/youth when possible, it is assumed that this was not always the case. Despite this, we expect that caregivers possess a deep understanding of their children. The lack of data representing children with the ages 7–10 years could be considered as a design limitation. Ideally, they would have been included. However, like the children 5–6 years (51 participants included in this study), the children between 7 and 10 years are expected to still be dependent on parental support for participation and independence. Nevertheless, this dependence is likely to gradually decrease before they reach the age of 11–12 years (56 participants included in this study) meaning that the included age groups represent important stages of childhood. The number of participants is limited partly due to the high attrition rate. Possible reasons for this might be that the FUNDES-Child-SE was only one of several questionnaires included in the overall research project resulting in an extensive and thus time-consuming battery of questions. In addition, the Covid-19 effects on societies and family life in the upstart of the project. Another design limitation of FUNDES is the inclusion of the response option 'Not relevant/Not applicable' without a clear definition or distinction from other possible responses. The data transformation approach used in this study, where 'Not relevant/Not applicable' was merged with 'Never does', may have introduced some bias, though this decision was informed by patterns observed in the data. Administering FUNDES as an interview, rather than a self-report questionnaire, could also have reduced the attrition rate as well as allowing the interviewer to clarify the intended use of the instrument.

Even though the TSQI was originally developed for assessing children aged 2–9 [19], and the GMFCS specifically for children with cerebral palsy [21], both

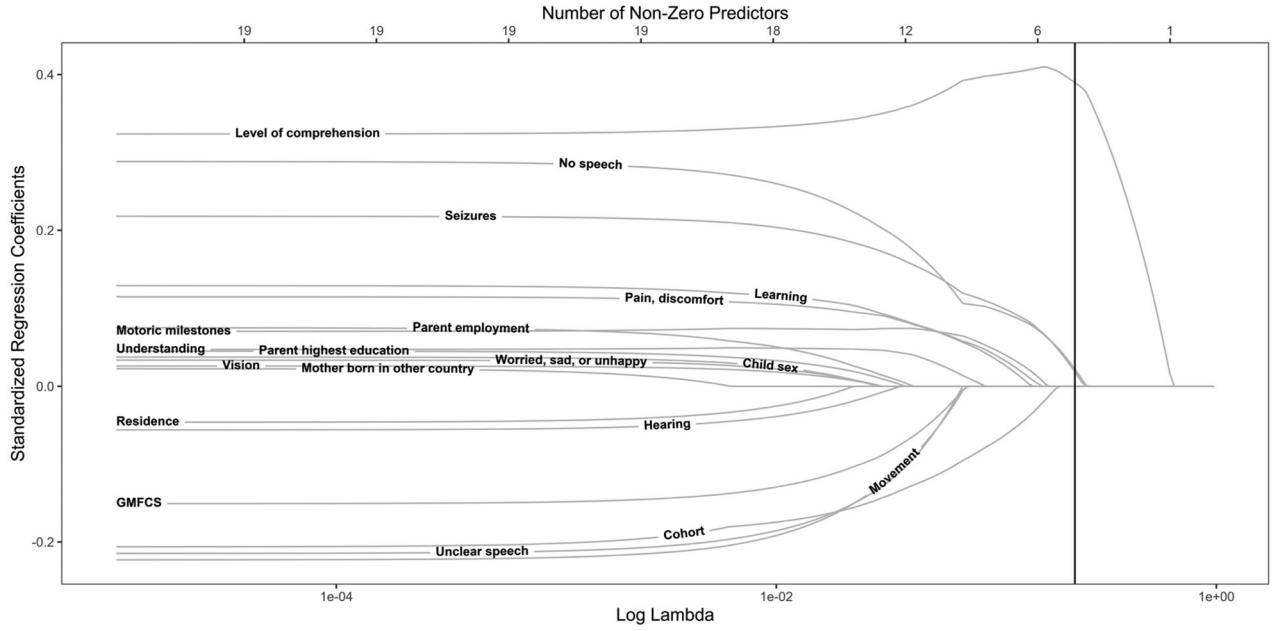

Figure 2. Visualisation of the number of coefficients at different levels of log(λ) for the frequency of attendance model. The figure illustrates the role of the tuning parameter, lambda (λ), in the LASSO regression. The parameter lambda mediates a trade-off between model complexity and the explanatory power of the model. As lambda increases, a greater number of model coefficients are constrained to zero, enhancing model parsimony and interpretability at the cost of reducing the variance explained for by the remaining predictors.

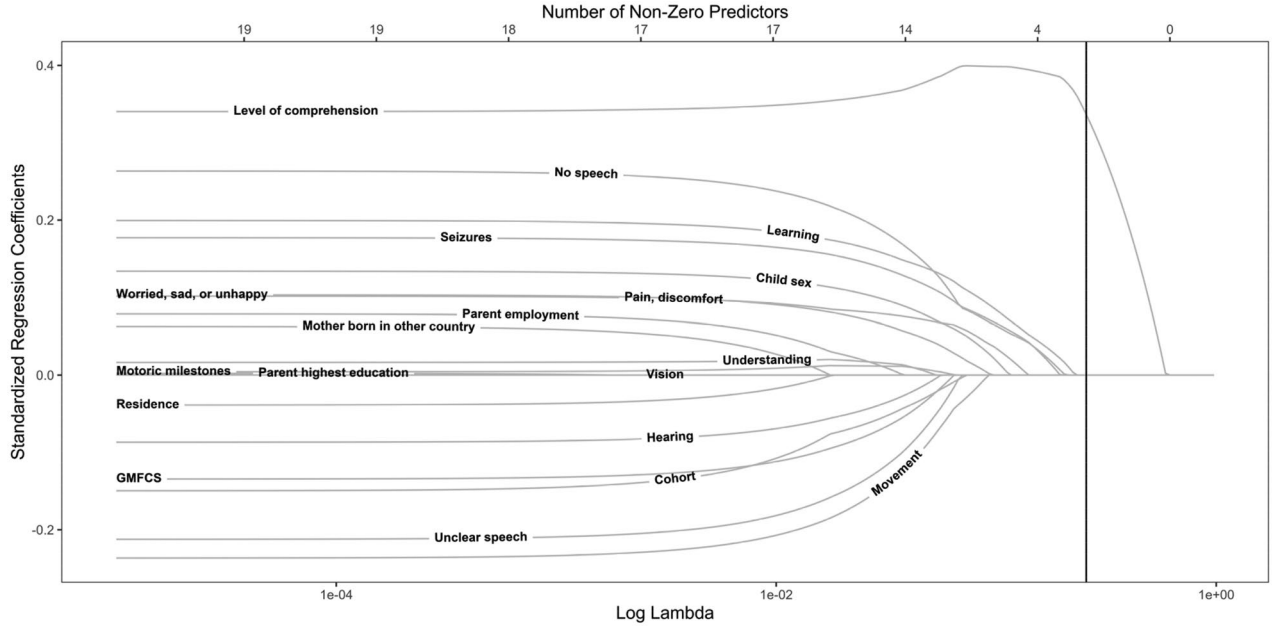

Figure 3. Visualisation of the number of coefficients at different levels of log(λ) for the total engagement model. The figure illustrates the role of the tuning parameter, lambda (λ), in the LASSO regression. The parameter lambda mediates a trade-off between model complexity and the explanatory power of the model. As lambda increases, a greater number of model coefficients are constrained to zero, enhancing model parsimony and interpretability at the cost of reducing the variance explained for by the remaining predictors.

instruments were considered valuable for obtaining overall information about the children's disabilities and were therefore included in the study. In addition, the TQSI included one question with a four-level ordinal scale, while the remaining nine questions only had yes-no options. To get a deeper understanding of the child's difficulties, it would have been beneficial to grade the response alternatives for the other questions

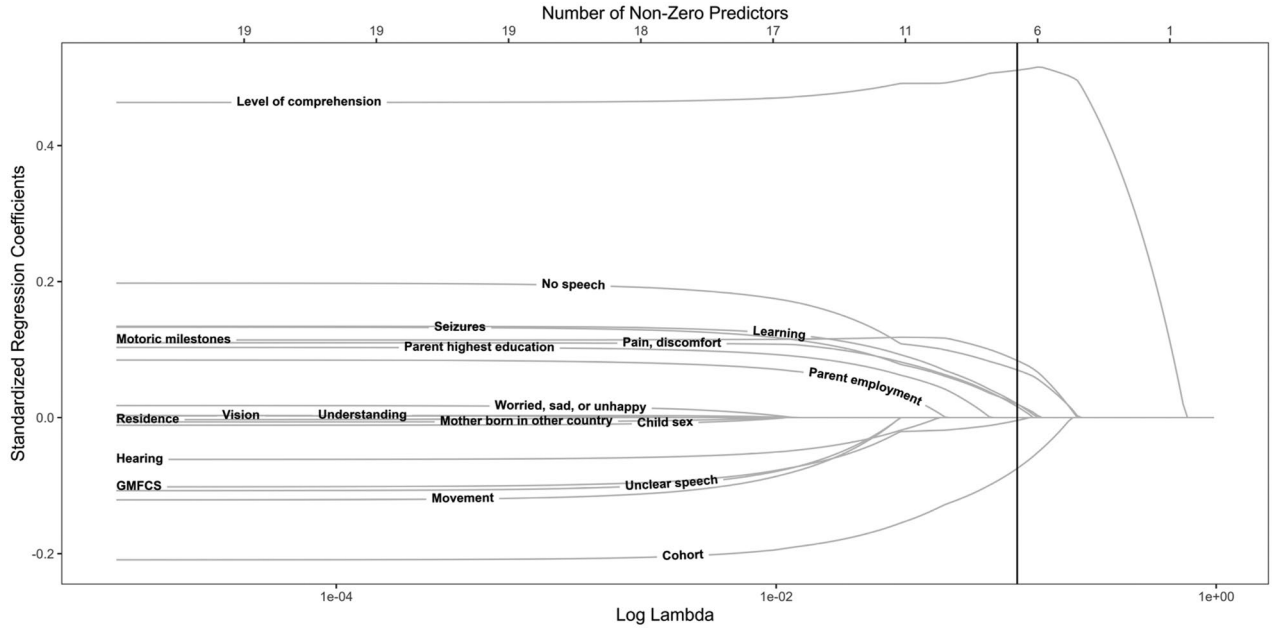

Figure 4. Visualisation of the number of coefficients at different levels of log(λ) for the total independence model. The figure illustrates the role of the tuning parameter, lambda (λ), in the LASSO regression. The parameter lambda mediates a trade-off between model complexity and the explanatory power of the model. As lambda increases, a greater number of model coefficients are constrained to zero, enhancing model parsimony and interpretability at the cost of reducing the variance explained for by the remaining predictors.

Table 4. LASSO models predicting frequency of attendance in activities, level of engagement, and level of independence.

	Frequency	Engagement	Independence
Cohort			−0.07
Pain/discomfort			0.02
Serious delay sitting, standing, or walking			0.08
Seizures, rigidity, or loses consciousness	0.02		0.02
Has learned to do same things as peers			0.02
Speaks at all	0.02		0.07
Level of comprehension difficulties	0.39	0.34	0.51

Note. The lambda one standard error above the level at which the mean-squared error of the model is minimised was used in the models.

as well. However, it is important to acknowledge that the TQSI provides only preliminary indications of impairments and cannot replace a comprehensive diagnostic or functional assessment.

In Sweden, not all children with disabilities are eligible for interventions from the habilitation services. Consequently, there may be some limitations to the variability of impairments in the study sample which could limit the generalisability of the results. However, the TSQI results showed that varying types and degrees of disabilities were represented in the sample.

Conclusion

The active participation of children and youths with disabilities in everyday activities is not just a matter of inclusivity but is pivotal for their development and integration into society. This study has illuminated the significant role of comprehension difficulties as a primary determinant of their level of participation and independence with a subsequent need for appropriate cognitive support. Alongside this, factors such as seizures, verbal communication challenges, age, pain, and motor functions further influence their engagement and independence in daily routines.

Consequently, the multifaceted nature of these challenges underscores the need for a diversity of interventions tailored for individual needs from a bio-psycho-social perspective where occupational therapists in cooperation with other rehabilitation personnel play an imperative role. A one-size-fits-all approach is insufficient. Instead, strategies must consider the intricate interaction between individual child attributes of different levels, and the settings in which the activities take place. By doing so, we can create supportive environments that not only recognise but also

address the unique challenges faced by these individuals over time.

Looking forward, it is imperative that both research and interventions remain adaptive, taking into account the evolving needs and challenges of children and youths with disabilities. Only through such a nuanced and integrated approach can we truly support their rights, potentials, and aspirations, ensuring they live fulfilling lives and, based on their abilities, actively contribute to society.

Disclosure statement

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

Funding

This work was supported by the Swedish Research Council [grant number 2018-05824], and Futurum - the Academy for Healthcare, Region Jönköping County [grant number FUTURUM-989510].

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Data availability statement

A reproducible version of this manuscript, including the code, can be found at osf.io/3rh2f/. The data for this study cannot be publicly shared but a synthetic dataset with similar properties as the original dataset has been created and is also available at the above link.

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