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A Swedish cultural adaptation of the participation questionnaire Functional Scale of the Disability Evaluation System – Child version

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ABSTRACT

Purpose: The aim was to culturally validate a questionnaire about children’s/youth’s participation to be used in a Swedish context.

Methods: FUNDES-Child, based on the well-established CASP, was chosen. Questions about engagement and hindering factors were added to the existing questions about frequency and independence in 20 activity areas. Using a qualitative, explorative design, 16 interviews with children/youths/caregivers were made to explore opinions about the questionnaire. Follow-up interviews confirmed the result of the revised questionnaire. Qualitative content analysis was performed.

Results: The interviews provided support for the questionnaire’s relevance by being a tool to assess important aspects of participation, to gain insights into one’s own/the child’s participation, and to promote ideas about what causes the degree of participation. To achieve comprehensiveness, no activity area was found to be missing nor superfluous. However, some examples were needed to be modified where “parades” are unusual in Sweden and therefore removed, while “singing in choir” was added. In search for comprehensibility, opinions about the layout of the first version were raised and a varying degree of understanding of wording and concepts were found and thus taken into account.

Conclusions: The questionnaire can be used for establishing meaningful goals and to potentially increase children’s participation.

IMPLICATIONS FOR REHABILITATION

- Participation is of great importance for children’s functioning, well-being, and development.
- Cultural validation of well-established participation questionnaires is a priority and questions about important aspects of participation need to be included.
- Interviews with children/youth and caregivers guided revisions to reach relevance, comprehensiveness, and comprehensibility of the Swedish FUNDES-Child (FUNDES II-SE).
- Children/youths, caregivers, and others may increase their awareness concerning the child’s/youth’s participation by responding to the questionnaire.

Introduction

On 1 January 2020, the United Nation’s Convention of the Rights of the Child (UNCRC) [1] became law in Sweden. In the UNCRC, all children’s rights are stressed – also rights for children with disabilities – and in the 23rd article it is stated: “a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community”.

When children get opportunities to participate in everyday activities, they get experiences that are of great importance for their functioning, wellbeing and development [2]. However, children with disabilities have shown to meet restrictions in their participation and participate less often compared to the children without disabilities [3–6]. A Taiwanese cross-sectional study including 18,000 children with and without disabilities aged between 6 and 18 years has shown that the children with disabilities participated less often than they had the ability to do and that the difference tended to increase by age and was greatest in children with mild or moderate levels of disabilities [7].

The reason for reduced participation can be a combination of factors in the individual and in the environment [8]. Problems with learning, communication, and moving and experiencing pain are examples of individual factors that make it difficult for children to participate. Environmental factors that are important for children to be involved in are, among other things, accessibility, range of activities, tools, attitudes in the environment and assistance [9,10].

According to regulations of the Swedish National Board of Health and Welfare [11], habilitation efforts will help a person with disability to create good conditions for an independent life and active participation in community life. These efforts should be done based on the person’s needs and conditions. By this approach an extended bio-psychosocial perspective is applied in the habilitation efforts [12] and this means that one of the main,
comprehensive treatment goals in Child and Youth Habilitation services are to promote participation of children and adolescents in different life situations. At the same time, there is no evidence of which interventions are most effective in promoting children’s participation [13]. One explanation for the knowledge gap may be the lack of internationally used valid and reliable evaluation tools that measures all aspects of participation. Especially, the subjective aspect of participation (i.e. involvement) is missing, interpreted as the experience of participation while attending such as engagement and motivation [14].

The international and well-established participation questionnaire called Child and Adolescent Scale of Participation (CASP) measures the participation of children and adolescents in a total of 20 activity areas (items) in the four subsections Home, Neighborhood and community, School and Home and community living activities [15]. The CASP has frequently been used [16] and is based on the World Health Organization’s International Classification of Functioning, Disabilities and Health (ICF) [17]. The CASP was developed primarily in the USA, originally to be used as a tool in the follow-up of children and adolescents with acquired brain injuries [18,19]. Questions are asked about the child’s level of participation with four response alternatives between “Age expected” and “Unable”. The caregivers in their responses are expected to compare their child with children/adolescents with typical development. The questionnaire has been shown to measure a unidimensional construct, with high internal consistency and evidence of test–retest reliability.

The CASP is internationally used and translated into French [20], German [21], and Chinese [22] among others.

In Taiwan, the Chinese version (CASP-C) [22] has partially been modified to become part II of a research battery of various questionnaires called the Functioning Scale of the Disability Evaluation System-Child version (FUNDES-Child) [23]. In the FUNDES-Child questions about frequency of participation have been added with answering alternatives between “The same or more than age expected” and “Never”. Questions have also been added about the level of independence with the answering alternatives between “Independently” and “Complete assistance” while using the same activity areas as in the CASP. FUNDES-Child has provided evidence of acceptable psychometric properties [22] and content validity and design validity of FUNDES-Child have been tested in relation to ICF-CY with acceptable results [23]. Also, a recent investigation of the construct validity of the frequency and independence dimensions of the FUNDES-Child showed acceptable structural validity [24].

In Sweden, until today there is no easily accessible, culturally validated instrument to measure participation in different settings among children with disabilities in school age, which in turn can guide to appropriate, assessable interventions for improved participation. As the FUNDES-child has shown evidence of psychometric properties, frequently been used and measures participation it is of interest to validate the FUNDES-child for Swedish conditions. To guarantee appropriate conclusions about the measurement properties, high methodological quality is needed, which includes a translation process. Beaton et al. [25] have developed guidelines for the process of cross-cultural adaptation of self-report measures. They emphasize that measures must be translated well linguistically, and also to be culturally adapted in order to maintain content validity at a conceptual level. Moreover, the COSMIN (COnsensus-based Standards for the selection of health status Measurement INstruments) checklist has been developed to evaluate the measurement properties of health-related patient-reported outcomes and includes general standards with a description of the included construct as a part [26]. Over the years the understanding of the construct of participation has improved and includes the dimensions of frequency and involvement. Recent research highlights the importance of having a process-oriented perspective on participation both in research and in clinical practice [27,28] where participation can be influenced by personal and environmental factors that act as either barriers or facilitators [27,29]. Consequently, it is important to include these factors in participation measurements as well as to deepen the knowledge in the area.

Aim

The aim was to culturally validate and modify the participation questionnaire FUNDES-Child for the Swedish context.

Materials and methods

A cultural validity study guided by Beaton et al. [25] and the COSMIN [26] was performed. The study included a translation process as well as cognitive interviews [30] with a focus on understanding how children/youths and caregivers perceived the relevance, comprehensiveness, and comprehensibility of the questionnaire. Further, a modification of the questionnaire was done by adding questions about engagement as well as about barriers for participation as these aspects were not previously included. An improved understanding of the participation construct and influencing factors highlighted the need to add these essential aspects. This study was carried out as a part of a research project about participation in children with disabilities, aged between 6 and 18 years, in Sweden. The project was approved by the Region Ethical Review Board in Linköping, reference no. 2017/496-31. To culturally adapt and modify the intended instrument for use in a Swedish context, approval was also granted by the developer of CASP (professor Bedell, MA, USA) and of FUNDES-Child (associate professor Hwang, Taiwan), respectively.

Participants

In focus were 13 children between 7 and 17 years, seven girls and six boys (Table 1). The children had different diagnoses including motor-, intellectual-, and neuropsychiatric disabilities, sometimes in a combination. To get extensive viewpoints about the questionnaire, younger children, older children, and caregivers were interviewed using a strategical selection of participants.

Procedure

Initially, the questionnaire FUNDES-Child was chosen based on the instrument’s psychometric properties and the frequent use of the instrument in the literature [16] which enables international comparisons of participatory patterns. The process of developing a Swedish version of the participation questionnaire followed 10 steps (Table 2).

Based on current research about the construct of participation including the two dimensions of frequency and involvement, the research group by consensus decided to add the questions about the child’s level of engagement to each of the 20 items in the questionnaire. Also, open-ended questions about hindering factors for each of the 20 items were added, partly for future clinical use. The questions about engagement could be answered on a Likert scale in the same way as the questions about frequency and independence. Written responses, using the participants’ own


In total, 16 cognitive interviews [30] were made, nine with the child’s caregiver. In one of these cases, both caregivers for a child were interviewed together, in one case two different caregivers for two, not related children were interviewed on the same occasion (Table 1). When younger children were interviewed, the caregivers were allowed to briefly add comments afterwards for clarification and for adding information that was lacking (these added comments were not counted as separate interviews). Of the 16 cognitive interviews, the final five interviews were made to follow up the result of the 11 first ones. This will be described further below.

All interviews were semi-structured with open-ended questions and conducted by the first and the last authors of this article. The informants had received the questionnaire beforehand to familiarize themselves with the questionnaire in preparation for the interview. The first eleven interviews (phases A and B) were conducted face to face and lasted for 21–65 min. Based on COSMIN [26], the content of the interview questions focused on:

- The relevance of the questions/content;
- The comprehensiveness of the questionnaires including the items;
- The comprehensibility of the questions including the concepts.

In the interviews, the structure of the questionnaire was followed, and follow-up questions were asked to get a deeper understanding of the opinions of the questionnaire. After the first three interviews (phase A), it was apparent that the existing version was perceived extensive and time-consuming. This resulted in a change of the layout before progressing, which made 16 pages into four by making each dimension of the questionnaire into a matrix. No changes in the number nor content of questions were made at this stage. These three interviews (phase A) had the same intention as the following eight interviews (phase B) and they equally became the base for the analysis of what other revisions were needed to be done for the cultural validation. All interviews were recorded and then transcribed verbatim. The final five interviews (phase C) were made after the revision of the questionnaire and were made either face to face or on the phone while notes were taken and lasted for approximately 15–20 min. These five interviews were made with three of the older children and caregivers already having been interviewed as well as with one older child and one caregiver who had not seen the earlier versions of the questionnaire. The final interviews intended to confirm whether the revisions made were sufficient to give a culturally validated participation instrument for the Swedish context.

Table 1. Participant characteristics and interviewed persons.

<table>
<thead>
<tr>
<th>Age (y.o.)</th>
<th>Gender</th>
<th>Main diagnosis</th>
<th>Interviewed</th>
<th>Interview phase a</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Girl</td>
<td>CP b (independent walker)</td>
<td>Caregiver h</td>
<td>B</td>
</tr>
<tr>
<td>9</td>
<td>Girl</td>
<td>ASD d, ID d</td>
<td>Caregiver h</td>
<td>A</td>
</tr>
<tr>
<td>9</td>
<td>Girl</td>
<td>Other disability, ID d, ADHD e</td>
<td>Caregiver h,k</td>
<td>A</td>
</tr>
<tr>
<td>9</td>
<td>Boy</td>
<td>EP d, CP b</td>
<td>Boy i</td>
<td>B</td>
</tr>
<tr>
<td>11</td>
<td>Boy</td>
<td>ADHD d, ASD d, ID d</td>
<td>Boy i</td>
<td>C</td>
</tr>
<tr>
<td>12</td>
<td>Boy</td>
<td>Other disability, ID</td>
<td>Boy i</td>
<td>B</td>
</tr>
<tr>
<td>14</td>
<td>Boy</td>
<td>CP b, HFASD g</td>
<td>Boy c</td>
<td>B</td>
</tr>
<tr>
<td>15</td>
<td>Boy</td>
<td>Movement disorder (wheelchair), HFASD g</td>
<td>Boy c</td>
<td>C</td>
</tr>
<tr>
<td>15</td>
<td>Boy</td>
<td>ASD d, ID d, ADHD e</td>
<td>Boy c</td>
<td>A + C</td>
</tr>
<tr>
<td>16</td>
<td>Girl</td>
<td>CP b (independent walker), ID d</td>
<td>Girl a</td>
<td>A</td>
</tr>
<tr>
<td>16</td>
<td>Girl</td>
<td>Movement disorder (wheelchair)</td>
<td>Girl b</td>
<td>B + C</td>
</tr>
<tr>
<td>17</td>
<td>Girl</td>
<td>Other disability</td>
<td>Girl b</td>
<td>B</td>
</tr>
<tr>
<td>17</td>
<td>Girl</td>
<td>ADHD d, ID d</td>
<td>Girl b</td>
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<td>17</td>
<td>Girl</td>
<td>Other disability</td>
<td>Girl b</td>
<td>B</td>
</tr>
<tr>
<td>17</td>
<td>Girl</td>
<td>ADHD d, ID d</td>
<td>Girl b</td>
<td>B</td>
</tr>
</tbody>
</table>

* a: before layout revision; b: after layout revision; c: follow up interviews.
* d: cerebral palsy.
* e: autism spectrum disorder.
* f: intellectual disability.
* g: attention deficit hyperactivity disorder.
* h: epilepsy.
* i: high functioning spectrum disorder.
* j: mother.
* k: father.
* l: short supplementary interview with caregiver, mother, afterwards.
* m: same interview occasion.

Table 2. The process of developing the Swedish Version of a Participation Questionnaire.

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The choice of an adequate questionnaire (FUNDES-Child)</td>
</tr>
<tr>
<td>2</td>
<td>Professional forward and back translation (English-Swedish-English)</td>
</tr>
<tr>
<td>3</td>
<td>Modifying the questionnaire by adding of questions about engagement and hindering factors</td>
</tr>
<tr>
<td>4</td>
<td>Three face to face interviews (interview phase A)</td>
</tr>
<tr>
<td>5</td>
<td>Layout adjustments</td>
</tr>
<tr>
<td>6</td>
<td>Further eight individual face to face interviews (interview phase B)</td>
</tr>
<tr>
<td>7</td>
<td>Qualitative analysis of the eleven cognitive interviews (phases A and B)</td>
</tr>
<tr>
<td>8</td>
<td>Adjustments of the FUNDES-child</td>
</tr>
<tr>
<td>9</td>
<td>Five follow up/confirming individual phone cognitive interviews (interview phase C)</td>
</tr>
<tr>
<td>10</td>
<td>Professional forward and back translation (Swedish-English-Swedish) of the final version</td>
</tr>
</tbody>
</table>

Throughout the entire process discussions were held in the research group until consensus was reached.

words were collected about the factors that hindered participation. A forward translation from English to Swedish of the 20 items including the examples from the CASP, and the rating alternatives from the FUNDES-Child, was made followed by a back translation. The group of translators included one professional translator with English as mother tongue, one bilingual translator and one with Swedish as mother tongue. This part of the translation process was followed by the three researchers (AKA, AU, PO) having discussions about the translated Swedish version. Based on the researchers’ experiences of the Swedish cultural context, the concepts of the measurement as well as being comfortable with the English language, a few questions were raised and thereafter resolved together with the translators. The emphasis was to preserve the meaning of the original with the target version.

Interviews

In total, 16 cognitive interviews [30] were made, nine with the child him-/herself, seven with the child’s caregiver. In one of these cases, both caregivers for a child were interviewed together, in one case two different caregivers for two, not related children were interviewed on the same occasion (Table 1). When younger
Table 3. Example of analysis.

<table>
<thead>
<tr>
<th>Predefined category</th>
<th>Chosen passage</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relevance</td>
<td>Maybe, like, that you get a conversation going with the parents, maybe about that I’d like to do this</td>
<td>Assess important aspects of participation</td>
</tr>
<tr>
<td>Comprehensiveness</td>
<td>That would like be parades, don’t have, like perhaps, very many of those in Sweden.</td>
<td>Superfluous activity areas or examples of activities</td>
</tr>
<tr>
<td>Comprehensibility</td>
<td>For him, it’s probably/I’d say it is to be part of, like when dad […] is working outside on something</td>
<td>Varying degree of understanding of wording and concepts</td>
</tr>
</tbody>
</table>

Analysis

A qualitative directed content analysis [31] was used to analyze the transcribed interviews. To start with, each of the 11 interviews (in phases A and B) was thoroughly read through by each of the three authors to get an overall picture of all interviews. Thereafter opinions about the questionnaire’s relevance, comprehensiveness and comprehensibility were systematically searched for. After having merged the information, subcategories were defined and discussed by the authors. The notes from the five follow up interviews were analyzed in the same way as the previously conducted interviews.

Finally, a translation of the changes based on the interviews was made by the same group as the initial translation (Table 3).

Results

The following results are based on the interviews using the first Swedish version of the questionnaire. All interviews gave valuable information and were included in the analyses. In total seven subcategories emerged, here structured according to the concepts relevance, comprehensiveness, and comprehensibility. Finally, the completed revisions of the questionnaire, based on the interviews, are presented. For this article, only the citations from the Swedish transcriptions have been translated.

Relevance

The relevance here refers to opinions about the importance of the questionnaire representing different aspect of participation in everyday activities. This category is illustrated by opinions about the questionnaire’s contribution by being a tool to:
- Assess important aspects of participation;
- Gain insights into one’s own/the child’s participation;
- Promote ideas about what causes the degree of participation.

Assess important aspects of participation

It was found to be highly relevant to be asked about different aspects of participation as well as to be asked questions representing different contexts of environments.

…so this, you get like a whole picture, if you’ve asked. (Interview 8. Girl, 17 y.o._a)
It’s like all connected and that it’s, these kids/children have, that it’s different for every child. (Interview 3. Caregiver)

Get insights into one’s own/the child’s participation

Insights upon one’s own/the child’s participation evoked as expressed by one youth.

…For example, at the P.E. at school, you have to adapt certain things for me to be able to participate, but then I’m still involved in joint activities and that’s kind of, it’s to be involved. (Interview 6. Girl, 16 y.o._b)

And comparison of frequency of participation with typically developing children was not experienced to be something weird but confirmed to be a natural way of thinking.

No, but I think it feels good in that way. (Interview 11. Caregiver)

Also, opinions about the possibility of following the child’s level of participation over time and/or to sometimes be able to compare with others were raised. In addition, open ended questions in the questionnaire were considered to be important in order to identify barriers and to be able to find strategies for solutions.

…what limits their independence […] is a bit the very heart in it all. (Interview 3. Caregiver)

Promote ideas about what causes the degree of participation

Reflections about what causes the level of participation were found to be promoted. This concerned both personal and environmental factors such as the child’s ability, interest in, mood, and earlier experiences of the activity, as well as the importance of having friends that draw, personal assistance, economic factors, and that technical aids being available when needed.

If she’s in the right mood, then she likes being good and then of course it’s fun, but generally, it’s like pretty, it’s more like a matter of the will. (Interview 4. Caregiver)

For some of the children, the area of relevance was too difficult to discuss. However, these children seemed to be highly attentive and engaged when asking about their activities and participation. This contributed to a found relevance of the questionnaire, i.e. of discussing participation in the included activities.

Comprehensiveness

The questionnaire included 20 everyday activity areas, each one exemplified by different activities which all together constituted what we define as the comprehensiveness of the questionnaire. This naturally developed in the subcategories:
- Missing activity areas or examples of activities;
- Superfluous activity areas or examples of activities.

Missing activity areas or examples of activities

No activity area was expressed to be missing. However, some common activities among children and youths were found to be lacking. The absence of these activities was mostly presented by the children/youths in the discussions about what kind of activities they were partaking in.

…I really try to learn my part in the choir […] and you really need to be on your toes and really, that you’ve got it down pat. (Interview 7. Boy, 14 y.o.)
Yes, I suppose it’s that I go to the scouts, but that is an organized activity. (Interview 6. Girl, 16 y.o._b)
With two of the children this area mainly became a general discussion about what they themselves were doing during the days and weeks.

... to go to M (name of short-term care) ... to eat candy ... to play ... But aren't you also out, like, in the woods, too, and grill hotdogs? ... Yes. (Interview 10, Boy, 12 y.o. with some help of his mother)

... I even got to go down the black slopes. (Interview 9, Boy, 9 y.o.)

Superfluous activity areas or examples of activities
Likewise, no activity area was expressed to be superfluous. However, two of the included examples of activities in the original questionnaire, clubs, and parades, were found not to be adequate examples of the activity area. In Sweden, clubs are not a term used for structured events or activities or for a kind of school activity. An uncertainty about parades was also expressed.

Who walks in parades? (asked by the interviewer) ... Don't know, maybe old people?? (Interview 5, Girl 16 y.o._a)

Comprehensibility
In this research, the comprehensibility represented opinions about how easy it was to understand and answer the questionnaire including the instructions. The opinions gave valuable information to avoid misinterpretations and less reliable answers. The opinions emerged in the following subcategories which in turn were needed to be taken into account in the revision of the questionnaire:

- Inaccessible layout (of the very first version);
- Varying degree of understanding of wording and concepts.

Inaccessible layout (of the very first version)
In the first three interviews (phase A), opinions were raised about the layout of the questionnaire which was perceived to be too long and time consuming to ascertain valid answers. The negative influence of getting tired resulting in inattention was raised.

... suppose I (you) should keep this shorter, because at the end it gets to be, ok, I've already answered this [...] you, like, mix it all up a bit and so I think that the quality goes down towards the end here, if I should be a bit self-critical. (Interview 3. Caregiver, father)

The clarity and length of the second version of the questionnaire was then well received.

... four sheets of papers are only four sheets of papers. Other was a whole stack and it was like, ok, where do we begin? You know, like that. Here's only two sheets, so this is much, much better. Better being compressed, because it's still only going to be two. (Interview 4, caregiver to girl in interview 1)

There were also opinions about the scales such as difficulties to choose response-alternatives and wanting to have grades between two possible levels of participation. Another opinion was that the direction of the scale where the lowest number (0), represented high level whereas 3 represented low level of participation was confusing, and that "Not applicable" was numbered 9.

... she actually ends up between 0 and 1 on everything, depending on what it is. (Interview 4. Caregiver, father)

Varying degree of understanding of wording and concepts
Different opinions were raised about the comprehensibility of the wording and concepts that were used in the questionnaire. For most children/youths being interviewed, it was necessary to describe and exemplify words and content.

I've actually never heard it before, the concept participation. (Interview 1. Girl, 16 y.o._a)

... level of independence I understood, like. Level of engagement I also understood a bit, but frequency, that's what I didn't understand. (Interview 5. Girl, 17 y.o._b)

While, in this case, the concept of participation did not cause any problems for the same 17 y.o. girl.

Being part of what you're in. That you really get involved and not that you're just there, like. (Interview 5. Girl, 17 y.o._b)

Sometimes an uncertainty resulted in a need for confirmation of one's own interpretation of certain concepts.

I wonder a bit about engagement, like how you are engaged, is that like the motivation you've got, then? (Interview 6. Girl, 16 y.o._b)

The comprehensibility of the questionnaire was interpreted to be difficult for children and youth but otherwise not difficult.

... and the questions are not so hard, but, of course, there are words that are difficult for a child or a young person to understand. (Interview 11. Caregiver)

Completed revisions based on the interviews
The interviews confirmed the relevance of the questionnaire. No included activity area was needed to be removed or added. However, based on the information from the interviews, some modifications of the examples connected to the activity areas have been done where e.g. "parades" and "clubs" (not common in Sweden) have been removed while "choir", "scouting", and "short-term care" have been added as examples. Outdoor winter activities, common in Sweden, were considered to be included in existing activity areas, and thus no changes were needed. As a help to guide in decision-making when choosing between two alternatives, the instruction about this in the introduction is now highlighted. The numbering of the response alternatives has been kept in order to stay as close to the original version as possible. In addition, a simplification and "modernization" of the language in the questionnaire has been done, where e.g. "Home participation" has been replaced with "To participate at home", "Not applicable" with "Not relevant/Not applicable", "Frequency" with "How often" and "Educational (academic) activities with other children in his or her classroom at school" with "Instructional activities together with classmates", exemplified by Swedish, math, geography, sports. These revisions were finally tested in the five follow-up interviews (phase C) confirming that no more adjustments were needed.

Discussion
The questionnaire FUNDES-Child was chosen to be validated for the Swedish context. The current understanding of the construct of participation suggested to include the more subjective aspect of engagement. Also, an open follow-up question about hindering factors was added before the interviews. All interviews gave valuable information for the development of a culturally validated participation questionnaire for the Swedish context, and thus included. The results support that the questionnaire has good relevance by being a tool to assess important aspects of participation, gain insights into one's own/the child's participation and to promote ideas about what causes the degree of participation. Questions about the comprehensiveness revealed that no activity...
area was found to be missing nor superfluous, while some examples were needed to be removed and some added due to what activities are common among children and youth in Sweden. Also, some aspects of comprehensibility were of importance where opinions about the accessibility of the layout (first version), as well as various levels of concept and wording apprehension were found.

Discussion of results

The English version of the CASP [15] as well as the related Chinese version in FUNDES-Child [23] are widely used and have thoroughly been tested for validity and reliability by their developers. This gave support to the choice of participation questionnaire. To get a solid foundation for the Swedish process of cultural validation, the main focus of the guidelines by Beaton et al. [25] as well as the COSMIN [26] was considered.

Relevance of the questionnaire was found including a desire to discuss the children’s participation in different activities. This could possibly be related to the willingness to participate in the study. One parent expressed, that the issue of participation might differ between parents and the child him/herself which is in agreement with what has been found by Vroiland-Nordstrand and Krumlinde-Sundholm [32]. At the same time, it was found that this questionnaire can stimulate the child/youth to initiate conversations about participation (and probably also the other way around). Consequently, it is important to obtain both perspectives of participation. As also found, there is a great benefit to discuss participation from different angles to achieve a wholeness of the meaning of the construct. The adding of questions about hindering factors were found to promote ideas about what causes the level of participation which in turn can be associated with which interventions that need to be in focus in order to achieve increased level of participation. In children and youth with disabilities, the literature has identified personal and environmental factors, especially barriers relating to services in the community as a major determinant of participation [8,33,34]. On a higher level, the relevance of a questionnaire about child participation is supported by the inclusion of the aspect in the Convention of the Rights of the Child [1]. Consequently, by now being a law in Sweden, there is a necessity to study participation of children with disability in Sweden.

The comprehensiveness of a questionnaire might differ, partly depending on in which culture it is used. However, no activity areas in the questionnaire were found to be lacking, nor unnecessary. The discussions in the interviews instead ended up being more about the given examples in the different activity areas, which in a concrete way may better have represented the children’s/youth’s everyday life. The frequent occurring online communication among young people were often mentioned in the interviews and already included in the questionnaire. Except by mirroring a culture [35], participation in activities is also dependent on weather/climate, time of year.

Another important aspect is represented by the comprehensibility of the questionnaire. These subcategories revealed an inaccessible layout of the very first version. There was an outspoken risk that no answers were given or that the answers were not reliable. Thus, the layout of the questionnaire was immediately revised. The varying degree of understanding of words and concepts gave focus on the need for a modernization of the language to ease the answering. Concepts of participation and engagement/involvement naturally proved to be more difficult to conceptualize even though often used in everyday language in Sweden and thus expected to be understood in an overall way. On one hand the questionnaire itself might widen the understanding of the concept according to the benefit of being forced to think about participation. On the other hand, it raised questions about the appropriate age and cognitive level for being able to answer the questionnaire independently. It has resulted in the recommendations that the questionnaire should be used for proxy-rating, when possible in common discussion with the child. The original versions (CASP and FUNDES-Child) are used only for proxy rating and as described in the manual of CASP [15], additional demographic information is needed to be gathered. This will be done when using the Swedish version.

Discussion of method

To achieve a valid translation processes, one professional translator with English as mother tongue, one bilingual translator, one with Swedish a mother tongue and three professionals of the field thereto comfortable with the English language, were included. The following steps consisted of qualitative research which needs to show trustworthiness. As described by Graneheim and Lundman [36], trustworthiness includes to ensure credibility, dependability, and transferability. In this research, credibility was reached through interviewing children and youths of different ages and genders with different types of disabilities and caregivers (both mothers and fathers) of children with different types of disabilities. This was made to obtain a variety of aspects important for the validity process. Initially, the intention was to have focus group interviews with groups of younger children, older children, and caregivers, respectively. However, due to recruitment difficulties including problems to gather participants at one and the same time, it was decided to conduct individual interviews. Though, with the facts in hand, the research group realized that children not knowing each other might become shy and that they might have been more outspoken in the individual interview than they would have been in a focus group. Yet, the selection of participants, the commonly developed interview guide, individual analyses followed by discussions in the research group throughout the analysis process in order to seek needed agreements about the data as well as using the concepts recommended by COSMIN [26], were also parts of the pursuit of credibility. In addition, the five follow up interviews were performed to confirm the result among potential participants users of the questionnaire. To reach dependability, consistency and stability were sought through making the interviews during a relatively short period of time, in this case half a year, and by the use of the same interview guide in all these interviews. It also included the researchers’ pursuit of stability in decisions throughout the analysis process. Generally, there is a limited transferability in qualitative research were seldom a very high number and various types of participants can be included. This research was limited to children and youths with disabilities in Sweden, which needs to be recognized. Still, it has to be emphasized that the given examples of activities in the activity areas are just examples.

Limitations

Even though a high quality of the translation and cultural validation process has been sought, there are limitations of this study. Further participants could have been included, yet some kind of saturation was found in the analyses. Also, based on recent research, questions about additional aspects of participation could
have been included. Moreover, the questionnaire could also have been tested among personnel at habilitations centers, schools, and other places where the questionnaire is expected to be used. Psychometric testing will be done in a forthcoming study.

Conclusions

Participation in everyday activities is important for children’s functioning, well-being, and development. An extended need for a Swedish validated instrument measuring participation in children has arisen since the Convention of the Rights of the Child become a law in Sweden. This culturally validated version of the FUNDES-Child comprises opinions about the importance of assessing and gain insights to participation as well as how to promote participation. By adding questions about engagement, the Swedish version adds another important dimension of participation. Likewise, the added questions about obstacles or barriers to participation were found to be valuable to discuss for the participants. Cultural differences in children’s/youths’ activities were then also needed to be taken into account, where, e.g. singing in choir and scouting are quite common activities in Sweden, while clubs and parades are not common, even though the activity areas presented in the questionnaire could stay the same. With clear and easily accessed layout, wording and concepts also taken into account, relevance, comprehensibility and comprehensiveness of the questionnaire is considered to have been achieved. Even though recommended for proxy-rating the questionnaire could in common discussions with children and youths be used for establishing meaningful goals and to potentially increase children’s participation. It could then also to be used for international comparisons. However, the questionnaire’s psychometric properties and sensitivity for change due to e.g. interventions for improved participation still needs to be tested. In Sweden, the questionnaire will be called FUNDES-II–SE meaning a Swedish, extended version of the FUNDES-Child, part II.

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