

Theoretical perspectives and childhood participation

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The concept of participation is at the centre of the concerns of those occupied with issues of disability. Although commonly used, it is seldom well defined and is conceptualized in different ways by different authors. This paper explores participation by juxtaposing conceptual frameworks of disability and the results of a recent study of school participation of disabled children. We start by outlining important conceptual frameworks in understanding disability, such as the International Classification of Functioning, Disability and Health (ICF) and social perspectives. We then present the study results which reveal participation as a complex interaction between the child and his or her environment where individual aspects interact with contextual requirements of different school settings. Viewed from the findings of this study none of the theoretical perspectives considered entails the level of complexity that is necessary to understand all the aspects of participation of the disabled children in their school environment.

Keywords: participation; childhood; disability theory; ICF

Introduction

The word participation originates from Latin, referring to part-taking – meaning to take part or to share in (Law 2002; Schenker, Coster, and Parush 2005). There is no uniform definition of participation and the term can be described from numerous perspectives and placed within divergent frames. The different frameworks and understandings reflect the orientation of their originators or supporters. While some stress the typical performance of common activities, others maintain that preferences, interests, opportunities, and satisfaction concerning involvement in activities should be incorporated. Common to many definitions is the importance of motivation and engagement. Within disability studies, the term is closely linked to human rights, social policies, and perceived membership (Gustavsson 2004b; Rioux 2002; Ueda and Okawa 2003). The International Classification of Functioning, Disability and Health (ICF) describes participation as a health-related concept, a person's involvement in a life situation meaning being included, engaged, taking part, or having access to needed resources (World Health Organization 2001). This definition has close links to execution of daily activities.

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Nordic scholars have debated several aspects of the concept of participation (Eriksson and Granlund 2004a, 2004b; Granlund and Björck-Åkeson 2005; Gustavsson 2004b; Nordenfelt 2003, 2006a). In their attempts to provide a comprehensive view of participation Granlund and Björck-Åkeson (2005:283) present it as multidimensional and based on four elements: (1) perceptions of engagement and motivation; (2) behaviour and activity; (3) information about contingencies and physical availability of niches; and (4) environmental prerequisites. These elements are related within a time frame from past to future although involvement in the present situation is in focus.

Thus, the concept of participation has been conceptualized in different ways by different authors. Although commonly used, it is seldom well defined and its meaning is not always clear. When studying the actual participation of disabled children and exploring the literature on childhood disability, it is important to examine the understanding assigned to the concept of participation each time, as well as its relationship to the concepts of disability and health. The aim of this paper is to discuss participation as portrayed in a recent study on school participation of children with physical impairments in light of different conceptual frameworks in understanding disability.

Perspectives on disability and health

Perspectives on health and disability have traditionally been classified as either bio-medical or social in nature. The bio-medical viewpoint on disability dominated and shaped much of rehabilitative and social services throughout the 20th century. Bio-medical perspectives define health as the absence of disease and view disability as a feature of the person, directly caused by disease, trauma or other health condition. The focus is on individual deviations of body and mind from socially recognized norms. Consistent with this perspective, impairment almost inevitably leads to social difficulties and exclusion, which is seen as causally attributed to the impairment. Health and function are thus reduced to inner mechanisms of the individual. Although some bio-medical models identify risk factors in the environment that may contribute to the process of disease, cause and effect is a linear process deriving from a specific pathology within the body or mind, resulting in a disease and disability. This perspective portrays an individualistic view of health as the 'problem' resides primarily within the person (Rosenbaum and Stewart 2004; Williams 2001). The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (World Health Organization 1980) was an example of this perspective, with its emphasis on portrayal of the consequences of diseases in terms of disability and handicap. The key concepts were linked together with arrows, indicating a unidirectional movement from impairment to the outcome, handicap.

Social perspectives on disability have been developed, in part, as alternatives to the bio-medical individualistic view of disability. Social approaches understand disability as socially-created, and not as an attribute of the individual. They reject the linear, cause-effect explanation of disease and disability, and emphasize the dynamic interactions that take place between a person and the environment (Barnes, Mercer, and Shakespeare 1999; Barnes, Oliver, and Barton 2002; Gustavsson, Tøssebro, and Traustadóttir 2005). This definition of disability has been confirmed by the United Nations' *Convention on the Rights of Persons with Disabilities* accepted by the UN General Assembly in December 2006. In the preamble of the Convention, paragraph

(e), it is recognized ‘that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others’ (United Nations 2007).

This way of understanding disability originates from many sources, one of which is the Nordic countries, where it is most often referred to as the ‘Nordic relational approach to disability’. The Nordic view of disability portrays a relative, situational and interactionist understanding (Gustavsson 2004a; Gustavsson, Tøssebro, and Traustadóttir 2005; Traustadóttir and Kristiansen 2004; Tøssebro 2004). Disability is considered to be relative to the environment rather than an always present essence of the person. The relative and situational aspect is evident in the gap that often occurs between individual functioning and societal demands. The relational approach is common in terms of underlying ideology and principles in social science literature and in government policy document in all the Nordic countries (Traustadóttir and Kristiansen 2004; Tøssebro 2004). As stated by Gustavsson (2004a, 62–3) ‘it is impossible to understand the processes producing disability, and consequently exclusion and discrimination, without studying the interaction between the individuals and the context’. The Nordic understanding of disability is closely related to fundamental ideas about citizenship and equality; basic principles and values of the Nordic welfare states. This view has led to attempts to ensure that welfare provisions and human rights will be extended to the entire population, including disabled people, who should be enabled to take part in everyday life in the society. Thus, the Nordic relational approach to disability emphasises the rights of disabled people to full participation in everyday life, and looks to the interaction between the individual and the environment for ways to support participation.

Another social approach to disability, and one much better known internationally, is most often associated with the ‘British social model of disability’, first articulated by the disabled people’s movement in Britain in the 1970s and developed by academics within British disability studies (Barnes, Oliver, and Barton 2002; Oliver 1996). The British social model distinguishes between ‘impairment’ (functional limitation due to a physical, mental or sensory condition) and ‘disability’ (which arises from discriminatory social attitudes and environmental barriers). This understanding of disability draws attention to social barriers, instead of individual impairments, and views disability as created in an interaction with oppressive social environments designed for non-disabled people (Barnes, Mercer, and Shakespeare 1999). Drawing on the social model, the disability rights movement launched a sharp criticism of ICIDH for its medical and individualistic understanding of disability, advocating a model that would direct attention to social barriers (Barnes, Mercer, and Shakespeare 1999; Hurst 2003). This criticism weighed heavily in the revisions of the ICIDH, especially in introducing an environmental dimension into ICF (Hurst 2003). From the perspective of the British social model, removal of social barriers is the most important aspect in enabling participation. However, the advocates of the social perspectives have rarely specified what active participation entails. Their primary focus has traditionally been on independent living, education, communication, access to the built environment, and civil rights. A few British social modellists have focused more explicitly on the subjective experience of living with an impairment (Thomas 1999, 2002; Shakespeare 2006) following criticism on the model’s overemphasis on environmental factors.

The International Classification of Functioning, Disability and Health

Participation is one of the key concepts of the International Classification of Function, Disability and Health (ICF) (World Health Organization 2001) which is gradually gaining status as a conceptual basis for the definition, measurement and policy formulations for health and disability worldwide. The ICF focuses on the interaction of physical or mental limitations with personal and environmental factors. Disability and functioning are viewed as outcomes of interactions between health conditions and contextual factors. The term ‘functioning’ refers to body functions, activities and participation, while ‘disability’ is an umbrella term for impairments, activity limitations and participation restrictions. ‘Participation’ is defined as involvement in a life situation. The ICF acknowledges that environmental factors interact with a health condition to create a disability or restore functioning, depending on whether they act as facilitators or barriers (World Health Organization 2001).

The list of domains becomes a classification when qualifiers are used. Two qualifiers are provided that, together, enable coding information and help determine the gap between capacity and performance. Capacity encompasses the ability to execute a task or action and describes what an individual can do in a standardized environment. Performance, on the other hand, describes what he or she actually does in his or her current environment (World Health Organization 2001). As an example, if capacity is greater than performance, then some aspect of the environment may be a barrier to performance. For most of ICF’s dimensions a negative scale is used to indicate the extent or magnitude of impairment or the difficulty within the environment. Only in the environmental factors section does the generic qualifier have both a negative and a positive scale to denote extent of barriers and facilitators respectively. Personal factors are described but are not included in the classification system.

Although ICF was primarily designed for the adult population the model has been used in studies, reports and papers addressing childhood disability (Battaglia et al. 2004; Beckung and Hagberg 2002; McConachie et al. 2006; McDougall and Miller 2003; Simeonsson et al. 2003; Simeonsson, McMillen, and Huntingdon 2002) where it is reported to provide a useful framework for defining domains and describing chronic disability. However, some important aspects of children’s activities, such as play, were found to be lacking. An ICF version for children and youth (ICF-CY) was developed

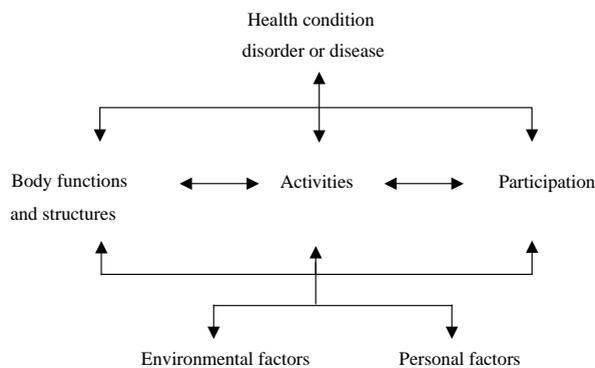


Figure 1. The International Classification of Functioning, Disability, and Health (ICF).

following a systematic review of the ICF in order to identify content needed to document functioning, health, and disability in children and youth (World Health Organization 2004). The structure of the main ICF volume was maintained with modified text descriptions of domains to document functioning, disability, and environmental factors from infancy through adolescence. To date, there are few publications to support or refute the use of ICF-CY for children and youth, but its potential as a taxonomy for use in clinics, schools, and other settings providing services for children has been emphasized (Simeonsson and Leonardi 2004).

Criticism of the ICF's concept of participation

The ICF has been welcomed by many professionals and academics in health care worldwide (Rosenbaum and Stewart 2004; Simeonsson et al. 2003; Stucki, Ewert, and Cieza 2002) although some suggest it requires further conceptual clarification and development (Hemmingsson and Jonsson 2005; Imrie 2004), especially the concept of participation. A criticism has been made that the categories of activity and participation and their elements are classified as components of health, especially the actual performance of actions (Nordenfelt 2006a). The focus of the ICF is on the tasks people typically engage in and it is assumed that people want to undertake these tasks and do so in a specific way. Hence, 'activities' and 'participation' are defined as what people do although it may not be what they would prefer to do. People's experience of autonomy, self-determination and independence are not included; instead the main emphasis is on performance. In the ICF 'participation restriction' involves a barrier to participation in the context of an activity limitation or a difference in function. The operationalization assumes that the difficulties people may have in executing activities inevitably will restrict their participation (Björck-Åkesson and Granlund 2004; Hemmingsson and Jonsson 2005; Perenboom and Chorus 2003). All the levels and factors of the ICF thus belong to the objective dimension of human life but the subjective dimension is hardly addressed.

The ICF has yet to conceptualize and fully acknowledge important personal factors, such as motivation and will, by formally including them in the classification system. As pointed out by Nordenfelt (2003, 1079): 'In order to act one must first intend to act and want to act'. Presently, there is no systematic treatment of the concept of will in the ICF apart from the term 'purposeful' which is used in some classes. The development of a 'will qualifier' has been stressed as priority in further development of the ICF, including how to use this in relation to the capacity and performance qualifier (de-Kleijn-de Varnkrijker and ten Napel 2006). Nordenfelt, on the other hand, argues that instead of the performance qualifier an opportunity qualifier should be developed, which could display whether or not opportunities for activity and participation are provided in the environment. Currently there is a lively debate on these issues in the literature (de-Kleijn-de Varnkrijker and ten Napel 2006; Nordenfelt 2006a, 2006b; Reinhardt et al. 2006).

The ICF continues to be criticized by many disabled people and theorists who adhere to sociopolitical perspectives on disability (Barnes and Mercer 2003; Hammell 2004; Thomas 2002). In particular, the practice of classifying people according to their differences has been questioned. Many claim the model retains a causal link between impairment and disability although not as evident as before, and still focuses too much on impairment at the expense of the social, practical and

attitudinal issues that trouble most people who live with impairment. Thus the ICF does not address the pressing concern of many disabled people: independent living, education, communication, access to built environment, and civil rights (Barnes, Oliver, and Barton 2002).

Participation in school: children with physical impairments

A recent dissertation study by the first author of this article (Egilson 2005) explored the participation of children with physical impairments, age 6–12, in regular schools in Iceland. The study was conducted in 2000–2003 with follow-up interviews in 2004 and 2005 to provide a more long term perspective. The study examined the most critical factors that influence school participation in order to provide an understanding of the complex processes that interact to facilitate or hinder function in this context. The study was informed by the major theoretical perspectives that affect the current understanding of participation and the disablement process, particularly the ICF (World Health Organization 2001) and social approaches to disability (Barnes, Mercer, and Shakespeare 1999; Barnes, Oliver, and Barton 2002; Gustavsson, Tøssebro, and Traustadóttir 2005). This was a mixed methods study (Creswell 2008, 2003) combining qualitative and quantitative data. The qualitative data were collected from 49 participants; 14 students with physical impairments, 17 parents and 18 teachers. Data were obtained through participant observations at schools and qualitative interviews with teachers, parents, and the students themselves. Interview and observations guides were developed to list the key issues that were to be discussed and explored in interviews with parents and teachers, and during participant observations in schools. The School Setting Interview (SSI) (Hemmingson et al. 2005), which considers disabled students' opportunities for participating in school, was used as an interview guide in the student interviews. Data analysis was primarily based on grounded theory procedures, emphasizing the constant comparative method most often used for multi-data sources in conjunction with multiple-site studies (Strauss and Corbin 1998). In the quantitative part of the study, the participation and performance of 32 students with physical impairments was measured using the School Function Assessment (SFA) (Coster et al. 1998). The SFA is a criterion based instrument designed to provide a comprehensive description of students' participation, support needs and functional performance in six different school settings: classroom, mealtime, bathroom, playground, transitions between school locations, and transportation to school. The instrument was constructed with the needs of elementary school students with physical and sensory impairments in mind. It is completed by one or more school professionals who know the students' participation and performance in school activities. The SFA is in accordance with the ICF terminology and general definition, although specific to the school environment. During the analysis and interpretation phase the data collected from the qualitative and quantitative methods were compared and contrasted to seek convergence among the results (Creswell 2008, 2003).

The findings of the study revealed that the children with physical impairments participated to a varying degree in different contexts in school. Open spaces with limited structures, such as the school playground and field trips, typically presented the most challenges to student participation. Related subject settings, such as physical education, were also problematic for many. Highest levels of participation among the students occurred at mealtime and occasionally in the general classroom.

Each school setting was specific in its characterization of the tasks required for participation and, despite their physical impairments all the children in the study were able to meet some relevant requirements for participation in different settings. Potential facilitators and obstacles to participation were identified within the three dimensions of environmental, task and child characteristics. The likelihood and severity of functional problems accumulated with an increasing extent and severity of the child's impairment. However, contextual factors such as task, environmental or child characteristics other than physical function often outweighed the challenges. The attributes of the different school settings strongly influenced the student's participation. In general, stringent structure, rigid adherence to traditional curriculum and ways of instruction, and lack of accommodations decreased the child's opportunities for participation. The more a setting was accommodated to meet the child's needs, the less the effect of the motor impairment on his or her participation. Better overall emotional, behavioural and social function was related to greater participation. However, if a child could not physically participate, strengths such as social skills were often of limited value in ensuring his or her participation – demonstrating the importance of opportunities being provided in the environment. The extent to which each child's strengths contributed to increased involvement was highly situational. Structures intended to promote and facilitate participation were often limited or inconsistently applied, thus, participation was sometimes coincidental rather than by design (Egilson 2005; Egilson and Traustadóttir, forthcoming).

The circumstances fluctuated for many children during the time of the study as environmental and task contingencies interacted with the children's character and coping styles to create different possibilities for participation over time. As a result, participation was an outcome of a complex and changing interaction between the child and his or her settings. The importance of the various features for each child commonly evolved over time and settings, redefining the influences and relationships among factors. The combined use of quantitative and qualitative methods provided insight into the linkages across the different dimensions. The findings of the study indicate a few necessary preconditions for successful participation in elementary schools. First, the child has to be physically present. Second, the child must participate (with or without adaptations and supports) in the activities that are an integral part of each school setting. And third, the child and key actors in his or her immediate environment (such as parents, teachers, and peers) have to be satisfied with the involvement and level of performance. The study results reveal participation as a complex interaction between the child and his or her environment where individual aspects interact with contextual requirements of different settings (Egilson, 2005; Egilson and Traustadóttir, forthcoming).

The complexity of school participation: different perspectives and considerations

The concept of participation is at the centre of the concerns of those occupied with issues of disability. It is therefore of importance that this concept be explored and clarified from different theoretical points of view as well as in empirical studies such as the present one. The following discussion will examine the results of the study in light of the ICF and social perspectives on disability.

Comparison to the ICF

By comparing and contrasting the study results to the ICF definition of the concept of participation as 'involvement in a life situation' (World Health Organization 2001, 7), several concerns arise. For the children in the study, the most important aspect of participation included self-determination, autonomy, and the feeling of being part of the group, although someone else assisted with various physical aspects of the tasks performed. This experience of belongingness and feeling of involvement was an integral part of the study participants' perceived participation. In various scenarios, the children were content with their involvement although they completed tasks differently than their peers. Teachers, parents and other students often agreed. The question is then raised as to whether a problem actually exists in these situations. According to the ICF these children would certainly not be considered active participants as this classification system focuses on typical performance of particular activities within a setting. Thus the ICF does not recognize whether the child enjoys or feels in control of his or her situation. This aspect of ICF has been criticised by McConachie and colleagues (2006, 1163) who point out that: 'More participation may not be better if the child does not have a say, or does not enjoy the activity much'.

Various contextual requirements affected the performance of the children in particular school settings. Physical accessibility was fundamental to whether or not they were able to participate. Laws and regulations determined what resources and services were made available, which in turn influenced the children's involvement in different contexts. Each school's culture, values and attitudes influenced methods of problem solving and how resources were used and related to other environmental dimensions. Yet, the ICF fails to acknowledge this complex aspect of environmental influences on participation and the fact that various effects often have to be considered simultaneously. This one-dimensional view of environmental factors as either facilitators or barriers is a major shortcoming of the ICF, as also suggested by others (Hemmingsson, Borell, and Gustavsson 2003; Hemmingsson et al. 2005). Provision of adult support to children is one example and the study results indicated a fine line between support that facilitates involvement in learning activities, and support that inhibits social interaction and the development of autonomy of the disabled child (Egilson 2005; Egilson and Traustadóttir, forthcoming).

It has been proposed that the ICF includes too much on health (Nordenfelt 2006a). In this study numerous attributes of the child, many of which have no direct relation to health, interacted with task and environmental factors to promote or hinder school participation. As previously mentioned, personal factors are acknowledged within the ICF but not specifically coded. While health conditions are at the core of the ICF, our study identified physical function as only one of many personal factors that affect school participation by children with physical impairments. Many child attributes were only of importance in a particular context. Although a child possessed specific skills, different structures within each school setting largely determined the extent to which he or she was able to use them. Hence, capacity was not enough. Without an opportunity a child's strengths were of limited value in ensuring participation, revealing once again the confluence of contextual factors that affect the child at a given time. These inferences are consistent with the findings of a previous study which demonstrated the importance of acknowledging the different roles of contextual factors in the disability process (Wang, Badley, and Gignac 2006). Similarly Coster and Khetani (2008) call attention to the spatial dimension to

participation, which becomes clear when a child cannot access settings in which important events or experiences take place.

Within the ICF only 'negative' aspects are coded, which limits the possibility of recognizing strengths that might be used to accommodate or compensate for difficulties in specific contexts. This operationalization is a major shortcoming as it is important to identify capacities that may compensate for a person's impairment. This is even more controversial as the ICF claims to adhere to a neutral focus in its descriptions of dimensions of functioning. Many students in the present study demonstrated strengths in communicative skills, social skills, behavioural skills, and cognition which were an important asset in various circumstances. However, the ICF was not helpful in acknowledging these abilities.

Lastly, the ICF only focuses on the present situation. A person's conception of participation is bound to relate to his or her experience, impression of the current situation, and its relation to the future. For children with chronic impairments who are dependent on accommodations for function and wellbeing, it is important to prepare for their future to prevent potential difficulties that may arise. Interestingly, the schools in this study focused first and foremost on the present while preparations for alternative ways for the children to partake in future pursuits were scarce. This had serious consequences for those children with the most striking impairments whose changing needs were scarcely anticipated nor met. The sole focus on the present situation is still another shortcoming of the ICF as it does not promote necessary modifications to accommodate disability in the future.

Thus, although the study results are consistent with the ICF's overall conceptualization of the nature of participation, the findings suggest that the operationalization of the concept is too limited and hardly reflects the philosophical tenets underlying the framework itself. Also, the ICF coding system only allows for objective data gathered by measurements tools (World Health Organization 2001). Use of qualitative methodology may better reflect the experiences and perspectives of participants themselves, and allow their voices to be heard. The qualitative and quantitative data in this study provided a different set of information and together they revealed the complexities entailed in school participation of the children in the study.

Comparison to social theories on disability

Some of the most important aspects of the participation experienced by the disabled children in the Icelandic dissertation study (Egilson 2005) included equal opportunities, membership in the school community, and treatment as a valued human being – issues strongly linked to civil rights and citizenship. These findings echo the Nordic emphasis on equality and human rights and are consistent with the writings of disability theorists whose main focus is on barriers imposed by society. However, the study results do not support the main claims of the British social model of disability, which is that social barriers disable people with impairments and that discriminating societal response constitutes disability (Finkelstein 2001; Thomas 2004). Although the study found the environment to be of importance, individual aspects were also essential in accounting for participation in different school settings. Opportunities were not enough, as individual factors within each child, such as his or her functional abilities, motivation, preferences, and will, often decided whether or how opportunities were used. Regardless of the arrangements made, some impairments involved restrictions that removal of barriers could not overcome.

The qualitative inquiry revealed that certain character traits contributed to the students' participation. Those children who had good behavioural and social skills were more often considered to be full participants by their peers and teachers and some teachers went a long way in trying to accommodate these children's needs as they themselves experienced personal and professional fulfilment related to the children's inclusion. Attributes of the child also affected the choice and possibilities for modifications in different situations. These findings are consistent with the Nordic relational approach in that they confirm the situational and contextual aspect of disability (Gustavsson, Tøssebro, and Traustadóttir 2005; Tøssebro 2004), and the complexity of the interaction between the individual child and his or her surroundings.

Conclusion

The results of the study have much in common with the social theories now being developed, such as the complex, situational, relative and relational aspects of disability and participation emphasized in the Nordic approach. Social theories provide an important insight and understanding of disability but they operate on a different level than the ICF and have not attempted to operationalize participation and disability. Rather, they provide a framework to understand the basic elements of these phenomena and their relations to other relevant issues and contexts.

None of the theoretical perspectives considered here have the level of complexity required to account for all the aspects necessary to understand the participation of the disabled children in their school environment. However, a promising approach would be for those different theorists to collaborate in their attempts to develop further our conceptual frameworks to create a better understanding of disability and participation.

The findings of the study reveal the transaction of the multiple aspects affecting children's participation within school. They support the perspective that participation is a multidimensional construct based on different elements (Eriksson, Welander, and Granlund 2007; Granlund and Björck-Åkeson 2005). However, it appears that neither the ICF nor disability scholars worldwide have acknowledged these complexities of participation fully to date. The study results indicate that a model and a classifier with health condition at its core, such as the ICF, may be of limited use in reflecting how disabled children lead their lives and how much enjoyment and control they experience through their performance and participation. Although the ICF-CY for children and youth provides new content to cover activities, participation, and environments unique to children and adolescents (World Health Organization 2004), it maintains the same structure as the main ICF volume. The ICF-CY may prove useful as taxonomy for use in settings providing services for children, but hardly in addressing the complex issues of childhood participation brought up in this current study.

The importance of active and full participation in school as a positive influential factor in disabled children's growth and development both socially and cognitively needs to be acknowledged and emphasized since they learn, as do all people, through their interpretation of events and experiences. The opportunity to make choices, express preferences, set goals and self-regulate learning and behaviour have all been linked to more favourable adult outcomes (Wehmeyer and Schalock 2001). Thus, participation should be recognized both as a process and a product of disabled

children's development, a means and an end. More research and theory development on the complex aspects of childhood disability is strongly needed.

Few studies have elicited disabled students' own perspectives and opinions of their school participation, or given them the opportunity to reveal their experiences. Instead much of the information available has come from parents or teachers. The new sociology of childhood directs us to see children as active agents negotiating their everyday interactions with peers and adults and encourages us to take children's own feelings and perspectives more seriously than has been done previously by researchers (James, Jenks, and Prout 1998; James and Prout 1997). Thus it is important to bring the voices, experiences and perspectives of children and youth into contemporary debates and research about participation.

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