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ORIGINAL REPORT

PARTICIPATION IN LEISURE ACTIVITIES FROM THE PERCEPTION OF CHILDREN WITH DISABILITIES AND THEIR FAMILIES IN BRAZIL

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Objective: **To understand the perception of children with disabilities and their families regarding factors that interfere with participation in leisure activities in Brazil.**
Methods: **This qualitative study included 14 focus groups, involving a total of 80 participants (40 children with disabilities and 40 family members). Discussions were recorded and transcribed. Coding was based on the International Classification of Functioning Disability and Health, following linking rules.**
Results: **A total of 80 individuals participated in the study. For parents and children the most-cited barriers to participation in leisure activities were related to environmental factors. For children, the main barriers were the attitudes of their nuclear family, acquaintances, and friends. Access to products and technology for personal mobility were also important obstacles. For them, support from immediate family was both a facilitator and barrier. Other barriers identified by family members were open-space planning services and assets. As facilitators, the attitudes and support of people in positions of authority also were reported by this group.**
Conclusion: **For parents and children, most disabling barriers were related to environmental factors, such as access to products and technology, support, and attitudes. Some differences in perception were observed between comments from children and parents; for example, regarding barriers due to immediate family. Parents showed greater awareness of barriers and facilitators to participation in leisure activities.**

Key words: disability; children; parents; participation; environment; focus group; International Classification of Functioning Disability and Health.

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LAY ABSTRACT

The aim of this study was to understand the perception of children with disabilities and their families regarding factors that interfere with participation in leisure activities in a developing country. This qualitative study included 14 focus groups, involving a total of 80 participants (40 children with disabilities and 40 family members). Discussions were recorded and transcribed. Coding was based on the International Classification of Functioning Disability and Health (ICF), following linking rules. For children, the main barriers to participation in leisure activities were the attitudes of acquaintances, friends or strangers. Lack of access to products and technology for personal mobility were also important obstacles. For them, support from immediate family was the both a facilitator and barrier. Other barriers identified by family members were open-space planning services, and assets. As facilitators, the attitudes and support of immediate family also were reported by this group. In conclusion, for children, the attitude of peers was the main barrier to participation in leisure activities, while, for family members, the main barrier was the attitude of strangers.

Participation is defined by the International Classification of Functioning, Disability and Health (ICF) as "the involvement of the individual in real-life situations" (1). The main elements of this construct are: "attendance", defined as "being there" and measured as frequency of attending and/or the range or diversity of activities; and "involvement", defined as the experience of participation while attending, which includes elements of engagement, persistence, social connection, and level of affect (2, 3).

Participation provides environmental exploration, achievement and improvement of motor, cognitive, behavioural, and social skills, as well as improved physical and emotional well-being (4). Assessment of participation requires a careful description of significant activities that frequently occur in the life of a child (5), such as involvement in games, play and leisure activities, as well as social and community interaction. These can be performed individually or in groups and reflects the engagement levels of children at home, at school or in the community (6).

Knowing the preferences of the children and the family may be a key aspect for enhancing their participation (7, 8). Listening to their voices and understanding their needs and choices are essential to offering the best activity options (9). However, identifying the involvement of the child during participation as well as their needs is a challenge for researchers (10).

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The ICF biopsychosocial framework considers that disabilities and environmental factors, such as the physical, social and attitudinal setting, may restrict participation in social and leisure activities (11, 12). Studies conducted in high-income countries show that attitudes, transportation, financial constraints, and support from service providers are some of the barriers to participation in leisure activities (13). However, in low- and middle-income countries, where environmental barriers, such as public transportation and financial constraints, are experienced by a large part of the population, it is challenging to understand how environmental factors hinder the participation of children with disabilities (14).

Most studies on the participation of children with disabilities are based on caregivers' perceptions (14, 15), but there is increasing interest in listening to the voices of children with disabilities themselves. Including these voices in research highlights the first-hand perspective of those who participate in leisure activities (16). The comparison between a child's and caregiver's perceptions may underscore different viewpoints (17) and better illustrate the situation.

Interventions focused on participation represent a more recent outlook on rehabilitation (18) and, for many children and families, achieving optimal participation levels is the most anticipated and valued outcome of the intervention. Thus, identifying barriers that limit the performance of activities and restrict participation, as well as the knowledge of facilitators, will help guide health professionals, managers and those responsible for children with disabilities (14, 19).

The aim of this study is to understand the perception of children with disabilities and their families regarding factors that interfere with participation in leisure activities in Brazil. This is a pioneering study in Brazil, which explores the topic in depth and places the most important stakeholders at the centre of decision-making.

METHODS

Study design

This study used a qualitative research approach with a focus group. Using this method, adults or children can share experiences, perceptions, needs, problems and opinions on a given subject (20). Focus groups, in particular, provide the potential to explore subjective constructs and clarify points of view and reveal dimensions of understanding that would be less easily accessible in other data collection formats.

The project was approved by the Research Ethics Committee of the Federal University of Rio Grande do Norte (UFRN), in accordance with National Health Council Resolution 466/12 (protocol number 1.659.780). The study was conducted at the Pediatric Physiotherapy laboratories of the Federal University of Rio Grande do Norte (UFRN – main campus and FACISA campus), Brazil. All parents/legal guardians provided written informed consent and audio-recording release forms, authorizing the child's participation.

Setting

Participants were recruited from the capital of Rio Grande do Norte state (Natal) and 2 nearby municipalities. Most of the children are followed at public rehabilitation services, including residents of both urban and rural areas.

Subjects

Participants with important common characteristics were purposely selected at Pediatric Rehabilitation Services in the cities of Natal (UFRN- main campus, Potiguar University, Heitor Carrilho, UniRN, and the Specialized Rehabilitation Center of Natal), Macaíba (Anita Garibaldi) and Santa Cruz (UFRN- FACISA campus) by members of the research team, through active search via phone calls or direct personal contact. The inclusion criteria for children were: displaying some form of disability (physical, congenital or acquired); being between 6 and 18 years old, of both sexes; and able to understand questions and communicate (verbally or with the help of assistive technology). Exclusion criteria were: non-attendance of the family member or child on the date and time scheduled for the focus group meeting; difficulty/inability to answer questions on the topic during the discussion, or lack of participation during the focus group. Family groups were formed by caregivers of children who had some degree of kinship with them.

Data collection methods and instruments

Sociodemographic questionnaire. An evaluation form developed by the researchers was used to obtain and record the personal data of children with disabilities and their families.

Focus group. To guide the focus groups and direct the discussions, an interview guide was used (Table I). Focus groups were conducted by a previously trained moderator. An assistant helped run the group, identifying the participants, checking the material to be used (charts and tape recorder) and subsequently transcribing the statements.

Data collection procedures and saturation

The groups were scheduled in advance and, after signing the agreement terms, the questionnaire was administered to family members in order to collect sociodemographic data. Next, family members and children were taken to different rooms, where the focus groups were held. Each group was led by a moderator, who was in charge of initiating and directing the discussion, using the

Table I. Guiding questions used in the focus groups

Focus group and guiding questions
Children with disabilities
1. Do you participate in leisure activities? Which ones?
2. In your opinion, what hinders your participation in leisure activities?
3. In your opinion, what facilitates your participation in leisure activities?
4. Is there any leisure activity that you would like to participate in but do not?
Family members of children with disabilities
1. Does your child participate in leisure activities? Which ones?
2. In your opinion, what hinders your child's participation in leisure activities?
3. In your opinion, what facilitates your child's participation in leisure activities?
4. Is there any leisure activity that your child would like to participate in but does not?

question guide. To facilitate dialogue in the children's group, in addition to the interview guide, the moderator used cards with images that illustrated children engaging in leisure activities (playing in a park, going to the beach, going to the movies, playing team sports). Each group consisted of 5–8 participants and lasted a mean of 50 min (maximum 70 min, minimum 30 min).

After 8 sessions (16 groups), collections were finalized after the saturation criterion was met. The concept of "saturation" refers to the point during data collection when the linkages among the qualitative data of 3 consecutive focus groups have no more than 5% additional second-level ICF categories compared with previous focus groups. Recent research has applied this definition when analysing executive functioning in children with cerebral palsy (CP) using qualitative methods (21).

Data analysis

The ICF model, the main framework for rehabilitation studies, was used as a reference for data analysis, by linking qualitative data based on the rules proposed by Cieza et al. (22). This methodology has been updated twice and is widely disseminated in the literature (23, 24). Five functioning categories are included in the ICF model: Body Functions (b); Body Structures (s); Activities and Participation (d); Environmental Factors (e); and Personal Factors. These components are divided into the subcategories shown in Table II.

Table II. International Classification of Functioning, Disability and Health (ICF) components divided into categories and subcategories

Category (first-level classification)	Subcategory (second-level classification)
Body Functions (b)	Mental functions (b1)
	Sensory functions and pain (b2)
	Voice and speech functions (b3)
	Functions of the cardiovascular, haematological, immunological and respiratory systems (b4)
	Functions of the digestive, metabolic and endocrine systems (b5)
	Genitourinary and reproductive functions (b6)
	neuromusculoskeletal and movement related functions (b7)
	Functions of the skin and related structures (b8)
Body Structures (s)	Structure of the nervous system (s1)
	The eye, ear and related structures (s2)
	Structures involved in voice and speech (s3)
	Structure of the cardiovascular, immunological and respiratory systems (s4)
	Structures related to the digestive, metabolism and endocrine systems (s5)
	Structure related to genitourinary and reproductive system (s6)
	Structure related to movement (s7)
	Skin and related structures (s8)
Activities and Participation (d)	Learning and applying knowledge (d1)
	General tasks and demands (d2)
	Communication (d3)
	Mobility (d4)
	Self care (d5)
	Domestic life (d6)
	Interpersonal interactions and relationships (d7)
	Major life areas (d8)
	Community, social and civic life (d9)
Environmental Factors (e)	Products and technology (e1)
	Natural environment and human made changes to environment (e2)
	Support and relationships (e3)
	Attitudes (e4)
	Services, systems and policies (e5)
Personal Factors	This category does not support subcategories

All focus groups were audio-recorded and transcribed verbatim by an external research assistant and checked for quality by 2 members of the research team (JSM, ARL). Three ICF-trained researchers (JSM, ERVPG, HNCF) read the transcripts several times and the texts were collated to enable qualitative analysis, using a content analysis approach (25). This analysis ensured identifying narratives referring to the categories established in the ICF. These findings were organized by ICF components and linked to the ICF categories according to established linking rules. The 3 ICF-trained researchers conducted this process independently. Consensus between the 3 researchers was used to decide which specific ICF category should be linked to each concept. Disagreement between the researchers was resolved by unanimous decision after discussion.

The parents' and children's perceptions were analysed separately and then compared in order to determine the differences and similarities between them regarding factors that influenced the children's participation in leisure activities. Based on the results, a model was proposed to illustrate the barriers to participation.

For results related to the subjects' characteristics (sociodemographic data), descriptive statistics were used to show the mean, median, standard deviation and frequency.

RESULTS

Fourteen focus groups were conducted, with a total of 80 participants (40 children with disabilities and 40 family members). In terms of the family group, mean age was 40.6 years (range 23–64 years) with a standard deviation (SD) of 6.01 years (median 41.0 years). For the group of children, the mean age was 10.7 years (range 6–18 years), SD 3.5 years (median 10.5 years). Of the 14 children who used a wheelchair, 7 (17.65%) were able to manoeuvre it independently, while 7 (17.65%) needed assistance. The remaining sociodemographic characteristics of family members and children are shown in Table III.

The analyses revealed 3 main barriers and facilitators to participation: Environmental Factors (e), Body Function (b), and Body Structure (s). Environmental Factors were the most responsible for restricting participation in leisure activities, both in the group of children with disabilities and family members. The Body Function component identified in the statements of children and family members was the second most cited, and Body Structure the least mentioned. The topics to follow present the main categories, based on the ICF framework, to reveal the factors involved in children with disabilities' leisure activity participation as well as discrepancies and similarities between parents and their children. Fig. 1 summarizes the results, illustrating the main barriers to participation.

Category 1 – Environmental Factors (e)

For both groups, Environmental Factors were a major influence on leisure activity participation, either as a barrier or a facilitator. In this category, attitudes (e4)

Table III. Characteristics of participants of the focus groups

Focus group and characteristics	*n*	%
Children with disabilities		
Schooling		
Child education	5	12.5
Elementary school	33	82.5
High-school	2	5.0
Studying currently		
Yes	36	90.0
No	4	10.0
Siblings		
Yes	23	57.5
No	17	42.5
Health condition		
Spina bifida	9	22.5
Cerebral palsy	10	25.0
Autism/ADHD	9	22.5
Others	12	30.0
Locomotion		
Walks without using devices	22	55.0
Walks with devices	4	10.0
Wheelchair	14	35.0
Communication		
Fluent speech	26	65.0
Speak with difficulty/help	14	35.0
Object handling		
Independent	30	75.0
Needs help	10	25.0
Family members of children with disabilities		
Schooling		
Incomplete elementary	9	22.5
Complete elementary	7	17.5
Incomplete secondary	6	15.0
Complete secondary	12	30.0
Complete university	6	15.0
Relation with the child		
Immediate family (parents, siblings, grandparents)	37	92.5
Extended family (aunts, uncles, cousins)	3	7.5
Currently employed		
Yes	10	25.0
No	30	75.0
Mean family income		
1 minimum monthly wage (≈USD 250.00)	19	47.5
2 minimum monthly wages	17	42.5
3 or more minimum monthly wages	4	10.0

ADHD: attention deficit hyperactivity disorder.

were highlighted by both children with disabilities and their families as the main barrier. While children reported support and relationships (e3) as the main facilitator, family members emphasized attitudes (e4) as the main motivators for children's participation in leisure activities. Next, the barriers and facilitators mentioned by participants were underscored in relation to the second-level classification. Table IV shows a predominance of barriers related to subcategories and the respective quotes.

Subcategory e1 – Products and technology. Both groups cited products and technology as a barrier to participation due to problems related to mobility and transportation, buildings for public use, and assets. Families and children also considered them facilitators to participation, for making mobility and personal transport easier, encouraging culture, recreational activities and communication. Parents and children also believe in the importance of technologies and architectural changes to facilitate mobility. When asked about the leisure activities that their children engage in, the families reported the use of technologies as being important for participation.

> *"Although he studied at a model school, we also had some difficulties ... it was necessary to make ramps..." (mother of 11-year-old boy, myelomeningocele)*

Subcategory e2 – Natural environment and human-made changes to the environment. This subcategory was mentioned only in the family group. For some mothers, the fear of their children becoming sick because of poor air quality makes them restrict their participation in leisure activities.

> *"I was afraid of her going to the circus because of the dust" (mother of 7-year-old girl, myelomeningocele).*

Subcategory e3 – Support and relationships. Both groups mentioned barriers classified in the immediate family and personal care providers categories. Immediately family, acquaintances, peers, colleagues, neighbours, community members, personal care providers and personal assistants were cited by several children and their families as facilitators to participation. Among the categories reported by the 2 groups, personal care providers and personal assistants were mentioned by family members as facilitators to children's participation at school.

> *"Well, at school he participates in everything, I never had any problems" (grandmother of 8-year-old boy, autism).*

Subcategory e4 – Attitudes The most frequently cited attitudinal barriers were immediate family members, friends, acquaintances, peers, colleagues, neighbours, community members, strangers and societal attitudes. The negative attitudes of immediate family members were identified in some of the parents' quotes. The overprotection exhibited by some families was also a barrier to participation. Negative attitudes of friends and colleagues from school and the community were also reported by a number of children. The attitudes of strangers and society in general were also related by both groups as barriers to participation.

Some categories, such as attitudes of immediate family members, friends, acquaintances, peers, colleagues, neighbours and community members, were equally cited by families and children as facilitators to participation, depending solely on the context where they emerge in the children's daily routine. Individual attitudes of nuclear family members were widely reported as facilitators in this domain, by both groups.

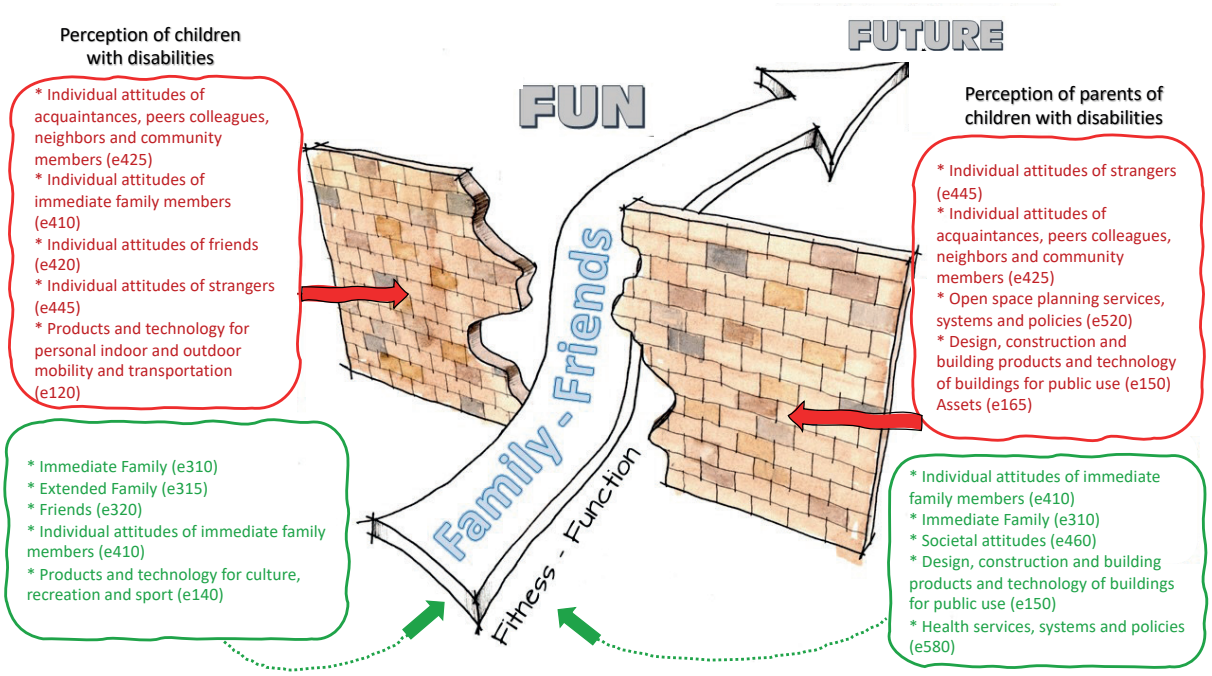

Fig.1. Barriers and facilitators to participation in leisure activities according to the perception of children with disabilities and their family members

People in positions of authority and societal attitudes were also mentioned by the families as facilitators.

"I never had any setbacks with the dune park security guards asking me to get out of the toy." (mother of 6 year-old boy, cerebral palsy).

Subcategory e5 – Services, systems and policies. Both children and families cited open-space planning, transportation and general social support. One mother found it difficult to leave the house with her son to engage in leisure activities, due to the poor quality of the public transportation system, and barriers related to general social support in the neighbourhood were also mentioned. Also, with respect to services, systems and policies, the families reported barriers related to architecture, construction, civil and legal protection, social security and health.

In regard to facilitators, the families cited the health services provided to the children as a facilitator to participation. This group discussed the sub-topic in greater depth, referring to aspects such as open-space planning, civil and legal protection, and general social support that could act as facilitators to the children's participation in leisure activities.

"My son is accompanied by a psychologist, participates in swimming and an art workshop. " (father of 13-year-old boy, autism).

Category 2 – Body Function (b)

Subcategory b7 – Neuromusculoskeletal functions related to movement. Although they were not the main barriers, musculoskeletal functions were cited by some children and families. They mention musculoskeletal functions related to weakness, lack of voluntary control, and involuntary movements as barriers to participation. The children stated that the desire to perform a leisure activity would be limited by functional and structural aspects, such as balance and muscle weakness. In addition, the families considered children's gait a relevant barrier to participation, whereas the children did not.

"She really wanted to skate, but it's complicated for her to ride alone". (father of 13-year-old girl, cerebral palsy)

Category 3 – Body Structure (s)

Subcategory s7 – Structures related to movement. Although structural changes were less cited by both groups, they reported that the structures related to movement are a barrier to participation in leisure activities. The children and families mentioned the structure of the head and neck region and upper and lower structures as barriers. However, these aspects were only minimally reported.

Table IV. Examples of quotes ordered by International Classification of Functioning, Disability and Health (ICF) for Children and Youth components

Question and ICF component	Subcategory	Quotes
Children with disabilities		
In your opinion, what hinders your participation in leisure activities?		
Environmental Factors	Subcategory e1 – Products and technology	Mobility, transportation, and buildings for public use: "When I go to the beach it is difficult because my wheelchair does not ride on the sand" (boy, 7 years old, myelomeningocele).
		Assets: "I wanted to go to the cinema, but you can't go ... it's expensive" (girl, 7 years old, ADHD).
		Lack of access to recreation and sports: "There is a playground close to home, I even go there, but it is not adapted" (boy, 9 years old, autism).
	Subcategory e3 – Support and relationships.	Personal care providers: "There is some equipment in the playground that I can't use and there is no helper at my school" (girl, 10 years old, cerebral palsy GMFCS III).
	Subcategory e4 – Attitudes	The overprotection of some families was also identified as a barrier to participation: "She really wants to ride a bicycle but I'm afraid and don't let her" (father of a 12-year-old girl, brain stroke).
		About immediately family: "I really wish I could play ball, but my mom is afraid I'll hit my head" (girl, 12 years old, stroke).
		Negative attitudes from friends: "most of them at school don't allow me to play, they think I can't" (boy, 11 years old, myelomeningocele).
		Negative attitudes from schoolmates and community: "I can get hurt by some child hitting my chair and it turns over" (boy, 13 years old, cerebral palsy).
		Barriers related to general social support in the neighbourhood: "I used to swim, but I stopped because it was too far" (girl, 15 years old, myelomeningocele).
	Subcategory e5 – Services, systems and policies	Participation could also be facilitated if the space was more prepared to receive the child: "It would be good to decrease the amount of sand to get to the beach… if it was compact and harder it would be much better" (girl, 15 years old, myelomeningocele).
		Barriers related to general social support in the neighbourhood were also mentioned: "I used to swim, but I stopped because it was too far" (girl, 15 years old, myelomeningocele).
Function and Body Structure	Subcategory b7 – Neuromusculoskeletal and movement-related functions	Musculoskeletal functions, such as weakness, lack of voluntary control, involuntary movement or movements and lack of balance were cited as barriers by some children and families "I can't stay on the playground ... I can't stand ..." (girl, 6 years old, cerebral palsy).
	Subcategory s7 – Movement-related structures	For some of the children, problems related to lower extremity structure make it difficult to participate in leisure activities: "If my foot was corrected, I could play ball" (girl, 8 years old, myelomeningocele).
		Among the family members, a mother said: "I don't think she has great difficulties, just her little arm that gets in the way of playing" (girl, 8 years old, obstetric brachial palsy).
In your opinion, what facilitates your participation in leisure activities?		
Environmental Factors	Subcategory e1 – Products and technology	Importance of technologies and architectural changes to facilitate mobility: "It would be nice if bikes were adapted for people with all types of disabilities because then they would be able to ride" (girl, 15 years old, myelomeningocele).
	Subcategory e3 – Support and relationships	Immediately family was cited by many children as facilitating participation: "I have a painting that my father bought for me to draw with this and that hand" (using both hands) (girl, 12 years old, brain stroke).
		The extended family was also mentioned as a facilitator: "My grandmother, she always helped me." (girl, 15 years old, cerebral palsy).
		Children also mention the importance of friends, support to facilitate and promote their participation in leisure activities: "My friend helps me at recess. She invites me for lunch and takes me to play" (girl, 8 years old, cerebral palsy GMFCS IV).
	Subcategory e4 – Attitudes	The attitudes of immediate family were mentioned by a child through experiences with siblings: "My brother helps me play at school, with friendships… he protects me" (boy, 11 years old, traumatic brain injury).
		Children realize the importance of having friends: "She is my friend. At recess she lunches with me, and takes me out to play" (girl, 6 years old, cerebral palsy).
Family members of children with disabilities		
In your opinion, what hinders your child's participation in leisure activities?		
Environmental Factors	Subcategory e1 – Products and technology	About assets: "This income is not enough to do everything you want, because there are priorities" (mother of 8-year-old girl, amniotic band syndrome).
	Subcategory e2 – Natural environment and human-made changes to environment	About natural environment: "She has breathing problems and places that have dust are bad…so when we go to the countryside, I'm afraid she'll get sick" (mother of 8-year-old girl, ADHD).
	Subcategory e3 – Support and relationships	This account was reinforced by her mother: "The school she studies at is well structured but there is no one to provide support" (mother of 10-year-old girl, cerebral palsy GMFCS III).
	Subcategory e4 – Attitudes	Negative attitudes of immediate family members were identified in some statements by parents: "His routine is intense, and he still has time for everything, the time for eating, bathing is different, so I have to plan all this. Sometimes his leisure is on television because I need a shower, I need to eat ... " (mother of 9-year-old boy, cerebral palsy).
		The overprotection of some families was also identified as a barrier to participation: "She really wants to ride a bicycle but I'm afraid and don't let her" (father of a 12-year-old girl, brain stroke).
		Negative attitudes from friends were identified by a mother: "There is a boy who keeps other boys from him ..." (mother of 9-year-old boy, autism).
		Negative attitudes from neighbours and community members were reinforced by a parent: "The neighbours keep gossiping that I have a special boy ..." (father of 13-year-old boy, ADHD).
	Subcategory e5 – Services, systems and policies	Stranger and societal attitudes were also presented by families and children as barriers to participation: "Drivers do not respect the accessibility ramps" (mother of 8-year-old girl, brain stroke).
		One mother said it was difficult to leave the house with her son for leisure activities due to the quality of the public transport system: "The transportation system where I live is poor, the buses are not adapted" (mother of 14-year-old boy, cerebral palsy GMFCS IV).
		About general social support a mother reinforces that: "Pedestrian crossings also do not work, because some stop and others do not, a traffic light should be installed soon" (mother of 9-year-old boy, autism).

Function and Body Structure	Subcategory b7 – Neuromusculoskeletal and movement-related functions	Family members recognized the health services offered to children as a facilitator for participation. An aunt said: "Here participates in some activities, such as occupational therapy and physical therapy" (aunt of 12-year-old boy, hydrocephalus).
		"He doesn't stand on his chair because of his balance" (mother of 6-year-old boy, myelomeningocele).
	Subcategory s7 – Structures related to movement	"She has a wheelchair, but she doesn't do more things because she can't walk" (mother of an 8-year-old girl, cerebral palsy GMFCS-IV).
In your opinion, what facilitates your child's participation in leisure activities?		
Environmental Factors	Subcategory e1 – Products and technology	A mother believes that using the cell phone offers the child ease of communication, culture and recreational activities: "Access to the cell phone allows her to learn many things" (mother of 6-year-old girl, cerebral palsy).
	Subcategory e3 – Support and relationships	Parents also believe in the importance of technologies and architectural changes to facilitate mobility: "Although he studied at a model school, we also had some difficulties ... it was necessary to make ramps ..." (mother of 11-year-old boy, myelomeningocele).
		The immediate family was quoted by a mother: "When I can't go out with my son, my sister takes him to the beach, to the mall... she just needs the opportunity" (mother of 13-year-old boy , ADHD).
	Subcategory e4 – Attitudes	Families also perceive the importance of friends to promote participation: "She ... has her friends. Every night there are five or six at home to play with her " (mother of 12-year-old girl, brain stroke).
	Subcategory e5 – Services, systems and policies.	Positive attitudes of immediate family were cited by family members: "She wants to go to the cinema alone, I stay at the mall, but I make her very comfortable" (father of 13-year-old girl, cerebral palsy).
		Family members recognized that health services offered to children as a facilitator for participation: "He participates in some activities, such as occupational therapy and physical therapy" (aunt of 12-year-old boy, hydrocephalus).
		A good open-space planning service could favour participation: "It would be nice if there was better accessibility at the beach" (mother of 16-year-old boy, brain tumour sequelae).

ADHD: attention deficit hyperactivity disorder; GMFCS: Gross Motor Function Classification System.

"if my foot was corrected, I could play ball" (girl, 8 years old, myelomeningocele)

DISCUSSION

This study aimed to determine the perceptions of family members and children with disabilities regarding the problems, barriers, and facilitators to participation in leisure activities. The results show that environmental factors were the major restrictors, but were also regarded as potential facilitators by both groups. To a lesser extent, problems related to body structure and function were also mentioned, but mostly by family members rather than the children with disabilities themselves.

Environmental factors

Environmental factors, especially the social environment, may have a positive or negative impact on the participation of children with disabilities in leisure activities. In the present study, both groups considered aspects related to the immediate family, personal care providers and extended family and friends as barriers to participation. Studies show that, to encourage children with disabilities to participate in leisure activities, parents need to be motivated, engaged and well informed. Negative family attitudes, whether by negligence or overprotection, may have an unfavourable impact on the frequency and involvement of children in leisure activities. In addition, the non-acceptance of their peers at school and in the community leads children with disabilities to isolation, distancing and exclusion (14, 26).

From the children's point of view, family support is an important facilitator. When they are in need, assistance offered by members of the nuclear family is very useful (27) and children feel they can participate with their parents' help (28). The support and attitudes of individuals within the nuclear family are considered an important factor in facilitating the participation of children with disabilities (14), given that they share a large part of leisure activities with their families (29).

According to Heah et al. (30), the family has a positive influence on children's participation in leisure activities, and the involvement of parents in playing, physical support, supervision and protection offered by the family environment encourages children`s participation in leisure activities (13). Thus, when they are apart from their parents, their friends, colleagues and neighbours may have the same emotional importance for the involvement of children with disabilities in school and community activities, acting as support for socialization and social inclusion (16, 31).

For the children included in this study, some attitudes of the nuclear family limit their participation in leisure activities. Fearing falls, people's reactions and even child protection services, mothers and fathers deny their children's participation in leisure activities when they cannot accompany them. According to Schiariti et al. (32), this minimizes the opportunities for children to be involved in motor, social, and emotional experiences that are essential to the development process, as well as socialization and leisure.

For family members, people in positions of authority, such as teachers and school directors, may act as facilitators to children's participation. According to Nathan et al., (33) teachers and other school staff members are key players in this process, especially since teachers ill-equipped to deal with people with disability also hinder participation.

With respect to services, systems and policies, accessibility issues (including ramps and public transportation) are important environmental barriers to participation. In this study, limited accessibility due to the quality of the services and systems offered (including transportation and architectural adaptations of recreational spaces) was identified as a barrier by all parents participating in the sample. This may be due to the financial conditions of low- and middle-income countries, which have limited access for wheelchair users and a scarcity of appropriate ramps and elevators in public buildings (14).

The physical environment (products and technology used for mobility and transportation, architecture and construction of buildings (entry, exit and facilities)) is a common barrier due to the lack of accessibility in public places (34). According to Earde et al. (14), children who are unable to walk may find it more difficult to access public spaces when other efficient mobility options are not available. Studies involving people with cerebral palsy (CP) and spina bifida showed that the physical environment has a direct impact on locomotor performance, thereby limiting the participation of people with motor impairment (35). The physical environment was also cited by the families in the current study as a facilitator to child participation. The parents of children with CP and spina bifida reported personal transport, culture, communication and architectural modifications. Indeed, motorized mobility may benefit children without a prognosis of normal self-directed gait to improve autonomy, social interactions and participation in general (36, 37).

Function and Body Structure

The Body Function and Structure categories were cited less frequently by the parents and children and were related to the upper and lower structures and head region. Other studies that also used the ICF to assess participation also obtained similar findings based on the discourses of parents, that is, function and structure impacting the participation of children in leisure activities (16, 23). Both groups reported control of voluntary movements, involuntary reactions and muscle weakness as factors that affected participation in leisure activities. This was also observed in a recent study that interviewed children with CP (16), where motor function was related to the participation in leisure activities of children with CP in Spain.

It cannot be confirmed that enhanced motor functioning improves the participation of children with disability. Kanagasabai et al. (38) published a systematic review that revealed a weak-to-moderate association between motor functioning and participation in leisure activities. The study showed that the improvement in children's motor function was not the main facilitator to participation. More recent studies have demonstrated that focusing on participation and eliminating the physical and social barriers of the environment may have a positive impact on the functional and structural components (3, 39). This fact should awaken the interest of physiotherapists and occupational therapists in interventions focused on the environment and the involvement of children in leisure activities (40).

Clinical considerations

This study showed ways to improve the participation of children with disabilities in Rio Grande do Norte state, Brazil, considering the children and families perceptions of themselves and enabling the children to speak about their health condition and aspects that facilitate or hinder participation from their point of view. In addition, this study analysed whether there are aspects of participation that only children can describe, highlighting the trend to listen to the voices of children with disability. Given these results, rehabilitation professionals should seek to identify which factors act as barriers to participation of children with disabilities in order to contribute to measures that can provide more effective involvement of these children in leisure activities. Facilitators should be encouraged, sought after, and used in these action strategies. Understanding the reality of children with disabilities, and involving them directly in the research, enables the formulation of better strategies to improve participation.

Study limitations

Despite being a pioneering study in Brazil, involving the assessment of the perception of families and children with disabilities, this study has a number of limitations related to the participants, since all of the subjects were recruited in rehabilitation services. Children with disabilities who do not undergo rehabilitation may experience other barriers and facilitators to participation. The focus groups were conducted in 2 cities and different contexts, but the sample was by convenience, and thus may not be representative of a wider geographical population. In addition, due to the need for children to communicate, the study contained few children with severe physical disabilities, which may affect generalization of the findings. More studies are required, involving children and adolescents with all levels of disability, who are receiving or not receiving rehabilitation, in order to broaden our understanding of participation in leisure activities.

CONCLUSION

Children with disabilities and their families agreed that environmental factors interfere more with the participation of these children in leisure activities than do the children's structural and functional aspects. Listening to children and their family members provided a more complete picture of children's participation. Parents consider the extended family and friends as barriers to participation, while children perceive the nuclear family as a barrier to participation.

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