The Participation Experience of Children with Disabilities in Portuguese Mainstream Schools

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The participation experience of children with disabilities in Portuguese mainstream schools

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Key words:
Children with disabilities, school, participation forms.

Introduction: This explorative study aimed to chart the participation experiences of children with disabilities enrolled in mainstream schools.

Method: The participants were 14 students with disabilities, with good communication skills, aged between 8 and 11 years and attending school in Portugal. The data were collected through open-ended interviews and analysed employing a psychological phenomenological method.

Findings: The findings suggest that participation at school took three forms: equal participation, special task participation and onlooker participation. Those three forms contrasted with situations of non-participation, in which the children felt completely excluded. Each form of participation and non-participation presented different performance characteristics and was influenced by the social environment.

Conclusion: The findings of this study provide insights that enhance the understanding of children's inclusion in mainstream schools, as well as the individual's experience of participation.

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Introduction

In Portugal, the education of children with disabilities has evolved over time. From the preconceived idea that children with disabilities should be protected from society in segregated institutions, there has been development towards the inclusion of such children in mainstream schools (Pereira 1996). The latest educational curriculum in Portugal encourages the inclusion of all children with disabilities in mainstream schools (Ministry of Education 2001). Therefore, it is important to understand whether the policy of inclusion has an effect on the participation of children with disabilities.

Under the current International Classification of Functioning, Disability and Health (ICF), the World Health Organisation defines participation as involvement in life situations and states that it is closely connected with integration (WHO 2001). Although the concept of participation has become a central concept in health care and rehabilitation, several authors have stated that further development is needed since the ICF suggests that one should assess participation by observing people's performance (Ueda and Okawa 2003, Hemmingsson and Jonsson 2005). When assessed through observation, the subjective dimension of participation is often neglected. Additionally, it has been argued that the best judge of participation is the respondent rather than the professional (Perenboom and Chorus 2003).

Participation has always been regarded as a significant feature both in practice and in research (Baum 2001, Law 2002, Kramer et al 2003). Current paediatric occupational therapy frameworks have adopted a top-down approach, in which the quality of children's participation is the main focus (Coster 1998, Brown and Chien 2010). According to this view, occupational therapists work with children with disabilities and with their teachers, school personnel, friends and families in order to maximise participation (Law et al 2006).

Participation in school activities is one of the most important outcomes of children's inclusion in mainstream schools (Eriksson 2005), but it seems

that children with disabilities still face restricted participation in comparison with their non-disabled peers (Hemmingsson 2002, Richardson 2002, Pitt and Curtin 2004). Successful inclusion requires the involvement of the entire school environment (social and physical) (Pereira 1996, Simeonsson et al 2001, Hemmingsson et al 2003, Almqvist and Granlund 2005), because the entire school must be designed to accommodate students with disabilities.

A comparative case study describing five Portuguese mainstream school teachers showed that the teachers experienced communication barriers when dealing with children with disabilities and, in some situations, the teachers did not feel responsible for the education process of children with disabilities (Freire and César 2003).

A Swedish survey (Eriksson 2005) investigated the relationship between participation in school activities of children with disabilities and their school environment. The results revealed that the individual's specific environment, especially when rated according to its provision of accessibility to activities for the children, bore significant relation to the children's participation (Eriksson 2005).

In conclusion, although there is a need to include the individual experience when considering the participation of children with disabilities, the experiences of the children themselves have rarely been investigated. The aim of this study was to explore and understand how children with disabilities experience their participation in mainstream schools in Portugal.

Method

A qualitative design inspired by phenomenology was used to describe the experiences of children with disabilities in mainstream schools. Owing to the specific characteristics of interviewing children, methodological recommendations by Zwiers and Morissette (1999) were followed. For that reason, it was anticipated that about 10-15 participants would be a reasonable target.

Ethical considerations

Studies should only be conducted with children when no other individual can answer the research question (Levine 1986, Thomas and O'Kane 1998, Smith 1999). The main concerns are that children are a vulnerable group, who may lack legal capacity to give informed consent, and that the unequal power relationship between adults and children can influence the data collection process (Thomas and O'Kane 1998).

Ethical permission was obtained from the occupational therapy department at Escola Superior de Tecnologias da Saúde do Porto (Higher Education School), which recognised that the study method was appropriate for children and that the circumstances in which the research was conducted provided for the physical, emotional and psychological safety of the child. After that, consent from the authorities at the participating schools, and then teachers, was sought as well.

Informed consent was obtained from the children and their parents before the interviews (Kvale 1996). The study was described briefly to parents, highlighting that participation was entirely voluntary and that their child might refuse to participate, and that they could withdraw from the study at any stage with no further consequences. The children's informed consent consisted of simple information, adapted to the age of each child.

Child-focused interviews pose a number of challenges and one of the most important aspects is to establish rapport (Zwiers and Morissette 1999), creating a friendly atmosphere in which the children can feel safe and comfortable about sharing their experiences. Since their ability to recall and outline events may differ from their experiences, the language of the interviewer had to be appropriate to the children's age and abilities (Irwin and Johnson 2005). The children and their parents could decide on the best site for the interview (at their homes or in a quiet room at school).

Confidentiality and anonymity about all information was ensured during all phases of the research.

Selection of participants

The following four criteria were used for the selection of participants: (i) children with disabilities, (ii) children aged between 8 and 12 years, (iii) children attending mainstream schools and (iv) children with good communication skills in Portuguese. The access to participants was gained through teachers. A variety of schools was contacted by phone and email and a short description of the work was sent first to the school management and then to teachers and occupational therapists. The professionals (teachers and occupational therapists who were willing to participate) spoke to the students and their parents and asked permission for the first author to contact them. Letters providing information and requesting informed consent were subsequently sent to parents and participants. Informed consent was also obtained from the school authorities.

Data collection

The first author collected the data through semi-structured interviews. A topic guide (Table 1) was used to provide the structure of the interview, although the children were encouraged to talk freely about anything they considered important. In order better to adapt the topic guide to the children's language, two pilot interviews were carried out, which resulted in some minor changes.

All the interviews were conducted in the participants' schools and lasted between 40 and 80 minutes, with the necessary breaks. The interviews were audiotaped and transcribed verbatim.

Data analysis

The data analysis started after completion of the data gathering and was guided by the descriptive psychological phenomenological method described by Giorgi (1985, 2005). The analysis was based on four steps:

Table 1. Topic guide

- I am curious to know what you like to do at school. Can you give examples?
- Tell me about what you don't like at school.
- How is it on the playground? What do you do there?
- Now I am curious to know something about your classes. What is your favourite subject at school? What makes you like it?
- In the opposite: which subject do you like less or do not like? What makes you feel like that?
- What is different between … (favourite subject) and … (non-favourite subject)?
- I would like to know something about your teachers. Can you tell me about your teachers?
- Can you tell me about sport/leisure activities?
- Can you tell me about your best friend(s) in school? What about your other friends. What do you do together? When and where do you usually meet?
- What do you like and do not like about being in this school?
- We get to the end of the interview. Is there anything else you would like to share?

All questions were followed by follow-up, probing, specifying and summarising questions.

1. The transcript of the interview was read as a whole and attuned not merely to the linguistic content but also to the intentional or lived experience of the participant
2. The entire transcription was re-read, the transitions of meaning were identified and, finally, slashes were inserted to frame all the meaning units
3. The meaning units with everyday expressions of the participants were transformed into professional occupational therapy language (Rodger and Ziviani 2006), highlighting the occupational therapy meaning of the participants' experience. This transformation was carried out using the scientific phenomenological reduction described by Giorgi (2005). These transformations are essential, since the participants' descriptions express multiple realities in a cryptic way
4. In the phenomenological reduction, the transformed meaning units were used to describe the general structure of the experience of being a child with disabilities and participating in a mainstream school.

During the entire analysis process, each meaning unit and each transformed meaning unit were constantly compared with the original data (Giorgi 2005).

Bracketing the researcher pre-understandings of the phenomenon was a task that preceded the interviews and analysis. A reflexive journal and discussions with a fellow master's degree student avoided focusing attention on particular predetermined aspects of the data. Scientific phenomenological reduction was used during the analysis. This was not merely a matter of bracketing the researcher's pre-understandings, but was rather a process in which the researcher constantly questioned the phenomena that were being described (Giorgi 1985).

To ensure trustworthiness, the study was planned, carefully followed and monitored at each step by two experienced researchers (Bogdan and Biklen 2003). Peer review was conducted: parts of the raw data, data reduction and the product of analysis were read and discussed with the co-authors and a fellow master's student. In-depth discussions were held until a clear text was agreed upon. The findings section includes parts of the data, with the intention of giving the reader the opportunity to evaluate the trustworthiness of the findings and their applicability to other contexts (Patton 1990).

Since the interviews were held in Portuguese (the children's native language), translation was done at the end of the analysis. This meant that the meaning of the descriptions was entirely preserved during the data analysis process. Ongoing discussions with an independent person fluent in both languages (Portuguese and English) were held in order to achieve the most appropriate translation.

Findings

Based on a criterion sampling method (Polit and Beck 2004), seven girls and seven boys, between the ages of 8 and 11 years, were the participants for this study. All of the 14 participating children attended mainstream schools and had access to a special educational teacher 3-10 hours a week. In order to protect the identity of the participants, pseudonyms were employed. The participants' characteristics are displayed in Table 2.

The children in this study described participation in mainstream school as generally positive, although, as the children related, attending a mainstream school was not an ideal situation for them. A number of experiences were described in detail, in relation both to educational situations and to interaction with peers.

The meaning structure revealed by the analysis consisted of three forms of participation, contrasted with non-participation. The three forms were equal participation, special task participation and onlooker participation. All forms of participation, as well as non-participation, had different characteristics of children performance and different social environmental features (teachers and other children), as illustrated in Fig. 1. This figure presents the children's perceptions regarding their own contribution to the occupation.

Equal participation

Equal participation was characterised by situations in which the children did things together with peers and felt that they contributed equally to the occupation. A subjective experience of being competent and totally involved was always present in these situations.

As Susana said, her feelings of happiness, enjoyment and satisfaction were linked to her feeling of competence and experience of being and doing things with friends:

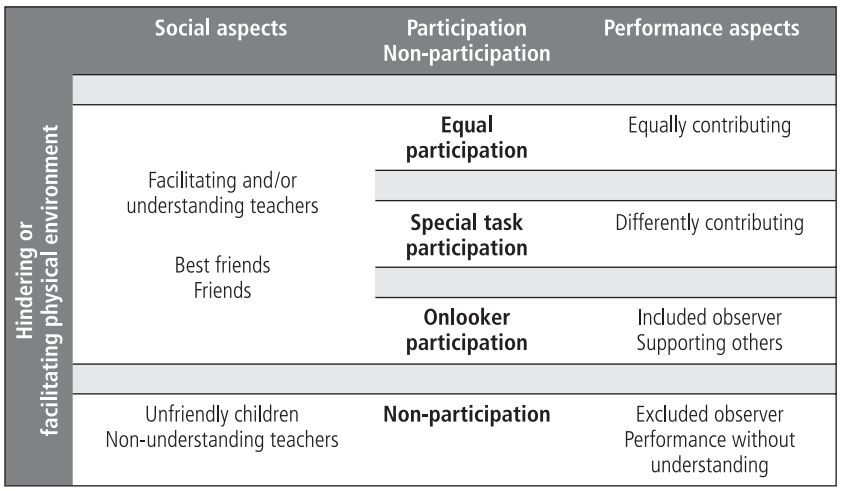
> The game I like the most is when we have to pretend that we're statues and we can't move. If the observer sees someone moving, this child is out and changes place with the observer. The game is really good fun and I could play it forever because I'm very good at it! (Susana.)

Table 2. Participants' characteristics

Name	Age	Type of school	Diagnosis	Access to a school assistant	Assistive technology/ equipment
Carmo	9	Primary school[1]	Cerebral paralysis	Yes	Walking stick – sometimes
Carlos	8	Primary school	Intellectual impairment – mild	No	None
Joana	10	Primary school	Intellectual impairment – borderline	No	None
Artur	9	Primary school	Asperger's syndrome	Yes	None
Susana	10	Primary school	Intellectual impairment – mild	No	None
Manuel	11	Primary school	Intellectual impairment – mild	No	None
Pedro	9	Primary school	Intellectual impairment – mild	No	None
Francisco	11	Secondary school[2]	Muscular dystrophy – Duchenne type	Yes	Power wheelchair
Raquel	12	Secondary school	Cerebral paralysis	Yes	Manual wheelchair
Daniela	9	Primary school	Blindness	Yes	Braille writing device
Jorge	9	Primary school	Blindness	Yes	Braille writing device
Paula	10	Primary school	Blindness	Yes	Braille writing device
Maria	11	Secondary school	Retinopathy	Yes	Magnification lens
To	9	Primary school	Blindness	Yes	Braille writing device

[1] 1st to 4th year of education. [2] 5th and 6th years of education.

Fig. 1. Forms of participation and non-participation in relation to social, performance and environmental aspects.



The impression from the transcripts was that the children's enthusiasm to engage in occupations was linked to their experience of mastering these occupations. The children compared their performance with that of their peers and appeared to place high importance on their perception about equal performance:

> I like maths and I'm very good at maths. Normally I get it all right [smile]. Once, the teacher told us about geometry. So we drew circumferences with the compass and in the end we coloured the inside of the circumferences … I did it like the others! It was great fun … (Carmo).

Equal participation was not only dependent on the student's competence, however. It was also clear that performance opportunities were influenced by the social surroundings. Some children interviewed reported that they saw their teachers as opportunity creators, facilitating the child's participation by adapting educational activities:

> When it's someone's birthday, my teacher organises a party. It's great fun and we have to say something about the birthday student … and we all say something good about each other … and the teacher helps us … it's very nice! (Manuel.)

Manuel felt happy when his teacher gave every student the opportunity to participate in the birthday celebration. The way the teacher structured the occupation allowed every child to contribute. In addition, the support given by the teacher was perceived as a facilitator to the children's participation.

Like the teachers, friends could also facilitate participation, resulting in the students experiencing equal participation. Maria, who was diagnosed with retinopathy, described how she liked to participate in playground activities when she was with her friends:

> I like to play 'hide and seek' with my friends … I can see a little bit … I can always find good places to hide! It's a lot of fun! [smile] In the school there's only one pavilion, with four classrooms, and one small playground, and I know all the places by heart! In the playground I can do everything … or almost everything, but my friends help me with the things I can't do (Maria).

The play opportunities in the playground seemed to be related to the child's perception of physical obstacles and facilitators. In addition, the support provided by friends enhanced equal participation in the playground.

Special task participation

Another form of participation in mainstream schools was the experience of being together with peers and performing a different task. This form of participation was frequently

highlighted during descriptions of sports lessons. In these classes, some children with disabilities faced more difficulties than their peers, particularly when understanding and performing the exercises. However, the teachers' ability to adapt the exercises improved participation and this made the children with disabilities feel as valued as the other children in the class. The following example shows how engaged Raquel felt when performing tasks requested by her teacher:

> The teacher calls me and asks me to be the referee in the game. I have to concentrate very hard to see who does something wrong … I like to be the referee (Raquel).

Raquel described how she really appreciated her task, although she did not perform exactly the same as the others. Furthermore, she felt that she was included in the class because her task brought something to the occupation as a whole. In this case, she did not have to compare her performance with that of her peers because she was assigned a special task in which other abilities were required.

According to the children, special tasks were also common during play activities, when they were together with their friends. In the following quote, Jorge, who has congenital blindness, described his engagement in a playground activity together with his best friend:

> I go to the playground with Paulo and he tells me what the others are doing … sometimes I also play football with Paulo and the others. Normally I stay between the goal posts and they say when they shoot the ball and I have to catch it … I like doing that! But I only play when Paulo is with me … (Jorge).

The adaptation of the task and the support given by peers enabled and enhanced participation, although when the best friend was not around the children tended to refuse to participate. The participation in an occupation together with a best friend had a special meaning that could not be found in participation with others.

Onlooker participation

The data analysis revealed that sometimes children with disabilities just observed what the others were doing, without an interaction that directly affected the outcome of the occupation, yet they still felt involved in the occupation. This form of involvement from the sidelines is called onlooker participation. In the following example, a child describes how he felt while observing his friends when they were playing football:

> Sometimes I go and watch them. There is a football field and I sit on the bench. I look at them while they play football. I see how they play and then I know what they did! It's great fun to see them playing, and I always support my best friends [smile] … I'm there with them! (Pedro.)

It is clear that joining in the occupation as an onlooker can also provide pleasure and involvement. Although Pedro was just observing without performing, he felt that he was also participating and this gave him a sense of belonging to the group of friends.

In general, the children's descriptions of peers revealed three kinds of friendship: best friends, friends and the 'other children'. Best friends were usually the schoolmates with whom the children with disabilities spent most of their time and to whom they felt closest. Participation in an occupation together with a best friend had a special meaning that could not be found in participation with others. Some children stated that they did not have a best friend, because there was no one who always did things with them, although they still had friends. This type of relationship was described as being not as strong as being best friends, but sufficient for the children with disabilities to enjoy being with them and doing things together. In the following example, Francisco stresses this idea, adding that he did not feel sad or alone because he still had various children with whom he spent time:

> I don't have a best, best friend … There are different children that spend time with me, but there's no child who is always with me … and they're different from me … they can play football or basketball and I can't … but I don't feel sad … I still have some friends, and I'm not alone … (Francisco).

The feelings of belonging to a group of friends and to the school could also be found in learning occupations. Being part of a mainstream school sometimes limits children with disabilities to having an onlooker role, because the occupations could not be adapted to all children in the classroom. This was fully experienced by Paula, who has congenital blindness. In the following example, Paula described a situation where she could not perform the same occupation as her classmates:

> The other day we were learning the demonstrative pronouns … and the teacher just taught them to the others, because they were reading from the book. I was just listening … she told me to do that because my other teacher [special education teacher] would teach me that later on … (Paula).

Like Paula, the other children with disabilities were more willing to participate as an onlooker when they were together with their classmates and when they understood the circumstances involved in the occupation and why they were not performing with the others.

The last quotation also highlights the role of special education teachers in the students' learning process. The children interviewed had access to both regular and special education teachers. The special education teachers provided support in tasks specifically chosen to suit the student's abilities. Some children stated that they were able to establish a stronger relationship with their special education teacher, because they knew him or her better. These children normally had individual educational support or received it in small groups of two or three students:

> When I was sad, Ms Margarida, who was my special education teacher, always noticed … I had classes with her alone – one hour a week – and sometimes I spoke to her about my problems … (To).

The descriptions of close relationships with these teachers were linked to the feelings of being understood and supported. Most of the interviewed children were fond of their special education teachers.

As mentioned above, support from special education teachers played an important role in the learning process of the children interviewed. The children with disabilities stated that they wanted to learn and to succeed in their studies; however, they were aware of their own difficulties and the special educational support was perceived as an aid to overcoming them.

Non-participation

The data analysis also revealed descriptions of non-participating. This referred to situations in which the children were not able to do the suggested activities and did not feel involved. The children described situations when they had to take on the role as excluded observers, such as a boy who during sports lessons observed his friends without the teacher giving him anything else to do. Therefore, he felt excluded from the class, which resulted in a feeling of boredom. Being an excluded observer was also experienced in the playground, which was often described as a hazardous environment, with dangerous objects, few means of access and lacking attractive activities:

> Staying in the playground is awful … the playground is a place with a lot of stones and it's too big. I don't like to be there because there are a lot of stones … and we can fall on the stones … I hate that! (Carmo.)

Carmo (who has walking impairments) felt upset and bored in the playground because the physical environment excluded her from taking part in activities. The lack of engaging activities in the playground was often mentioned by the children with disabilities. The activities available in most playgrounds were not suited to the needs and preferences of the children with disabilities.

A social aspect of non-participation was associated with some peers, who were perceived as a barrier to participation. Most of the children interviewed designated them as 'the others'. This expression conveys the distance between them since, in contrast to friends and best friends, 'the others' were unfriendly and not acquainted with the children with disabilities. Frequently, 'the others' were older and/or stronger children, who created unpleasant situations of exclusion, not allowing the children with disabilities to participate. Sometimes they went even further and bullied the children with disabilities. The feeling of sadness was closely linked to these experiences. As shown in the following example, the children with disabilities had a propensity to find another type of occupation, out of sight of the others, or to ask for adult intermediation when these situations occurred. Furthermore, they tended to avoid being together with 'the others':

> The others … they sometimes make fun of me (…) I start crying and I call the teacher … I don't like to play with them … (Joana).

Like Joana, who is a child with an intellectual impairment, the other participants declared that they did not like to do things with children who made fun of them. In such cases, the children felt excluded from occupations resulting in non-participation. The children with intellectual impairment referred more often to situations of being humiliated by peers than the other children interviewed. For all these reasons, most of the children with disabilities stated that they would rather spend all their breaks in the classroom with their best friends than as an excluded observer in the playground.

The data analysis revealed that performance without understanding was also experienced as non-participation. For example, one child expressed how difficult it was for her to be in a mathematics class:

> I am just there [in the mathematics class], but I can't do anything … and I don't like being there. It's as if I was not there. For me it's like Chinese, I can write numbers, but I don't understand anything … (Raquel).

Teachers who failed to understand were described in connection with non-participation situations in the classroom. The relationship with regular teachers was often described as a hierarchical one, which contained some communication problems. The children with disabilities did not feel that they could influence their own learning process and stated that the teachers had the power to decide everything for them. This position seems to hinder the participation of children with disabilities in their own educational process:

> At the beginning of each day, one student has to distribute the material for the class. I'd like to do it, but the teacher never asks me … and I can't do anything because she's the one who decides that (Susana).

In this example, the teacher was experienced as a barrier because she excluded the student with disabilities from ordinary school activities. Moreover, Susana felt that she could not communicate her requests to the teacher. She felt excluded from her own decision-making process and this made her feel powerless to solve her problems. Similarly, several of the children interviewed stated that teachers were not available to answer questions. The teachers set the difficulty level for the subject too high and they were hard to understand. In all these situations, the children with disabilities were excluded from the learning activities, and this brought about feelings of sadness, annoyance, frustration and anger.

Discussion

The aim of this study was to explore and understand how children with disabilities experience their participation in mainstream schools in Portugal.

A major finding in this study was the complexity of the children's participation in mainstream schools. Although both performance and social aspects have been described in the literature as important for participation (Law et al 1996, Hemmingsson and Borell 2002, Hemmingsson et al 2003,

Hemmingsson and Jonsson 2005, Heah et al 2007, Asbjørnslett and Hemmingsson 2008), this study goes one step further and contributes by identifying different forms of participation and connecting those forms to performance characteristics and social environmental aspects.

The participation form, equal participation, is linked to the subjective experience of being competent and totally involved in the occupation. Attending a mainstream school allowed children to compare themselves with non-disabled peers. The children's comparison with their peers offers a dynamic process in their self-perception and seems to be significant in the decision to participate fully. Peer significance in children's development and in children's feeling of participation is supported by recent literature (Hemmingsson et al 2003, Asbjørnslett and Hemmingsson 2008). Simultaneously, this form of participation highlights the importance of perceived self-efficacy when participating. Along similar lines, Bandura and Schunk (1981) had previously claimed that self-efficacy judgement plays a role in the decision of taking part in a situation.

The special task participation characterises situations in which the children with disabilities perform a different task inside a group occupation. The main difference between this form and the onlooker participation form is that the child contributes directly, interacting with others and influencing the occupation's final result. It is interesting to note that performing a different task does not jeopardise the children's identity but, rather, gives them the opportunity to demonstrate their talents. This did not suggest that children with disabilities felt unique, but that they valued participating with peers even though they had to perform in a different way. The value of social togetherness as an integrated part of participation matches other similar findings; the same feeling was found in a study of people with chronic pain (Borell et al 2006).

The onlooker participation form comprises situations in which the children with disabilities shared a feeling of participation, although they neither played any role in the occupation itself nor contributed to the occupation's final result. For the children interviewed, there was no problem in being passive observers in some school occupations, as long as they understood the observed situation and felt that they engaged at some level. A good relationship between the observing child and those who were performing seems to influence the way in which the child experienced being an observer. Onlooker participation highlights the importance that children with disabilities confer on being in the same environment as their peers. The opportunity to be able to know what peers do by observing them is experienced as a kind of involvement in the peers' occupation. These findings have similarities with the experiences of disabled older people (Leven and Jonsson 2002) or of people with advanced cancer (la Cour 2008), who considered themselves to be engaged in occupations without actually performing them. In these circumstances, being in the atmosphere of the doing was described as having the same qualities as the actual doing.

Non-participation is associated not only with feelings of powerlessness but also with a sense of being excluded. Surprisingly, situations of non-participation were not just those in which the child did not perform an activity. Not being able to understand the situation where the child was involved seems also to be experienced as non-participation. From this point of view, it is understandable that the social environment has a strong impact on the participation experience and, as Egilson and Hemmingsson (2009) suggested, school occupational therapists should extend their focus from physical accessibility to the children's wellbeing and their feeling of involvement in their groups and occupations.

The participation forms described in this study challenge the definition proposed by the WHO. The WHO defines participation as involvement in life situations and appraises it through the observable dimension of participation. The findings of the present study show that, when considering the individual experience of participation, different forms of involvement in life situations can be revealed. This supports the suggestion of several authors that the ICF, as an instrument to classify participation, should be further developed, so that the individual's experience of participation is incorporated (Ueda and Okawa 2003, Hemmingsson and Jonsson 2005).

Limitations of the study

A limitation of this study is the selection of participants. A broader perspective of participation in mainstream schools could have been obtained by including children with different communication skills, for example deaf students or younger children. However, the method of data gathering and data analysis made it necessary to exclude those who had limited verbal language skills. The fact that data were gathered only from interviews might also limit the results and the inclusion of observations could be considered. Nevertheless, this is a phenomenological study that focuses on descriptions of a particular phenomenon as 'participation experience of children with disabilities in mainstream schools' and, for that reason, interviews were chosen as the proper data gathering method (Polit and Beck 2004) since one cannot observe the subjective experience.

Another limitation is that methodological triangulation, through researcher triangulation (Harvey and MacDonald 1993), was decreased, as only the first author speaks Portuguese. Nevertheless, the co-authors had access to parts of the raw data because the first author translated some of the interviews into English in order to proceed with the analysis.

Implications

The different forms of participation presented and the interacting social and occupational aspects might expand opportunities for supporting children with disabilities in mainstream schools. According to the results of this study, children's participation may be facilitated by arranging activities so that the best possible form of participation is achieved. The aim is to increase the children's participation

at school, avoiding the non-participation form. Thus, in some activities full participation might be obtained, whereas in others onlooker participation or special task participation might be the best available option.

Additionally, this study draws attention to the importance of social interaction in mainstream schools. Professionals should take into consideration the importance of peers and friendship when planning interventions in this field. There is also an important need to work in close collaboration with teachers, guiding their understanding and modifying tasks or environments, and thereby facilitating children's participation. Therefore, this study is relevant not only to occupational therapists but also to parents, teachers and other school personnel.

The implications of this study for further research are primarily related to the individual experience of participation and the possibility of generalising the forms of participation to different age groups (children, adults and older people).

Conclusion

In this study, three forms of participation were found – equal participation, special task participation and onlooker participation – and one form of non-participation. Data analysis revealed that these situations were connected both to the characteristics of the children's performance (that is, how involved the student was in the actual performance) and to the characteristics of the social environment (that is, support and understanding from peers and teachers). Engagement was identified at all forms, except in non-participation. Observable performance was present in two forms, equal participation and special task participation, but not necessarily in onlooker participation, indicating that students can experience participation without directly performing in the activity. Non-participation could also be described as doing without involvement and/or performing without understanding.

The present study provides information about the importance of being with peers, showing that children with disabilities, in some situations, feel actively engaged in their peers' activities mainly by observing or by doing different tasks.

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Conflict of interest: None declared.

Key findings

- Both the physical and the social environment influence the participation and non-participation experiences.
- Three forms of participation – equal participation, special task participation and onlooker participation – and one form of non-participation were found.

What the study has added

This paper presents a new insight into the children with disabilities' experiences of participation in mainstream schools. Through this phenomenological study, it was revealed that personal experiences can contribute to a broader definition of participation.

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