



BMJ Open What does social participation mean? A qualitative study exploring the concept of participation from the perspectives of experts and parents

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ABSTRACT

Objectives This study aimed to assess the theoretical framework regarding social participation from the perspectives of experts and parents of youth aged between 10 and 17 years, and therefore, provides new insights into the concept of social participation.

Design A qualitative study was conducted to understand the construct of social participation in more detail. Eight focus groups were held with experts (n=21) and parents (n=24) and analysed based on content analysis.

Participants We used purposive and snowball sampling to obtain a comprehensive sample of (A) parents of adolescents with and without chronic and/or physical-motor impairments and (B) experts involved in participatory research and/or treatment of adolescents with chronic and/or physical-motor impairments. The final sample consisted of 3 focus groups with a total of 21 experts and 5 focus groups with 24 parents. This included 10 parents who had disabled children.

Results The concept of social participation consists of subjective and objective components. The focus from the experts' perspective is clearly on the subjective level; that is, revolving around the question 'Does the adolescent feel involved?' In contrast, the parents' focus is more on normative expectations. The possibility of participation in all areas of life through the adjustment of environmental factors was identified as a central factor.

Conclusions The results underline the importance of the subjective feelings of adolescents, as well as the significance of normative requirements. To capture the subjective component of participation, suitable measurements are needed.

Trial registration number DRKS00014739.

INTRODUCTION

Following the International Classification of Functioning and Disability (ICF), social participation is defined as 'involvement in a life situation'.¹ Activity, on the other hand, is understood as 'the execution of a task or action by an individual'.¹⁻⁴ Although both concepts, participation and activity, are distinguished from each other in the ICF, they are nevertheless combined in one component:

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study is one of the first that analyses the theoretical understanding of participation from an outsider's perspective (experts), as well as an insider's perspective (parents).
- ⇒ The use of a qualitative design enables us to get a deeper understanding of social participation and to add profound insights to this topic.
- ⇒ Special care was taken in selecting the participants to achieve a heterogeneous sample.
- ⇒ As is common in qualitative studies, we used a relatively small sample of respondents. In larger-scale studies, the results could be further validated.

'The WHO has left it open for users of the ICF to decide whether they focus on activity or participation'.⁴

Social participation is essential to the health and well-being of children and youth.^{5 6} It influences the development of children and adolescents at different levels (eg, competence experience and social-emotional development).^{7 8} Numerous studies show that social participation is crucial for a sense of belonging.⁹⁻¹²

The ICF was introduced by the WHO as a framework for measuring health and disability.¹³ With its publication in 2001, the interest in social participation as a key goal of rehabilitation processes has risen significantly.¹⁴ Accordingly, social participation is of great importance in the context of rehabilitative processes.¹⁵⁻¹⁷ The ability to assess social participation is therefore essential.

However, there are hardly any reliable instruments for adolescents to self-assess their social participation. The available measurement tools are based on very different definitions of social participation since it is a multidimensional construct that is still not clearly defined.^{4 18-22} The current state of research provides different explanations for



the definition of participation. One of the best-known definitions of social participation is that of the ICF, which has already been described. At the same time, the international discussion is moving away from the ICF towards a more extensive understanding of the multidimensional concept of social participation, which is mainly developed by Imms *et al.*^{4 18–20}

Following Imms *et al.*, social participation consists of two main components: attendance and involvement.^{18 19} In their systematic review, Imms *et al.* found several subthemes that are related to but not synonymous with social participation.¹⁹ Based on this, the authors developed the family of participation-related constructs (fPRC).^{18 19} Within the fPRC, attendance is defined as ‘being there’ and measured as the frequency of attending and/or the range of activities, whereas involvement is the experience of participation while attending. Involvement includes elements of engagement, motivation, persistence and social connection. Attendance is a necessary but not sufficient requirement for involvement.¹⁸ In addition, the authors describe intrinsic person-related concepts that are tied to social participation: activity competence, sense of self and preferences.^{18 19} Moreover, the fPRC is situated within an environmental context including different dimensions such as availability, which is described as the objective provision of activities or services and accessibility; this includes the ability to access an activity or situation.¹⁹ Simpson *et al.* also asked children on the autism spectrum about their views on social participation and found that participation is seen as a transactional and dynamic process.²³ Children described involvement as an individual and subjective experience, with participation influenced by personal, social and physical factors.²³ Although this is a step in the direction of defining participation more comprehensively, there are still missing or incomplete aspects. For example, according to Imms *et al.*, the relationship between attendance (objective) and involvement (subjective) is still not clearly understood.^{18 24} Little is known about the individual weight given to different components of social participation.

Further, studies in which individuals were asked about their understanding of participation are still rare. There is a consistent finding that the subjective component of participation seems to be more important than objective factors.^{9 25 26} In the study by Hammel *et al.*, the interviewees described social participation using diverse concepts, for example, active and meaningful engagement, choice and control, access and opportunity, having an impact and supporting others.²⁵ From the perspective of the people concerned, the subjective, individual components of social participation seem to be more critical than external aspects such as social norms and expectations.²⁵ This is underlined by Granlund *et al.*, who argues for introducing a third qualifier to gauge subjective experiences of involvement in order ‘to facilitate the split between activity and participation in the ICF, Disability and Health, Children and Youth Version [...]’.²⁷ Using qualitative data from children with disabilities between the ages of 10 and 13,

Nyquist *et al.* also found that a vital component of social participation is the subjective component.⁹

Nevertheless, even though research has been conducted on this topic for many years, the construct of social participation remains unclear. Moreover, to the best of our knowledge, there are no studies that take different perspectives into account when defining social participation. For example, parents’ and young people’s perceptions of social participation can be extremely different. For guardians in particular, enabling their children to participate often involves a great deal of effort and deprivation, because they are the ones who often create the conditions for their children’s participation. It is their perspective on this issue that is particularly valuable and missing from previous research. It offers an ‘overhead view’ of young people’s participation, which they themselves are not (yet) able to reflect on to a sufficient degree. The same is evident with the professionals’ perspective that accompanies those affected in therapy and treatment. Therefore, it is of great interest to explore the different perspectives of parents and experts.

As long as the construct of social participation has not been adequately defined, it cannot be measured accordingly, and the problems of existing measurement instruments remain. For example, many instruments mix items of activity and participation,^{2 28 29} no single instrument measures the whole extent of participation in all areas of life,³⁰ and the quality criteria (validity, internal consistency, reliability) are not convincing.^{2 31} Especially in German-speaking countries, the fPRC still seems to play a minor role. Here, further development of the multidimensional construct of adolescents’ social participation is required. To address this gap, the objective of this work was to conduct a qualitative study with parents of adolescents with and without chronic and/or physical-motor impairments, as well as experts from the field of social participation, to explore their understanding of the concept of, as well as their experiences with, social participation. This offers the opportunity to obtain a range of insights from different perspectives and contexts, which help to deepen the understanding of social participation. Thereby, this research provides a foundation for the development of new measurement tools for adolescents in Germany to self-assess their social participation. In parallel, the perspective of adolescents was examined and published in a separate article.³² Adolescents describe social participation as involving reflexive interaction with their social environment. Furthermore, forming a social environment plays an important role. All components of the concept are embedded in a context that influences the ways adolescents participate.³² However, interviewing parents and experts makes it possible to explore aspects that might remain hidden from the adolescents’ perspective. They may look beyond the horizon of the youth and therefore provide important insights, next to the adolescents’ perspective on social participation. Parents and experts have a broader view of youth participation, which is why we examine their perspectives in this article.

Table 1 Case selection experts

	Focus group 1	Focus group 2	Focus group 3
Participants	n	n	n
University	4	1	3
Clinic/social paediatric centre	1	4	2
University and clinic/social paediatric centre	–	–	2
Administration	–	–	1
Other (eg, early intervention)	1	1	1
Total (n=21)	6	6	9

Professions: occupational therapists, paediatric neurologists, physiotherapists, social workers, paediatricians and adolescent physicians, psychomotor therapists, special pedagogues, researchers from the field of participatory research.

MATERIALS AND METHODS

Study background

The study uses data from a research project on the ‘Development and psychometric testing of an instrument to measure social participation among adolescents’ funded by the German Research Foundation. The main objective was to develop a self-assessment participation measurement instrument for adolescents with and without chronic and/or physical-motor impairments aged between 12 and 17 years.³³ In order to develop this measurement tool, it was necessary to first conduct qualitative research to understand the concept of social participation in more detail. Therefore, we asked adolescents³² as well as parents of adolescents with and without chronic and/or physical-motor impairments and experts about their experiences and understandings of social participation. This article will focus on the perspectives of parents and experts.

Sampling

We used purposive and snowball sampling to obtain a comprehensive sample of (A) parents of adolescents with and without chronic and/or physical-motor impairments and (B) experts involved in participatory research and/or treatment of adolescents with chronic and/or physical-motor impairments.³⁴ We were careful to ensure that the sample was as balanced as possible, comprising experts from different regions in Germany, and to further ensure that we would recruit professional, well-experienced experts from different professions (table 1). The inclusion of well-experienced experts was particularly important regarding the introduction of the ICF in 2001 and the associated growing importance of social participation. We expect that more experienced experts can report on this development in more detail. The final sample of experts included scientific national researchers dealing

with the theoretical construct of social participation, as well as professionals from rehabilitation clinics and social paediatric centres. We recruited the parents with help from various schools and medical facilities (eg, social paediatric centres) in urban and rural parts of central and south Germany. Parents of youth with and without chronic and/or physical-motor impairments aged between 10 and 17 years were included in this study. Since parents of youth with intellectual disabilities face very different challenges in the context of social participation, we decided to exclude them from the study. We used different ways to approach participants: via telephone, email and parents’ information letter. In total, we contacted 53 experts. The main reasons for non-participation were time-related and organisational. Thirty-eight parents agreed to participate in the study, 14 of them dropped out during the research process, we did not ask for reasons. When we reached data saturation (the point in data collection when no additional issues were identified),^{35 36} we concluded the recruitment. The final sample consisted of 3 focus groups with a total of 21 experts and 5 focus groups with 24 parents (tables 1 and 2). This included 10 parents who had disabled children (eg, cerebral palsy, metabolic disorders, type 1 diabetes and short stature).

Data collection

The empirical data collection involved a consecutive, two-stage process.³⁷ First, we held interprofessional focus groups with experts, followed by homogeneous focus groups with parents. Two well-experienced interviewers (LH and CV) conducted all focus groups. Data collection took place at the experts’ workplace as well as the Martin Luther University Halle-Wittenberg. The study followed a realist epistemological approach³⁸ and we used findings from the literature on the current scientific discussion about the concept of

Table 2 Case selection parents

	Total	Focus group 1	Focus group 2	Focus group 3	Focus group 4	Focus group 5
Participants	n	n	n	n	n	n
Parents of youth with impairments	10	2	0	0	4	4
Parents of youth without impairments	14	0	7	7	0	0
Total	24	2	7	7	4	4

adolescents' social participation^{2 4 18 24 39–41} to inform and construct three interview guides, which were pilot tested beforehand (online supplemental appendices 1–3). The questions in the interview guides acted as prompts to elicit a general discussion and contained open questions, without specifying the order of topics. This allowed the interviewer to elicit a broad range of information on social participation. In addition, the participants were able to raise topics that they found relevant. We used three different interview guides: one for focus groups with experts, another one for the focus groups with parents of youth with impairments and another one for the focus groups with parents of youth without impairments. We also made a protocol to gather further information during each focus group. Prior to the respective focus group, each participant completed a short questionnaire so that we could gather basic sociodemographic information (eg, age, gender, occupation, work experience, and in case of the parents additional information about their children). All focus groups (lasting approximately 2 hours) were conducted in German, audiorecorded with the respondents' permission and fully transcribed verbatim. Interview extracts were translated after the analysis by the authors of this article.

Data analysis

We used qualitative content analysis to analyse the focus group discussions.^{42 43} The analysis was carried out in German. In the first deductive part of the analysis, we separated the text material into different thematic sections (experts: 'meaning of the term social participation', 'importance of social participation for rehabilitation', 'planning and evaluation of rehabilitation processes', 'requirements of a participation measurement tool for practice'; parents: 'meaning of the term social participation', 'experiences with social participation in everyday life, individual meaning of social participation related to the children', 'experience with social

participation outcomes in the rehabilitation process'), which were informed by the guiding questions from the interview guide. This was followed by an inductive step in which we developed new categories closely oriented to the interview text. We used MAXQDA (V.18) to organise and store the data. We included several criteria for measuring rigour in our study.^{44 45} We achieved rigour and quality by following the internationally consolidated criteria for reporting qualitative research.⁴⁶ To achieve reliability as well as intersubjective comprehensibility, validity and transparency, two research associates and one research assistant coded the data. Any inconsistencies that arose were put up for discussion until an agreement was reached.⁴⁴ Further, we held regular team meetings to discuss and refine the coding tree and category system.⁴⁴ In the end, we merged and contrasted the results of the parents' and experts' focus groups, thus adding to the construct of social participation.

Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

RESULTS

Social participation from the experts' perspectives

Based on the views of the interviewed experts, the construct of social participation consists of two components: subjective and objective (figure 1). The subjective component includes, on the one hand, a feeling of being included and one's respective perceptions in different life situations.

That is this subjectivity. This is also very important for young people and often much more crucial for them.

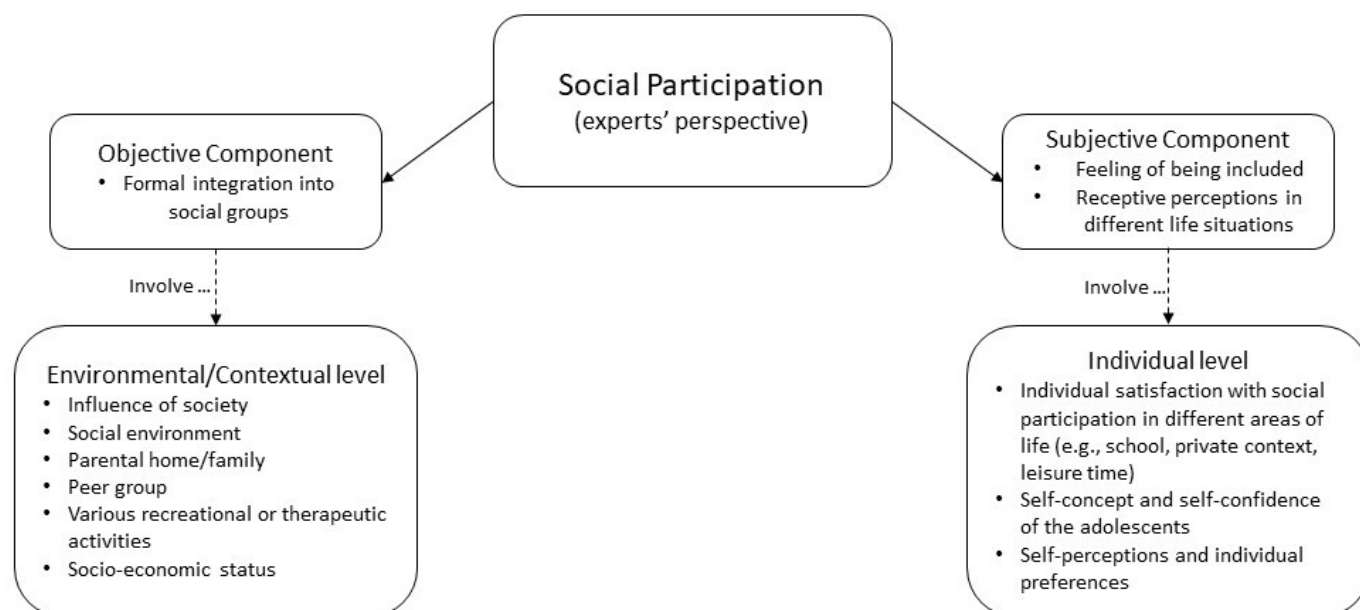


Figure 1 Social participation from the experts' point of view.

Do I feel included? Does that appeal to me? Am I accepted? FG03, B9

The objective component, on the other hand, includes formal integration into social groups, such as sports clubs or school classes.

Moreover, these subjective and objective components of social participation involve the individual level and the environmental/contextual level. Individual and contextual factors can take place at both components—subjective and objective. They further include determining factors, which can be both helpful as well as rather hindering participation. On the one hand, the individual level includes determining factors such as individual satisfaction with social participation in everyday life in different areas of life (eg, school, private context, leisure time), as well as adolescents' self-concept and self-confidence. One psychomotor therapist describes individual satisfaction as follows:

I would also have [summarised] it under the aspect of individual satisfaction with participation in my life, with the aspects that belong to it for the individual [...] with all its activities. So how satisfied am I to the extent that I can participate? FG02, B5

From the experts' perspectives, above all, it is about individually defined normality. The main question is: What does the individual want? Adolescents, in particular, might not necessarily want to participate in everything. It is precisely these self-perceptions and individual preferences that complement the concept of social participation from the expert's standpoint.

This perception of the one who is affected. [...] everyone is an individual. I think that is very important. Then, it is about [...] What does the individual want? What does this child want? What does the adolescent actually want? FG01, B6

The interviewed experts were clearly in favour of giving the individual's self-perception a greater role in the concept of social participation in the future. A special pedagogue and paediatric neurologist described this as followed:

[...] and I have argued quite often that you cannot truly think about participation without assessing the self-perception of the children and the families and taking that on board [...], because of course my participation totally depends on whether I trust myself to cope in this situation. FG02, B4

On the other hand, the context or environmental level includes those determining factors that influence social participation outside the individual. These include the social environment, their home, the peer group, various recreational or therapeutic activities, and higher-level factors such as socioeconomic status (SES). From the standpoint of the interviewed experts, therefore, all levels, micro (individual factors such as parental home or family), meso (institutions) and macro (society), influence social participation and must be taken into account as determinants of participation. Further, the influence of society also plays a crucial role and should not be disregarded in the concept of social participation. The following quote describes the views of a physiotherapist:

I thought that the social aspect would have been clearly identified through inclusion, that people are hindered by the structures that exist. In addition, that would actually be tried with the inclusion, the barriers that society has created, so to speak, or the structures that are now being removed. So that is what one calls the individual and one calls society. FG02, B1

Social participation from the parents' point of view

Compared with the experts' perspectives, the construct of social participation, from the parents' perspectives

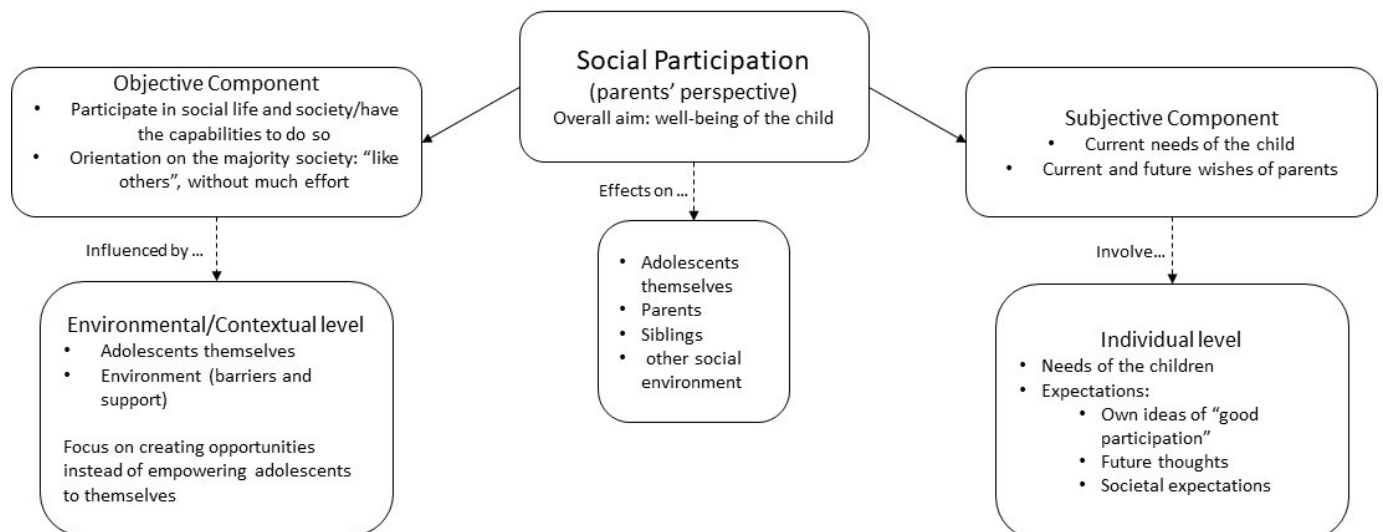


Figure 2 Social participation from the parent's point of view.



(figure 2), mostly includes various objective components. Next to this, we found a subjective component in the parents' interviews that plays a rather minor role. For the interviewed parents, the focus was on the well-being of their children, which they also define as the general aim of social participation.

From the parents' perspectives, social participation consists of two rather objective main components: (1) participation in social life and society or having the opportunities to do so and (2) orientation towards the majority society. Participation in social life and society includes all the opportunities that exist for adolescents such as social ties, friendships, institutions such as school and recreational opportunities. For the interviewed parents, social participation means that their children have the chance to take part in all these areas. This also includes aspects of freedom of choice and decision-making, regardless of the possible impairment.

Well, for me, social participation means that my child has the same opportunities as the non-disabled—if you want to call it that—children to develop, to participate in normal life, to receive an appropriate education, to train for an appropriate job, and later to manage their own lives independently. Yes. In addition, that society creates opportunities for him to do that. The possibilities in terms of personally. The structural possibilities. The financial possibilities. FG01, B2, parent of youth with impairment

It seems less important that the adolescents be able to do everything completely on their own and more important that they receive the support they need at relevant points in time. Regarding one's orientation towards society, the interviewed parents pointed out that it should be possible for children to do everything that 'most others' do without much effort.

The interviewed parents emphasised external factors concerning enabling social participation; that is, in their eyes, it is less about enabling individual adolescents to participate, but rather the environment needs to be designed in such a way that adolescents can participate. A parent of 16 years old with short stature described this as follows:

And I think the challenge now, also through the new Participation Act, is that one creates this possibility, so to speak, that everyone is able to participate [...] or to open up the possibility to participate in the offers that exist, perhaps even despite certain impairments. FG04, B4, parent of youth with impairment

According to the parents, adolescents' social participation is influenced by the following factors: the adolescents themselves, such as by their impairment, but also by their personality, experiences, wishes and needs, and by environmental factors. These include the parents themselves and other individuals, such as teachers and coaches, as well as social and political factors. A parent of 11 years old with type 1 diabetes said the following:

There were kindergarten teachers who said, 'We will take care of this. We want him to stay here.' And it was the same at school. Now at high school, I have to say, no one is truly interested. [...] This is a highly complex disease. You have to know a lot about it. FG04, B1, parent of youth with impairment

Successful or unsuccessful social participation has several effects, especially from the perspectives of the parents of children with impairments. On the one hand, (a lack of) social participation affects adolescents, their self-efficacy and self-image, and their choice of leisure activities.

And besides that, he's similarly busy because he has occupational therapy. He has talking therapy. He has afternoon activities. He has after-school tutoring and music school. [...] So he does not have much free time. FG04, B4, parent of youth with impairment

On the other hand, (a lack of) social participation has a significant impact on adolescents' social environment. This includes parents and siblings, but also grandparents and friends. The interviewed parents said that it costs them much effort to make social participation possible for their children, which can manifest, among other things, in the worsening of their performance. A parent of 12 years old with metabolic disorder reported the following:

And of course with such a child, I personally have not managed in my—let's say, further education or re-training or whatever—to invest time and everything so that I could now work full time or something. With a university degree in applied sciences, I now do part-time cleaning work. FG05, B2, parent of youth with impairment

From the parents' point of view, the well-being of their children is significantly determined by the subjective component (ie, the needs and wishes of adolescents themselves and parents' wishes for their children) of social participation. Parents' wishes for their children are shaped by their children's needs and by their socialisation-related expectations. These include their own idea of what 'good participation' should look like. Parents' expectations are also significantly influenced by objective societal expectations and norms. Broadly speaking, the interviewed parents wanted their children to be able to lead what they see as the 'best possible' life. It should be noted that the needs of parents and adolescents could differ significantly. It is not only a question of what their social participation should look like, but also whether adolescents want to participate at all.

He does not want any social participation at the moment. [...] that is the problem for me. I have to force him to be happy now and then and say: 'You're coming with me to the zoo.' [...] He goes along with it. He is pleased. As I said, when he's there, he's also happy. [...] I always have to give him this imaginary kick in the ass, right? [...] He just wants to be at home. In his

home, where he knows every dust crumb, where he does not have to adapt somehow—yes, and as I said, social participation is something completely different for me. FG01, B1, parent of youth with impairment

That I am in a position, that I am given tools to participate in social life at some point perhaps completely on my own, without having to be supported. FG02, B4, parent of youth without impairment

DISCUSSION

Despite a large body of research, the concept of social participation is still not sufficiently defined. To the best of our knowledge, this study is one of the first that analyses the theoretical understanding of participation from different perspectives: from an outsider's perspective (experts), as well as an insider's perspective (parents). Through focus group discussions, we explored, contrasted and analysed the experiences and views of these two groups.

Based on both perspectives, results indicate that social participation consists of subjective and objective components. However, the two interviewed groups value these two kinds of components differently. The focus from the experts' perspectives is clearly on the subjective level; that is, on the question 'Does the adolescent feel involved?' Compared with that, the parents' focus is more on the objective component, on their normative expectations, which are strongly influenced by their expectations of society. The insider perspective gives more weight to the objective components of participation than the outsider perspective, even though the overall objective is the child's well-being. This could be because parents in particular are keen to enable their children to participate as much as possible. They often create the environment for their children's participation. They take a broader view, which also includes the future participation of their children. In this context, it is important to them that social conditions are also created that enable their children to participate as fully as possible. Compared with the youths' perspectives, more similarities are found with the perspectives of the experts, who also tend to focus more on the subjective dimension of participation. While the parents tend to place more emphasis on the objective components, the adolescents themselves focus on their subjective and individual perceptions of participation in different life situations.³²

Our findings partly support results from studies that worked on the conceptualisation of the construct of social participation.^{9 18 19 25} According to Imms *et al* social participation consists of two components: attendance and involvement.^{18 19 24} Their findings are generally in line with our findings from the experts' perspectives. Attendance, described as the person's presence ('being there'), can be described as the objective component ('formal integration into social groups'), whereas the person's involvement functions as the subjective component ('feeling of being included').

Other concepts related to social participation are activity competence, sense of self and preferences,^{18 19} which can be found in our results in the subjective component at the individual level. This reflects individual preferences as well as the self-concept. Additional factors that we could identify are individual satisfaction with social participation and self-confidence, which are constructs tied to the concept of a sense of self. Imms *et al* (2016, 2017) also identified environmental and contextual factors, to which our results provide new insights. The experts describe various factors that influence social participation outside the individual, including the influence of society and the social environment, peer group, parental home and SES. In line with previous findings, the interviewed experts continue to call for greater emphasis to be placed on the subjective level in future research.^{9 20 25 27}

This is partly in contrast with the results of the interviewed parents, who focus more on the objective components of social participation. Even if the primary aim of social participation—the children's well-being—can be included in the subjective component, the path to this end is different from their perspectives compared with those of the experts. This means that for the interviewed parents, the focus is on orientation towards the normative expectation of society and enabling their children to do everything that most other young people do. At this point, important aspects of the concept of functional health are reflected. In addition to physical functions, the concept of functional health includes the possibility of being able to live one's life in all areas that are important to one in the same way, and to the same extent, as an individual without impairment would be able to do.¹⁴ They do not hold the children themselves responsible for this, but their environment, or more precisely, society. This is consistent with the view of disability in the biopsychosocial model, which describes disability as a socially created problem, rather than one that exists as a medical problem within the individual.¹ Managing disability requires a social change in terms of attitudes and ideologies. Even if the children's own wishes and needs play a role in their social participation from the parents' perspectives, the normative orientations, wishes and expectations of the parents and society tend to dominate.

The call for greater attention to the subjective perspective of the people concerned—as found in the expert interviews and existing literature—is not reflected in this form in the parents' perspectives. In their eyes, it is primarily the responsibility of society and the social environment to enable children to create opportunities instead of empowering adolescents themselves. However, existing findings on influencing factors of social participation, such as preferences and sense of self,¹⁸ are also reflected in the parents' views in the form of concepts such as freedom of choice and decision-making.

In addition to existing results from the perspective of those affected in different age groups,^{9 20 25 27} our results show that the 'overhead view' is also important



to define participation comprehensively. For this, different perspectives are necessary.

Overall, both the experts' and parents' perspectives reflect the basic findings on the understanding of social participation from existing studies. In addition, the present results provide new evidence on the weight of subjective and objective factors from different angles and add new elements to the construct of social participation. Existing evidence is limited to mostly Swedish-speaking and English-speaking countries. With this study, we were able to expand the existing evidence and extend these results to German-speaking countries. Our results contribute to a better understanding of the relationship between involvement and attendance, and the importance of both components from two different standpoints. The current understanding of social participation goes far beyond the definition provided in the ICF. Social participation is a crucial factor for child development and should therefore be taken into account in the planning and evaluation of rehabilitation processes.^{2 47} The present results, together with existing evidence on the concept of social participation, make it possible to develop new measurement instruments that can measure participation comprehensively. These new instruments should be used in practice to improve the participation of adolescents with disabilities in the future. In particular, the subjective component must be taken into account in the development of new measurement instruments for adolescents to self-assess their social participation. The instrument should not only collect data about what opportunities young people have to participate in different areas of life but also how satisfied they are with these and whether they are relevant to them. Existing instruments remain mostly on the objective level and are designed as external assessments in which legal guardians (parents or caregivers) assess the participation of the children or adolescents. The individual satisfaction of adolescents with their participation as well as the relevance they attach to it, can only be assessed by themselves. With our results, we were able to close some of the existing research gaps and provide a basis on which new measurement instruments can now be developed. Nevertheless, further studies are also needed to examine the relationship between the subjective and objective components in more detail. Along with this, it is necessary to ask those who are affected by different disabilities about their perspectives on social participation. In particular, the views of affected adolescents must be given greater focus in future studies. The results of this study extend the existing evidence of the construct of social participation and contribute to the development of new reliable measurement tools. In this way, the social participation of adolescents with impairments and/or chronic medical conditions can be improved in the future.

Some limitations of the current study need to be acknowledged. First, the direct recruitment of the respondents suggests that the participants were highly motivated experts and parents, which could have influenced the findings. However, we can assume that this selection bias is rather low, as parts of our results are in line with existing evidence. In addition, we took special care in selecting the experts to achieve a heterogeneous sample. We found largely homogeneous findings in the definition of participation and its diverse components and determinants across professions. This may be because the well-informed experts were at least partially aware of the current state of research. Second, even though the examination of the experts' and parents' perspectives is novel and needed in this context, there are some limitations: Our findings and insights on what is important to the adolescents themselves can only be ultimately investigated from their own perspectives. Even if the parents' views in particular already represent an insider's view, they may be partial or different to a certain extent as the parents see their child's participation through their own experiences and understandings. That is why we published the adolescents' views in a separate paper.³² Last, as is common in qualitative studies, we used a relatively small sample of respondents. In larger-scale studies, the results could be further validated. However, this limitation has a rather small influence on the results, since we took care in selecting an appropriate sample size to interview an adequate number of participants to achieve data saturation, in order to be able to draw reliable conclusions.^{36 48}

Conclusion

This qualitative study provides new insights into the concept of social participation from the perspectives of experts and parents. Our results indicate that social participation goes far beyond what has been defined thus far according to the ICF. The results underline the importance of adolescents' subjective feelings, as well as the importance of normative requirements and the role that society plays to enable social participation. To capture both components and especially the subjective, context-dependent component of participation, suitable measurements that can be applied in practice are urgently needed. This would help to measure participation more precisely in the future, especially in rehabilitation processes, and to increase future participation opportunities for disabled adolescents. In this way, social participation of adolescents might be significantly improved. This is especially critical for adolescents' development, as social participation is essential to children's health and well-being.

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Ethics approval We carried out the study following the principles of the Declaration of Helsinki and the standards of good scientific practice. Our study was approved by the Ethics Review Committee of the Medical Faculty at Martin Luther University, Halle-Wittenberg (ID:2017-67). All participants were extensively informed about the project and the handling of the collected data. Written informed consent was gathered from each participant.

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Interview Guide Focus Groups PartJu – Experts

Topic	Guiding question(s)	In-depth aspects
<i>Meaning of the term social participation</i>	<p>First of all, I would be interested to know what each of you understands by social participation in general? Can you give me your perspective on participation?</p> <p>In the ICF-CY, participation is defined as "being involved in a life situation." However, the current scientific debate shows that this definition is not sufficient and has evolved in recent years. On the one hand, the ICF is internationally recognized as a classification tool and is widely used, but it has little theoretical foundation. We want to separate a bit from the ICF, because the international discourse shows that the development is moving away from there.</p> <p>Therefore, I ask a similar question as at the beginning but a bit more specific: Which constructs do you consider to be part of social participation?</p> <p>What would need to be looked at in order to describe participation in detail?</p> <p>What role do intrapersonal factors and context play?</p>	<ul style="list-style-type: none"> • General in-depth questions: Can you elaborate on this? How would you justify that? Why is this the case? • Personal/intrapersonal factors: e.g., illness. Environmental factors: The environment in which the child lives. • What role does the individual attribution/meaning of participation play? (keyword: meaningful participation), importance of an activity • Participation in the context of independence? • What role do (the quality of) social interactions play?
<i>Importance of social participation for rehabilitation</i>	<p>Now that we have talked extensively about the concept of participation, I would like to ask you what significance or importance does social participation have for rehabilitation? In this context, we want to break up rehabilitation a bit, because we don't just mean</p>	<ul style="list-style-type: none"> • What is the current status of participation in rehabilitation? • Barriers and possibilities for improvement

	<p>medical rehabilitation, but all areas of life in which the child/adolescent is "rehabilitated" (e.g., this also includes, in addition to rehabilitation clinics and SPCs, outpatient settings, possibly school contexts and so on).</p> <p>How do you currently perceive participation in rehabilitation? What can rehabilitation achieve in terms of participation (both as a rehabilitation goal and in rehabilitation)?</p>	
<i>Planning and evaluation of rehabilitation processes</i>	<p>Now I would like to talk to you again in a little more detail about determining goals of rehabilitation. What is the current significance of participation in the planning of goals in rehabilitation? How would you describe/assess the current situation?</p> <p>What would you change in terms of social participation regarding determining goals of rehabilitation processes?</p>	<ul style="list-style-type: none"> • Deficits and possibilities for improvement
<i>Requirements of a participation measurement tool for practice</i>	<p>What does an instrument for measuring participation have to do? What requirements must it meet?</p> <p>Which participation measurement instruments do you know?</p> <p>What is already well measured by existing instruments? (What is not?)</p> <p>What changes/developments compared to existing instruments are necessary?</p> <p>If you had to create a participation measurement instrument now, what would it look like? What components would it include?</p>	<ul style="list-style-type: none"> • Can it be used in practice and science? • What should be considered for the use in practice? • What are the special features?

<i>Conclusion: open aspects</i>	We have reached the end of our focus group, is there anything else you would like to say that has not been addressed so far? Have we forgotten any aspects regarding the topic?	
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Interview Guide Focus Groups PartJu – Parents of adolescents with chronic and/or physical-motor impairments

Topic	Guiding question(s)	In-depth aspects
<i>Meaning of the term social participation</i>	<p>We want to talk about social participation today. For this, we would like to first clarify what you understand by the term, i.e. what does social participation mean for you?</p> <p>How would you personally describe social participation in your own words?</p>	<ul style="list-style-type: none"> • General in-depth questions: Can you elaborate on this? How would you explain the reasoning behind this? Why is that the case?
<i>Experiences with social participation in everyday life, individual meaning of social participation (related to the children)</i>	<p>Now that we have talked about what each of you understands by social participation, I would like to talk to you about your children's experiences with social participation in everyday life.</p> <p>What does your child/do you children do in their free time or how does your son/daughter spend their free time?</p> <p>If you think of a "normal" day/typical day in the life of your child/children, how would you describe it?</p> <p>What role does social media play in this? (What social media channels do they use? How does this influence your child's/your children's participation?)</p> <p>What things would your child like to do but can't? Is there anything related to your child's participation?</p>	<ul style="list-style-type: none"> • School, family & leisure, weekday, weekend • Are there problems in everyday life (always related to participation)? • What do your children participate well/badly in? Why? • What is going well? • What is going badly? • What are the problems? • What would you like to see happen? (Suggestions for improvement) • When do your children feel especially at ease/socially accepted? • When might your children feel excluded?

	<p>Now that we've talked a lot about leisure time, I'd be interested to know what everyday school life is like. Could you tell me about your child's participation at school?</p> <p>How would you describe your child's participation overall? What factors influence your child's participation and why? (Environmental factors & personal factors)</p> <p>How satisfied do you think your child/children are with their overall participation in school?</p> <p>And how satisfied is your child/children with their participation in leisure time and family?</p> <p>How satisfied are you with the participation of your child/children? What do you also experience as challenging? What is your wish regarding the future of your child/children?</p> <p>→ Now we have talked about many areas in which participation takes place. I would now like to ask the question from the beginning again, or slightly modified: What do you consider social participation to be, or what can you perhaps add now?</p>	<ul style="list-style-type: none"> • How well can your child participate in class? • How comfortable does he or she feel in the class? • Does he/she feel like he/she belongs? • Does your child have friends/group of friends? • Are there any problems, if so which ones? • How does your child spend his/her breaks?
<i>Meaning of self-determination</i>	<p>Now, I would be interested to know how you perceive your child's/children's self-determination?</p> <p>How self-determined do you think your child can act?</p>	<ul style="list-style-type: none"> • To what extent can your children make their own decisions? • To what extent can your children make their own decisions about their life? • Related to different areas (family & leisure, school) • How important is it for your children to make their own decisions? And can they do so to the extent they wish?

<p><i>Experience with social participation outcomes in the rehabilitation process</i></p>	<p>Now I would like to talk to you about rehabilitation and treatment processes given by medical professionals, therapists and educators. To what extent were you and your child involved in treatment planning (e.g., at the social pediatric center or in therapy)? What was the exact process?</p> <p>How did you feel about this process? (satisfaction, requests for changes)</p> <p>To what extent do you feel that the support and treatment goals were participation-oriented?</p>	<ul style="list-style-type: none"> • How satisfied are you with the setting of the goals and the goals themselves? • How satisfied is your child with them? • How satisfied are you with the treatment? How satisfied is your child? • What does your child want in terms of treatment? What do you wish for? • And why?
<p><i>Conclusion: open aspects</i></p>	<p>We have reached the end of our discussion round, would you like to say anything else that has not been addressed so far? Have we forgotten any aspects regarding the topic?</p>	

Interview Guide Focus Groups PartJu – Parents of adolescents without chronic and/or physical-motor impairments

Topic	Guiding question(s)	In-depth aspects
<i>Meaning of the term social participation</i>	<p>We want to talk about social participation today. For this, we would like to first clarify what you understand by the term, i.e. what does social participation mean for you?</p> <p>How would you personally describe social participation in your own words?</p>	<ul style="list-style-type: none"> • General in-depth questions: Can you elaborate on this? How would you explain the reasoning behind this? Why is that the case?
<i>Experiences with social participation in everyday life, individual meaning of social participation (related to the children)</i>	<p>Now that we have talked about what each of you understands by social participation, I would like to talk to you about your children's experiences with social participation in everyday life.</p> <p>What does your child/do your children do in their free time or how does your son/daughter spend their free time?</p> <p>If you think of a "normal" day/typical day in the life of your child/children, how would you describe it?</p> <p>What role does social media play in this? (What social media channels do they use? How does this influence your child's/your children's participation?)</p> <p>What things would your child like to do but can't? Is there anything related to your child's participation?</p>	<ul style="list-style-type: none"> • School, family & leisure, weekday, weekend • Are there problems in everyday life (always related to participation)? • What do your children participate well/badly in? Why? • What is going well? • What is going badly? • What are the problems? • What would you like to see happen? (Suggestions for improvement) • When do your children feel especially at ease/socially accepted? • When might your children feel excluded?

	<p>Now that we've talked a lot about leisure time, I'd be interested to know what everyday school life is like. Could you tell me about your child's participation at school?</p> <p>How would you describe your child's participation overall? What factors influence your child's participation and why? (Environmental factors & personal factors)</p> <p>How satisfied do you think your child is/children are with their overall participation in school?</p> <p>And how satisfied is your child/children with their participation in leisure time and family?</p> <p>How satisfied are you with the participation of your child/children? What do you experience as challenging? What would you wish for your children in future?</p> <p>→ Now we have talked about many areas in which participation takes place. I would now like to ask the question from the beginning again, or slightly modified: What do you consider social participation to be, or what can you perhaps add now?</p>	<ul style="list-style-type: none"> • How well can your child participate in class? • How comfortable does he or she feel in class? • Does he/she feel like he/she belongs? • Does your child have friends/group of friends? • Are there any problems, if so which ones? • How does your child spend his/her breaks?
<i>Meaning of self-determination</i>	<p>Now I would be interested to know how you perceive your child's/children's self-determination?</p> <p>How self-determined do you think your child can act?</p>	<ul style="list-style-type: none"> • To what extent can your children make their own decisions? • To what extent can your children make their own decisions about their life? • Related to different areas (family & leisure, school)

		<ul style="list-style-type: none">• How important is it for your children to make their own decisions? And can they do so to the extent they wish?
<i>Conclusion: open aspects</i>	We have reached the end of our discussion round, would you like to say anything else that has not been addressed so far? Have we forgotten any aspects regarding the topic?	