

When participation of children and youth with disabilities is not merely activity: a study of the literature

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Abstract *This article analyzes the approach to children and adolescent participation in disability studies. Methodologically, it combines a literature review and a theme-based content analysis to look at which dimensions of participation are explored in the literature. As the result of this study we highlight four areas: Sports, Quality of Life/Well-Being, School and Participation Metrics. We find that the focus is on participation as performing activities within a given context, with very few broader discussions about the domain as a human value related to socialization and the development of a support network, the management of independence and levels of dependence.*

Key words *Child, Adolescent, Disability, Social involvement*

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Introduction

Participation is a key concept for the health of every child and adolescent, and is related to their involvement with interactive activities within a social definition. This definition focuses both on the nature and extent of this involvement, within a discussion of the sense of community and belonging^{1,2}.

To situate the reader, we should explain that references on disablement or people with disabilities or the disabled in general appear in the academic literature under three major headings: special healthcare needs (easily found by searching for “special needs”), chronic health conditions and disabilities as affirmative expressions of an identity that promotes protagonism and the recognition of rights. The term “special healthcare needs” is defined based on the need for support of those with chronic conditions or disabilities³. The term chronic health conditions is in itself a broad term, and may reduce the uniqueness of each disease to a single and general category³. The term disability is supported on a specific theoretical field that recognizes disability as a sociological problem, and as something that grants authorization for the individual to become a protagonist and claim the ability to lead a public life, as the identifier of a social movement⁴.

In the field of Disabilities, the International Classification of Functioning, Disability and Health (ICF)⁵, and its version for children and youth (ICF-CY)⁶, are a milestone in the discussion of participation, in that they relate participation to the social perspective of functionality and conditions it to contextual factors. According to the ICF-CY, participation is the interaction of the child or adolescent’s capabilities with the surrounding physical and social environment⁶. It is related, for example, to interpersonal relationships developed as individuals are inserted into education, work, recreation and leisure activities. In this paper we use Participation with a capital P to refer to the total component described in the ICF and ICF-CY, whereas participation with a lower case p is used exclusively for the social domain.

In public health, the consideration of physical and social dimensions in the discussion of participation of people with disabilities dialogs with recent healthcare models, serving as the conceptual framework for documents such as *Healthy People 2010 and 2020*⁷ on the interaction of an environment free of barriers and participation in daily activities as important areas to promote

the health of people with disabilities. In Brazil, the Law for Inclusion of People with Disabilities⁸ uses restrictions to participation as an indicator for defining disability, and defines the guidelines for the social insertion of this population.

The emergence of models based on social determinants is a step forward in the process to change the paradigm regarding the outlook of disability in public health^{9,10}. In the traditional outlook, disablement is considered a morbidity, with practices focused on preventing the risks and controlling the diseases capable of producing disablement^{9,11}. This view of disability prevention may appear strange, and can move us towards a different perspective, inserting it into the healthcare agenda primarily from the point of view we discuss here, or the participation of children and youth.

The contemporary outlook incorporates quality of life as a health outcome and, since the 2000s, the emerging outlook also includes participation as a health promotion tool^{9,11}. It is worth mentioning that most of the care provided to the disabled is still based primarily on the traditional model^{9,11}.

Considering participation as a mechanism to promote the health of children and adolescents still gives rise to questions in the healthcare environment. Which dimensions, possibilities and limits are associated with the participation of these subjects in their social environment? What consolidated knowledge is already available to enable promoting healthcare focused on this population?

In light of these questions, and bearing in mind the recent inclusion of this domain in discussions about public health and disablement, this study attempted to analyze knowledge produced on the participation of children and adolescents with disabilities to map and discuss those aspects and dimensions of this domain that have been highlighted and selected for attention.

Materials and Methods

One of the paths to achieve our objective is to look at the literature, in particular articles published in scientific journals, and more specifically those focused on this topic.

The methodological design is a literature study using scientific articles as sources for analysis. Because of the uniqueness of this theme, we chose to review the literature in a disabilities studies journal that focuses on disability

and public health. After looking at the journals published in this field, we selected the *Disability and Health Journal*. This is a publication of the American Association on Health and Disability and focuses on public health, health promotion, health education, well-being and prevention to reduce the incidence of secondary and medical conditions.

The search was limited to articles published in 2008 and beyond. The initial marker was the 2007 ICF-CY publication as a conceptual model to understand the participation of children and adolescents. The terms used in this survey were previously checked in the list of health science descriptors searched for using child OR adolescent AND social participation. Adolescents were defined as people aged 10 to 19, as defined by the WHO and Ministry of Health¹².

We found a total of 142 articles. After reading the abstracts, we selected those that focused on those covering the full descriptor (and). We excluded 119 articles discussing adults, focusing on access to healthcare services, the prevalence of obesity and caregiver health. After reading the remaining articles in full we excluded those where the average age of the participants exceeded 19, and theoretical articles on disability with no focus on participation. This left 19 articles that made up the analytical body of this study.

The analysis took place in two phases. Initially we ran a descriptive analysis of the samples in terms of date of publication and type of study, the core content, the health conditions studied and finally, the study subjects.

In a second phase the objective of the articles was analyzed, and the specific considerations in the discussions were noted. A technical adaptation of Bardin's content analysis was applied to the material¹³.

This author believes that the theme is a unit of meaning that frees itself from the text under analysis and may translate it in the form of an abstract, phrase or work¹³. To find the theme one must be aware of the nucleus of meaning whose presence or frequency may mean something to the analytical objective selected. In this literature review the theme is understood as a broader category that can cover more than one nucleus of meaning. Based on the approach of Gomes et al.¹⁴ this analysis followed the following sequence: 1 - Identification of the central ideas of the transcribed sections of all articles; 2 - classification of the meanings underlying the ideas into themes

that summarize the production of knowledge on the topic; 3 - preparation of interpretative summaries of each theme.

In preparing the interpretative summaries we used works outside of the analytical body to expand the discussion on the topic.

Results

Description of the literature

In terms of the date of publication of the articles, over half (10) were published in 2014 or 2015, being considered recent production, possibly associated with a series of official documents questioning the quality of life and participation of people with disabilities, fostering strategies to remove barriers and improve access to healthcare services and programs. As an example we would mention the *World Health Organization 2014-2021 Action Plan: Better Health for People with Disabilities*¹⁵, and the *2010 Healthy People*⁷ document.

Of the articles analyzed, 17 used a quantitative approach, 1 a qualitative approach and 1 was an editorial/opinion. This demonstrates that standardized tools are valued; the view of study subjects themselves on their participation experience using a qualitative approach is not often explored.

Analyzing the core content of the articles, 12 addressed sports, 3 discussed quality of life and well-being, 2 addressed the use of standardized metrics and 2 discussed participation in the school environment.

Regarding the health conditions studied, we found a diversity of themes: 11 looked at children and adolescents with disabilities that included intellectual and physical disabilities, 5 addressed special healthcare needs, 1 chronic health conditions, 1 spina bifida and 1 Movement Coordination Disorder. This finding exposes the lack of a standard term to designate this population, with different aspects considered in each definition.

Considering the study subjects, 6 articles covered only adolescents, 7 covered children and adolescents, 2 covered children and adolescents and their parents, and 4 discussed only the parents. This data shows that children and adolescents are valued as study subjects, despite the prevalence of methods using closed tools such as tests and scales, limiting a more spontaneous and unfettered expression of these subjects.

Themes and meaning nuclei under discussion

The analysis of the content of the articles reviewed can be placed on a theme map with areas related to three concentric circles, the center of which is the concept, the middle circle, split into four sub-areas, covers the themes, and the external circle integrates the meanings associated with the themes and the references used by the study authors (Figure 1). The analytical path started out by identifying the meanings of the outer ring, then classifying the intermediate ring for the summary concept of *Participation*, which comprises the internal area.

A thorough reading of the material led to four themes: *Sports*, *Quality of Life/Well-Being*, *School* and *Participation Metrics*.

The first theme - Sports, is the most prevalent in the studies and addresses four nuclei. Based on the social dimensions of sport proposed by Tubino³², in the articles on this theme, we explored the dimensions of sports-participation focused on ludic pleasure and sports-performance.

The first nucleus refers to the psychosocial aspects involved in performing physical activities such as attitudes, perceptions of health and self-image, and orientation towards sports¹⁶. This nucleus also includes the contribution of performance sports for the self-perception of en-

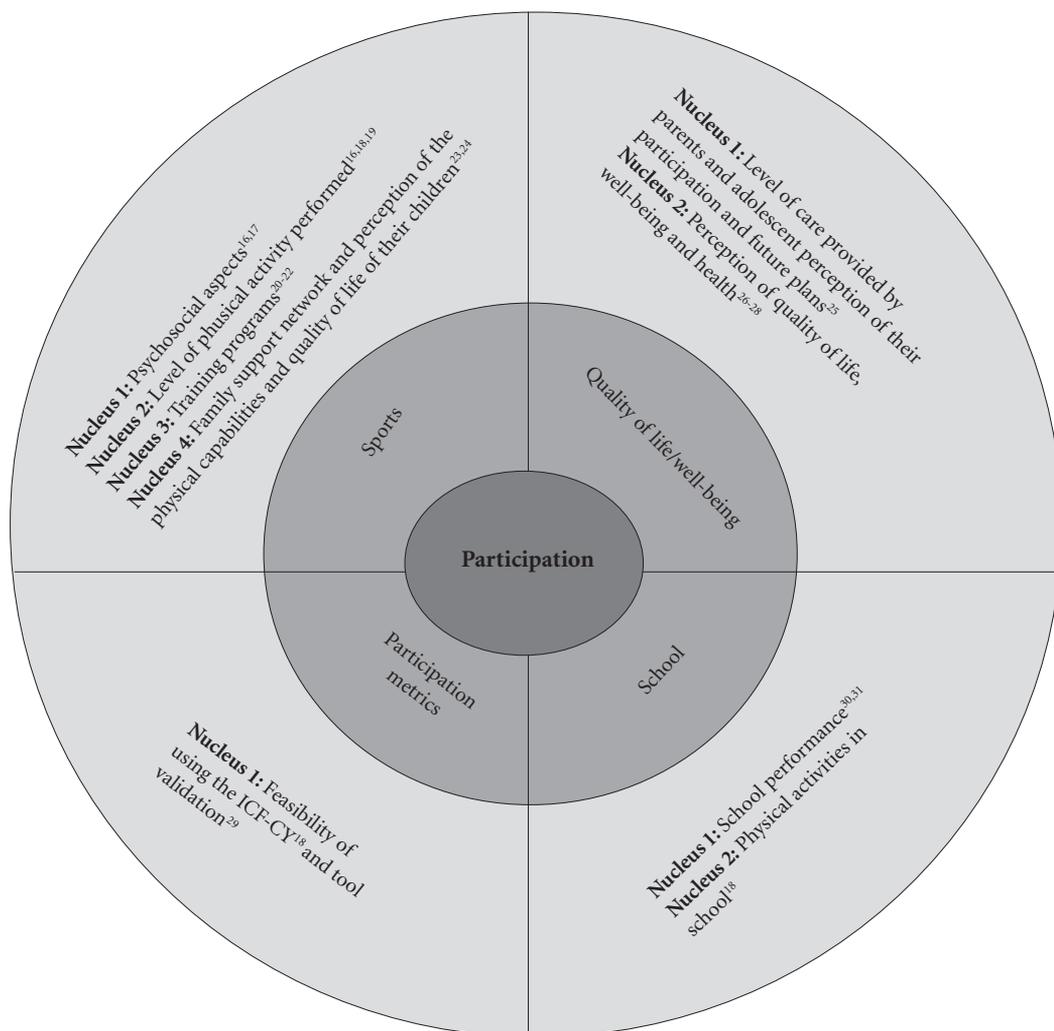


Figure 1. Theme map.

thusiasm, physical capability, satisfaction, social acceptance and friendship, making a bridge to building an identity³³ and quality of life^{17,23,33,34}.

The second nucleus corresponds to the approach of physical activity performed by children and adolescents with disabilities, also focusing on discussions about the prevalence of obesity in this population^{16,18,19}.

Physical training programs are the third nucleus covering discussions of processes to implement physical activity programs, their psychological impact, weight-loss and improved physical performance²⁰⁻²².

The fourth nucleus focuses on the interface with the family, addressing the support network parents provide to enable their children to perform physical activities and their perception of the physical skills of their children²⁴, and the quality of life of those who practice sports²³. Among the studies analyzed we found that parents encourage their children to practice sports, and that this is not necessarily related to the physical capabilities they assign to their children²⁴. On the other hand, parent perception of the quality of life of their children who practice some sort of physical activity was worse than the perception of their children²³.

The second theme -*Quality of life/Well-being*, combines the materials that enable a deeper discussion of the construct, including both meaning nuclei. Despite its subjective character, it is interesting to note that only one article²⁶ used qualitative methods to address the construct. The preference for using standard tools may have neglected aspects of the experience of disability, as the literature has already demonstrated that these tools address both objective and subjective aspects³⁵.

Starting with a discussion of the impact of insertion in recreational and social activities on quality of life, the first nucleus refers to the influence of parental care in adolescent perceptions of their participation and plans for the future²⁵.

The second nucleus addresses the perception of the dimensions of quality of life such as physical, emotional and social health as well as school performance, relating them to the symptoms of chronic health conditions²⁷, the correlation between well-being and functional limitations²⁸, and the view of children and adolescents on health and well-being²⁶.

Participation Metrics refers to a single nucleus of meaning.

Based on the discussion addressed in ICF-CY on the participation of children and adolescents,

this nucleus refers to the validation of standard tools based on classifications for measuring this domain²⁹, and the feasibility of using the ICF-CY structure to identify restrictions to participation³⁶.

The fourth theme - *School*, is summarized in two meaning nuclei.

The first nucleus addresses the relationship between the severity of the health condition and school performance^{30,31}. The second nucleus is related to physical activity in school¹⁸, addressing the sports-education dimension and linking social integration to psychomotor development and educational physical activities.

Discussion

The themes submitted are part of some nuclei of meaning associated with the concept of Participation and quality of life in the ICF-CY.

The emphasis placed on discussing Sports corroborates the rationale of emerging models of disability, attempting to displace the concept of disability associated with incapacity, a point of view related to the medical model where body injuries are responsible for the disadvantages.

In this model, all of the beliefs and values about disability are embodied in the body of the disabled, which is non-productive and at a disadvantage. The assumption that a body with limitations limits output and ensures to those with disabilities a status of being passive and receptors of the decisions made by others regarding their lives³⁷. Disability in this context, is presented as an anomaly compared to fixed standards of normalcy, without taking in consideration the subjective experience of those involved, which is what really leads to understanding and accepting the condition of being disabled³⁷. For Canguilhem³⁸, human beings in their dynamic polarity are responsible for determining where disease starts, considering that when it comes to biological standards, the individual must always be the point of reference.

From this we realize the significant contribution that sports play in the perception of quality of life by children and adolescents, and its potential as a means of recovering capabilities with an investment in whatever capabilities they have³⁷. Individual awareness of limitations and possibilities enable increased self-knowledge and value, the development of an identity and self-esteem, and a sense of belonging.

In this scenario, intervention in the form of training program is an effective means to under-

stand disability beyond its physical characteristics and limitations, making it easier to develop skills and potential in disabled children and adolescents through social interaction, or what according to Simmel³⁹ we may call ludic forms of socializing.

According to Simmel, the basis of society is the interaction between individuals, in particular the play of similarities and differences as the two major principles of human development. This difference enables the emergence of human beings in their uniqueness³⁹. The principle of sociability in the Siemmelian perspective states that each individual must ensure to the other, sociable values (happiness, release, vivacity) compatible with the maximum values received by that individual. It is therefore a game, where the happiness of one individual is linked to the happiness of others, thus configuring a ludic form of sociation. These postulates are relevant when we think about the disabilities of children and adolescent and sport as a mechanism of sociability, and something essential to promote the necessary support for the growth and development of children and youth⁴⁰.

The development of skills based on the social relations fostered by sports exposes a complex network of interdependences of which we are a part, placing us as being who build and are built within a network⁴¹. This then shifts the concept that autonomy is built on the independence of individuals, to an intersubjective concept ensured by social interactions of recognition⁴², such as managing the dependences of diverse orders depending on age, life cycle and health condition⁴³.

As a society, we value sports. When children and adolescents with disabilities participate in socially valued activities, there is the possibility that they will be seen as “non-deviants”, enabling the deconstruction of disability. According to Becker⁴⁴: *Social groups create deviation by setting rules whose infraction constitutes deviation and, in applying them to specific individuals, branding them as outsiders*. However, this classification depends on the situation and reaction of the group to a given behavior⁴⁵. The practice of sports is an “activator” of social inclusion. Based on the recognition of social groups, the deviant label placed on disable children and adolescents is made relative.

Within the context of deviant as a social label, we reiterate the importance of the family as the primary and main agent of sociability and promotion of the basis for support. Acceptance of the rules imposed on disabled children and adolescents by social groups is influenced by

family member actions and mindsets, which may or may not recognize or limit their children, but that can also encourage and facilitate the development of their children’s potential. Parental recognition of the capabilities of their disabled children plays an important role in making them subjects who desire and are capable of transforming their impulses into desires, seeking to realize them within or through their disability⁴⁶. The family, as the primary social group, is a determinant to trigger and maintain the process of social integration⁴⁷, including for example, participation in sports. The discrepancy between the perception of parents and adolescents regarding sports-related quality of life, which is the topic of one study²³, could be a hurdle for participating in this type of activity. If the parents do not recognize the benefit of sports for improved quality of life, it is doubtful that they will encourage their children to participate.

The construct quality of life was highlighted in all of the articles analyzed. Participation and quality of life often dialog in the literature on disablement, and we would like to take a moment to differentiate between these concepts. Participation refers to insertion in social situations, and is an objective measure. Quality of life on the other hand, addresses how a person feels when participating in these activities, and their individual perception of their place in the world and society⁴⁸. Although the literature^{34,49} shows a relationship between the participation of disabled children and quality of life, studies on this theme focused more on the biological factors that influenced quality of life, such as the severity of the healthcare condition and the associated symptoms^{27,28}. In other words, here we highlight an additional construct defined using a quality of life metric rather than its conceptual, philosophical aspect, which might help us value “quality of life” in relationships, promoting values that qualify life based on differences, rather than on scores and standards.

The interface between participation and quality of life may be explored using the *Capability Approach* and the theoretical focus of Nussbaum⁵⁰. Discussing justice, fundamental rights and the models to analyze quality of life, this approach supports that one solution would be to develop the means to enable each individual to achieve and develop his or her essential capabilities⁵¹. In healthcare, contributing the perspective of capabilities means demonstrating the importance of what can be done and is done for the perception of quality of life.

According to Nussbaum, the starting point is to know what people are capable of being and doing, also considering the material and institutional conditions so that people are in fact ready to perform at the top of their capability⁵¹. Capability in this case means the various combinations of ways of being and acting, reflecting on quality of choice of the diverse ways of life⁵². To consider the contextual barriers to freedom of choice, the *Capability Approach* discourses with the social model of disablement and is particularly useful for a discussion of participation. Within the scope of public policy, in light of the promotion we give to individual capabilities, society has the duty of removing the hurdles that impede or diminish an individual's ability to choose and impact his or her quality of life⁵².

If the discussion of quality of life in the articles highlights an assessment of life dimensions and components, at a metric level one must reflect that this trend is not limited to this construct. The ICF and ICF-CY incorporate these advances, as they value functionality and do not classify it based on the disease, but live with the tension of classifying levels of functionality, dialoging with standards that may provide information about health and assessments. Fostering participation is known as an important outcome for disabled children and adolescent included in Healthcare Services. Because of the need to address this domain with metrics, ever since the ICF and ICF-CY were published, there have been efforts to develop tools that cover the multi-dimensional nature of participation⁵³. However, current discussions around the ICF and ICF-CY talk about the difficulty of conceptually differentiating between Activity and Participation. This impasse is reflected in the difficulty of selecting suitable metrics that address the profile of participation of disabled children and adolescents^{54,55}. Also discussed is the failure to consider the subjective experience of participation in the classification structure. Measuring performance alone neglects the meanings assigned to involvement in social situations, and the experience of autonomy and self-determination⁵⁶.

In the *School* dimension, the medical model of understanding disability had a strong influence. The severity of the health condition was used to explain low school performance of children and adolescents with special healthcare needs^{30,31}.

Thus, two aspects should be encouraged in the discussions surrounding *School*: (a) a preponderance of analyses discussing school perfor-

mance and disability, which may reinforce or anticipate disadvantages, stigma and the deficiency of these children and youth; (b) the invisibility of the discussions about Schools as an important element to promote health, development, growth and sociability.

By including and discussing these aspects, we remove the discussion of disability from a generic agenda, and focus strategically on its interfaces with childhood and adolescence. Here we find a differential, a value we wish to assign to what the space the disability occupies in the growth and development of children and youth. Unlike adults, disabled children and youth may be exposed to processes that make them vulnerable due to their age and dependence on a reference adult, while they live with the markers of disability. Here we reflect on the power of School, not only as a place to work on cognitive content, but as an important point of support for the growth and development of any child or youth, and more so whose condition bears the marks of disability. According to Rizzini et al.⁴⁰, support bases are family and community resources that provide physical and emotional security for children and youth. In terms of formal (day-care, schools, religious program,...) and informal or spontaneous (friends and solidarity networks, significant others) organizations.

This outlook steps away from a vision of individual behaviors, enabling an analysis of context and the presence of subjects based on their relationships and the identity they assume⁵⁷. The notion of identity traits covers three important significance dimensions: otherness, recognition and belonging. These three dimensions dialog and contribute to reflections on the dimension of social interactions in terms of associations and the development of social networks by subjects within and outside institutions.

Finally, we find that discussions of studies classified as School say little or nothing of the educational move to include and insert those viewed as disabled in regular classrooms, with no segregation. This aspect needs to be further explored in terms of scientific production, addressing the limits and challenges of the political/educational principle of inclusion, especially in terms of preparing the school environment and educators to integrate disability into the "normal" curriculum. In light of these findings, two considerations are important. First one must consider the technical-financial side of school inclusion⁵⁸. In light of the specificities imposed by different levels of commitment, different in-

vestments in technology, staff training and environment adaptation are required to provide truly equivalent opportunities for diverse people or, barring that, reducing the restrictions to participation to a minimum⁵⁸.

The second consideration is based on the concept of disability as being socially constructed, meaning that a person will only be disabled and experienced restrictions to participation in front of an audience that considers the person to be disabled, according to its own criteria⁵⁹. This shines a light on the contextual aspects that impact school inclusion, pointing to the need remove attention on bodily impediments and focus it on the factors of the social and physical environment that accentuate the restrictions imposed on those with disabilities.

Final Considerations

This review shows the need to advance towards recognizing participation as a concept that is not resumed to activity, in the sense of what the individual is capable of doing in his/her normal environment. Considering that activity is something that may further evoke the ideals of yield and performance, a lot of emphasis must be

placed on participation as a human value, relating it to sociability and support, the management of autonomy and levels of dependence. Thus it touches all of us as human beings, but in the case of disabled children and youth, it must be taken as an ethical principle, ensuring the right to exist and be recognized, to have any possible vulnerabilities built relationally, minimized using protective mechanisms of a social, health and education nature. In other words, even if we recognize the concept of functionality and its operability as in the ICF and ICF-CJ, valuing Participation as a component of disability, we must pay attention to possible distortions when applying it to health actions. The tradition of evaluation may compromise the philosophical basis of the concept and hence its power to address the ludic forms of social interaction.

This review looked at articles published in a single journal, which may be understood as a limitation. On the other hand, in addition to the features we already pointed out when justifying our selection, this journal has been published since the nineteen eighties to promote a social model, vocalization and claims for participation of the disabled as intellectuals, authorizing them to produce primary knowledge. In other words, the disabled have a lot to say about disability.

Collaborations

TV Santos structured and drafted the article and searched for and analyzed sources. MCN Moreira and R Gomes helped design the methodology, draft and review the final article.

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