The participation of children and youth with disabilities in activities outside of school: A scoping review

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Étude de délimitation de l'étendue de la participation des enfants et des jeunes handicapés à des activités en dehors du contexte scolaire

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Key words: Child development; Developmental disabilities; Leisure activities; Occupation; Participation.

Mots clés : activités de loisir; développement de l'enfant; handicap lié au développement; occupation; participation.

Abstract

Background. Participation in occupations is vital for learning and development. Children with disabilities are at risk for decreased participation. **Purpose.** The purpose of this study is to examine peer-reviewed literature about the participation-based experiences of children and youth with disabilities in activities outside of formal preschool and school academics. **Method.** A scoping review was conducted to examine research studies published between 1990 and 2012. Studies included participants from 2 to 18 years who had at least one physical or intellectual/cognitive disability. **Findings.** Forty-nine articles discussing 32 studies and three systematic reviews met the inclusion criteria. Perceptions of and influences on participation were important emerging themes about direct impacts on patterns of participation. A child or youth's level of functioning, activity level, level of enjoyment, and contextual factors were found to influence their level of successful participation. **Implications.** Occupational therapists can use the findings from this review to consider supports and barriers within interventions to enhance participation in meaningful life situations.

Abrégé

Description. La participation à des occupations est essentielle à l'apprentissage et au développement. Les enfants handicapés risquent d'avoir un degré participation moindre que les autres enfants. **But.** Le but de cette étude est d'analyser la littérature examinée par les pairs traitant des expériences liées à la participation d'enfants et de jeunes handicapés à des activités en dehors des activités préscolaires et scolaires. **Méthodologie.** Une étude de délimitation de l'étendue a été effectuée en vue d'examiner des études réalisées entre 1990 et 2012. Les participants à ces études étaient âgés de 2 à 18 ans, et ils avaient au moins un handicap physique ou intellectuel/cognitif. **Résultats.** Quarante-neuf articles décrivant 32 études et trois revues systématiques répondaient aux critères d'inclusion de l'étude. Les perceptions face à la participation et les facteurs influant sur la participation comptaient parmi les thèmes importants ayant des impacts directs sur les schèmes de participation. L'étude a permis de déterminer que le niveau de fonctionnement, le niveau d'activité, le degré de plaisir et les facteurs contextuels exerçaient une influence sur le degré de participation des sujets. **Conséquences.** Les ergothérapeutes peuvent s'appuyer sur les résultats de cette étude pour examiner les mécanismes de soutien et les barrières face aux interventions, en vue de rehausser la participation des jeunes et des enfants handicapés à des situations significatives de la vie.

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R esearch indicates that children and youth with a wide range of physical and intellectual/cognitive disabilities experience limitations in participation in meaningful occupation within their home, school, and community environments (Coster et al., 2011; Fauconnier et al., 2009; Law et al., 2006; Majnemner et al., 2008). As defined by the International Classification of Functioning, Disability, and Health (ICF), this decrease in participation occurs when a lack of fit exists between the child's or youth's functioning, as a result of the disability, and the activities in which he or she desires to participate in everyday life (World Health Organization, 2001). The level of participation is further influenced by a variety of contextual factors, including aspects of both the person and the environment (Polatajko et al., 2007; World Health Organization, 2001).

For occupational therapists, participation has been most clearly defined by Coster and Khetani (2008) as "sets of organized sequences of activities directed toward a personally or socially meaningful goal" (p. 643). Taking part in everyday occupations for children or youth with disabilities, as with typically developing children, is vital for a sense of belonging within their environment (McManus, Corcoran, & Perry, 2008). In addition, meaningful participation for children or youth with disabilities is particularly important for their learning, development, and motivation to achieve social inclusion, all of which can have a significant impact on a child's present and future quality of life (Bedell, 2009; Raghavendra, Olsson, Sampson, McInerney, & Connell, 2012).

Striking differences in participation between children with and without a disability were found in a study conducted in Canada and the United States (N = 576) in which 37% of children and youth with disabilities *never* took part in organized physical activities in the community as compared to only 10% among their typically developing peers (Bedell et al., 2013). Overall, youth with physical disabilities tend to participate more in informal (i.e., unstructured) activities alone at home and less in formal (i.e., structured) community-based activities (Engel-Yeger, Jarus, Anaby, & Law, 2009; Klaas, Kelly, Gorzkowski, Homoko, & Vogel 2010; Law et al., 2006). The environment has been identified as one of the prominent determinants of this population's participation, both theoretically (King et al., 2003) and empirically (King et al., 2006). To illustrate, 36% of parents of children and youth with disabilities living in Canada and the United States reported no access to, or a lack of availability of, programs and services, in comparison to only 3% of children without disabilities (Bedell et al., 2013). Lack of parental access to information, resulting in unfamiliarity regarding available resources and policies, is yet another barrier to participation (Law et al., 1999; McManus et al., 2008); therefore, the need for parental education and guidance by service providers is evident.

Based on the premise that more successful activity participation may occur in individuals with increased functional abilities, an informed understanding of the participatory experiences of children and youth with disabilities will enhance knowledge about the factors affecting one's ability to participate. To date, there have been three reviews of this literature (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; Imms, 2008; Shikako-Thomas, Majnemer, Law, & Lach, 2008). The reviews by Shikako-Thomas and colleagues and Imms were published in 2008 and focused only on children with cerebral palsy (CP), while the review by Bult and colleagues (2011) focused only on determinants of participation for children with physical disabilities. Research on children's participation has increased dramatically over the past few years, and research focused on disabilities beyond physical disability has been published. Thus, an updated review using inclusion criteria focused on a broader range of health conditions can assist in determining important new knowledge and trends in this area of research. The aim of this review was to examine patterns and determinants of participation of children and youth across all disability areas in activities outside of formal preschool and school.

Method

Scoping Review Questions

A scoping review methodology was chosen because this methodology enables a rigorous review of a broad topic area as opposed to a more narrowly defined systematic review. The review was completed using the Arksey and O'Malley (2005) framework, with recommendations from Levac, Colquhoun, and O'Brien (2010). Recent recommendations to include an assessment of study quality as part of a scoping review were also followed (Daudt, Van Mossel, & Scott, 2013; Gough, Thomas, & Oliver, 2012).

There were two primary research questions for this scoping review: (a) What are the patterns of participation of children with disabilities in activities outside of formal school academics? (b) What are the factors that facilitate or hinder participation of children with disabilities in activities outside of formal school academics?

Study Identification and Selection

To complete the scoping review, the research team identified relevant studies and papers within AMED, CINAHL, EMBASE, MEDLINE, PsycINFO, Pubmed, and the Cochrane Library. Searches were also conducted in databases containing systematic reviews: Occupational Therapy Critically Appraised Topics (CATs; Queens University, Kingston, Ontario, Canada), Occupational Therapy Seeker, Physiotherapy Evidence Database (PEDro), and Education Resources Information Centre (ERIC). Reference lists of relevant articles were also hand searched to identify any additional sources. Search terms were generated based on the research questions and entered in the following sequence: (a) participation OR involvement OR engagement. (b) pediatrics OR child OR adolescent OR teenager OR kid, (c) disability OR impairment OR disease OR illness OR disorder, (d) play OR social OR sports OR activity OR recreation OR leisure, and (e) school OR education OR community OR home. Once these search terms had

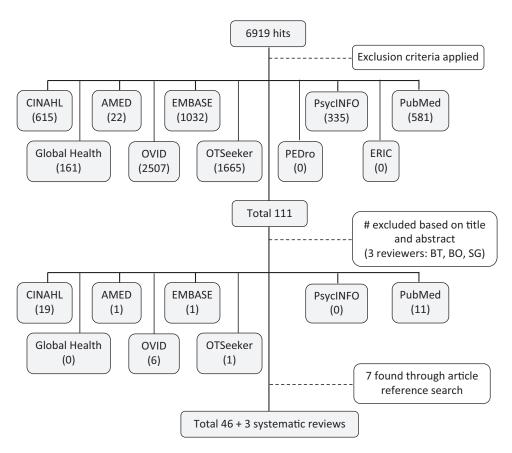


Figure 1. Flowchart of article selection process.

been entered, each of the five categories was combined using the AND function. Finally, limits regarding English language and research between 1990 and 2012 were applied, and duplicates were removed. The terminology/keywords used across databases varied slightly depending on the database. Searching involved articles published from 1990 to 2012, inclusive.

Studies with participants between preschool and high school age (2 to 18 years) having at least one physical or intellectual/ cognitive disability were included. Studies involving any adult participants (unless results discriminated between ages), participants with chronic conditions (e.g., cancer, asthma, heart disease), and participants with visual and/or hearing impairment were excluded from this review. Studies involving data on participation in formal preschool and/or school academic settings only were also excluded.

Study Charting and Analysis

Three researchers (BT, BO, SG) independently analyzed and appraised study findings and quality using the McMaster University's Critical Review Forms (Law et al., 1998; Letts et al., 2007). The use of a validated data capture tool ensured accuracy in data collection and provided detailed information to assist in evaluating the importance of specific findings. Studies were discussed until a consensus for inclusion was reached. For any disagreements, a fourth researcher (ML) made a decision about inclusion based on her extensive experience in this research area. The following information was charted for all selected studies: citation, country, study design, sample size, participant age and sex, outcome measures, study findings, factors influencing participation, and limitations.

Using a summary table of study data, a thematic analysis was completed through a cross-comparison of the main findings from each article. Once the overarching themes were determined across the articles using this strategy, discussion by three of the researchers yielded three broad themes: perceptions, influences, and patterns of participation. Further, seven subthemes were generated. The findings demonstrated considerable consistency across the literature; thus, the main role of the researchers was identifying themes and subthemes that captured these data. To achieve methodological rigour, the themes and subthemes were reviewed by a fourth researcher with over 30 years of clinical and research experience working with children with disabilities and their families. Data on "influences of participation" were synthesized and organized based on ICF domains of functioning and disabilities: body function/structure and contextual factors (personal + environmental).

Findings

The literature search resulted in 111 articles when duplicates were removed (see Figure 1 for the search flow diagram).

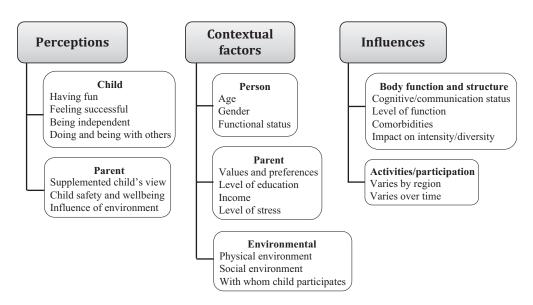


Figure 2. Summary of thematic findings.

Application of the inclusion and exclusion criteria revealed 49 articles discussing 32 studies and three systematic reviews. From the 32 studies, 27 were quantitative, 1 was qualitative, and 4 used mixed methods (see Appendix 1 at http://cjo.sagepub.com/ supplemental).

The majority of the papers (excluding systematic reviews) were from Canada (14), the United States (13), and Europe (9), with other studies from Australia (5), Israel (2), China (2), and Singapore (1). The number of studies published each year were 1990 to 1995 (0), 1996 to 2000 (1), 2001 to 2005 (4), 2006 to 2010 (26), and 2011 to 2012 (15). Most studies focused on children with physical disabilities (29) and intellectual/cognitive disabilities (12), with 5 studies including a mix of diagnostic categories. With regard to age, studies focused on children in preschool (1), elementary school (17), and high school (7), with 21 studies including mixed age categories. Approximately half of the studies (20) used the Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004). The CAPE has five domains: recreational (e.g., playing with toys), active physical (e.g., sports, hiking), social (e.g., talking with friends), skill based (e.g., learning to play a musical instrument), and selfimprovement (e.g., doing a chore). Participation has been measured according to diversity (number of activities), frequency (times per week/month), and intensity (average amount of time across all possible activities). The thematic findings of the scoping review are depicted in Figure 2 and discussed below.

Patterns of Participation

Many studies have found that children with disabilities do not participate in as many activities or have the same level of participation as their age-matched peers. When the average amount of time or intensity of participation is examined across all possible activities, children with disabilities participate at a lower intensity (Engel-Yeger et al., 2009; Kelly, Altiok, Gorzkowski, Abrams, & Vogel, 2011; Majnemer et al., 2008) and/or diversity (Engel-Yeger et al., 2009; Michelsen et al., 2009) of participation than their typically developing peers yet were found to enjoy similar activities (Engel-Yeger et al., 2009; Hilton, Crouch, & Israel, 2008; Imms, Reilly, Carlin, & Dodd, 2008; Law, Anaby, DeMatteo, & Hanna, 2011). Level of functioning, including physical and cognitive/intellectual ability (including communicative functioning), was found to have the greatest influence on overall patterns of participation.

Differences with whom and where children and youth with disabilities participate were noted across activity types. Specifically, children were found to participate more with family (King, Law, Hurley, Petrenchik, & Schwellnus, 2010; Kraemer, Blacher, & Marshal, 1997) and closer to home rather than with friends within the broader community (Imms et al., 2008; Majnemer et al., 2008). Youth were found to participate more with friends in active-physical (King et al., 2010) and leisure activities (Kang et al., 2010). They were, however, more likely to participate in social activities with relatives than their typically developing age-matched peers (King et al., 2010). Children with cognitive/intellectual disabilities, such as highfunctioning autism spectrum disorder (HFASD), autism spectrum disorder (ASD), intellectual disability, and Down syndrome, were less likely to spend time with peers (Hilton et al., 2008; Orsmond & Kuo, 2011; Shattuck, Orsmond, Wagner, & Cooper, 2011; Solish, Perry, & Minnes, 2010) and were found to engage in more activities alone (Buttimer & Tierney, 2005; LaVesser & Berg, 2011; Oates, Bebbington, Bourke, Girdler, & Leonard, 2011; Wuang & Su, 2012) or with family members (Buttimer & Tierney, 2005). In one study, one third of parents of children with Down syndrome reported that their child had no friends (Oates et al., 2011).

To date, there have been few studies that have examined differences in participation by country or region. The SPAR-CLE study, a multicentre European study, shows that participation of children with similar types of CP differs according to where they live (Fauconnier et al., 2009; Hammal, Jarvis, & Colver, 2004; Michelsen et al., 2009). For example, Denmark was found to have the highest rates of participation of children with disabilities, while Italy was found to have the lowest. Participation patterns in children or youth with disabilities from Denmark nearly matched participation of their typically developing peers. A study comparing findings across two regions of Canada, the United States, and Australia found regional differences only in physical and self-improvement activities (King et al., 2013).

Perceptions of Participation

A common theme identified across the literature focused on perceptions of successful participation, including by the children or youth themselves and their parents. Findings suggest that children or youth tended to focus on factors associated with the person, while parents also considered environmental factors.

Child perceptions. Findings from a phenomenological study suggest that for children or youth, successful participation included having fun, feeling successful, doing and being with others, and doing things themselves (Heah, Case, McGuire, & Law, 2007). Other studies highlighted that children placed high value on equal performance with peers (Pereira, La Cour, Jonsson, & Hemmingsson, 2010); they wanted to engage in activities that were stimulating but not overwhelming to promote feelings of mastery. A child's enthusiasm in a task was related to his or her ability to master that task (Pereira et al., 2010). Children who had a greater extent of age-expected participation encountered fewer environmental barriers than those who had unsuccessful participatory experiences with age-matched peers (Bedell, 2009).

Parent perceptions. Parents wanted their child to have fun, but they also worried about their child keeping up with other children and considered their child's safety and wellbeing while engaging in tasks (Heah et al., 2007). For parents, the greatest perceived barriers encountered by their child were in the school environment as well as in the natural and built environments. Barriers were also experienced with institutional and government policies/services, assistance and attitudes (Law, Petrenchik, King, & Hurley, 2007). The lowest impact of perceived barriers was general attitudes at home and in the community (Law et al., 2007).

Influences on Participation

Body function and structure. Since the majority of studies have focused on physically based disability, there was more information about the influence of the physical aspects of body function and structure. Severity of impairment was an important influence on patterns of participation (McManus et al., 2008). For children following acquired brain injury (ABI), severity of injury was a significant predictor of change in participation intensity across the majority of activity types

(Anaby, Law, Hanna, & DeMatteo, 2012). For children with CP, physical ability was found to have the strongest influence on participation (Kerr, McDowell, &McDonough, 2007), with increased levels of impairment associated with decreased levels of participation (McManus et al., 2008). The need for supervision and personal and continence care (Kerr et al., 2007; Mihaylov, Jarvis, Colver, & Beresford, 2004) was found to be associated with increased restrictions to participation. This was also found to be true with children or youth with feeding difficulties (Hammal et al., 2004) and impaired walking (Fauconnier et al., 2009; Hammal et al., 2004; Palisano et al., 2011).

Fine and gross motor ability, including the ability to be independent, was a significant factor influencing the participation of children and youth with CP (Beckung & Hagberg, 2002; Fauconnier et al., 2009). Children with CP are typically classified using the Gross Motor Functional Classification System (GMFCS), where a higher score (on a scale of 1 to 5) signifies greater gross motor impairment (Palisano, Rosenbaum, Bartlett, & Livingston, 2007). Findings indicate that children who have lower scores on the GMFCS had greater intensity and diversity of participation across activity types (Imms et al., 2008; Orlin et al., 2010). Children with CP who have better motor function were found to be more involved in activephysical and social activities (Majnemer et al., 2008) and had better social integration (Kerr et al., 2007), including decreased restrictions in mobility, education, and social relationships (Beckung & Hagberg, 2002). Children with CP with an additional impairment, such as a learning disability or epilepsy, were found to have the greatest restrictions of participation in these domains (Beckung & Hagberg, 2002) and overall participation (Hammal et al., 2004).

Motor ability was also found to influence the participation of children with developmental coordination disorder (DCD). Poor manual dexterity was associated with high participation in social nonphysical activities (Poulsen, Johnson, & Ziviani, 2011). Children with DCD with greater motor impairments experienced decreased diversity and intensity of activities; they participated less frequently, were found to choose activities with greater solitude, and had decreased participation in skillbased, informal, and total CAPE activities (Jarus, Lourie-Gelberg, Engel-Yeger, & Bart, 2011). In contrast, children with DCD with greater visual perceptual and motor abilities participated in more diverse active-physical and formal activities with greater intensity (Jarus et al., 2011).

Cognitive/intellectual ability, including one's ability to communicate, was also significantly related to participation patterns. Among children with CP, higher cognitive/intellectual ability was associated with increased levels of participation (Fauconnier et al., 2009; Imms et al., 2008), particularly in informal activities (Imms et al., 2008; Majnemer et al., 2008). Children with CP with mild to moderate intellectual disability used a computer, played nonsporting games, and ate out more than their age-related peers. Children with cognitive/intellectual disabilities, including ASD, Down syndrome, and ABI, were found to engage in more sedentary activities, such as watching television, and less in social and/or community-based activities, such as joining a group or club (Hilton et al., 2008; LaVesser & Berg, 2011; Law et al., 2011; Oates et al., 2011; Orsmond & Kuo, 2011; Solish et al., 2010; Wuang & Su, 2012). Finally, communicative functioning was a key influence on participation affecting children and youth across diagnostic categories (Fauconnier et al., 2009; Hammal et al., 2004; Kang et al., 2010; King et al., 2009; Majnemer et al., 2008; Oates et al., 2011; Poon, 2011).

Contextual Factors

Contextual factors, including personal and environmental factors, were found to influence participation. Personal factors include characteristics of the child and the family, while environmental factors include variables within the physical and social environments.

Personal factors. Age and gender were found to influence the participation of children and youth with disabilities. In general, children 12 years and younger participated in more informal activities (Klaas et al., 2010; Law et al., 2006), such as recreational, social, and self-improvement activities (Law et al., 2006; Majnemer et al., 2008), than their older counterparts. Children were found to have greater levels of intensity in informal activities (Law et al., 2006), with greatest intensity in recreational activities (King et al., 2010; Majnemer et al., 2008; Orlin et al., 2010). Participation does not seem to be influenced by age in the context of active-physical (Orlin et al., 2010) and skill-based activities (Oates et al., 2011; Wuang & Su, 2012). In fact, low levels of participation in active-physical activities were found across age groups (Orlin et al., 2010). For children with ABI (Law et al., 2011) and CP (McManus et al., 2008), level of impairment is more influential than age. Across age categories, 6- to 8-year-olds were found to enjoy recreational, active-physical, and selfimprovement activities more than the others (King et al., 2010), while youth tended to have greater enjoyment of social activities but lower levels of recreational, social, and selfimprovement activities (King et al., 2010, Wuang & Su, 2012).

Participation was influenced by gender in several studies (King et al., 2010; Law et al., 2006; McManus et al., 2008). Overall, levels of participation tended to be higher in girls than boys (Law et al., 2006; McManus et al., 2008). Girls tended to participate more in informal (Michelsen et al., 2009), social, and skill-based activities (Law et al., 2006) and have greater enjoyment in these activities than their male counterparts (King et al., 2010; Klaas et al., 2010; Law et al., 2006; Majnemer et al., 2008). Boys participated more in active-physical activities (Mihaylov et al., 2004), such as bike riding and playing sports (King et al., 2004). Differences in the literature exist for boys with CP who participated through watching sporting events and playing nonsporting games, such as using a bicycle or wheelchair for fun (Michelsen et al., 2009). For children with ABI (Law et al., 2011), spina bifida (Kelly et al., 2011), and Down syndrome (in sports only), participation was not found to be influenced by sex. Girls with CP were found to

have significantly greater levels of enjoyment in social and self-improvement activities than their age-matched male counterparts (Engel-Yeger et al., 2009). Likewise, girls with a spinal cord injury were found to have greater levels of enjoyment of informal activities (Klaas et al., 2010).

Family factors. Several characteristics of the family were found to influence the participation of children and youth with disabilities, including parental values and preferences, level of education, income, and stress. In several studies, parents were identified as being the primary organizers of leisure activities for their child (Buttimer & Tierney, 2005; LaVesser & Berg, 2011), with values and preferences playing a role in activity type and frequency (Heah et al., 2007; LaVesser & Berg, 2011). Findings suggest that children participated more intensely in activities when parents had greater preferences for either sports or cultural activities (Law et al., 2006) and that there were fewer changes in activities that were parent controlled (King et al., 2009). Parent preferences for activities stemmed from the activities in which they were involved while growing up as well as from their perceptions of their child's ability to engage in a task (Heah et al., 2007).

Level of parent education was negatively correlated with participation diversity and frequency of participation in selfimprovement activities (Law et al., 2006). Youth with a spinal cord injury whose parents had a college education experienced increased participation in formal activities and experienced greater enjoyment of these activities (Kang et al., 2010). Similarly, youth with CP whose family members had a higher level of education were more likely to engage in activities with nonfamily members (Kang et al., 2010). Conversely, level of caregiver education did not relate to participation for children with spina bifida (Kang et al., 2010).

Across a number of studies, parental income was identified as having a significant influence on participation (Anaby et al., 2012; Kelly et al., 2011; Law et al., 2006; Mihaylov et al., 2004; Shattuck et al., 2011). Lower income levels were associated with lower levels of participation in both formal and informal activities and in self-improvement, active-physical (Law et al., 2006), and social activities (Kelly et al., 2011; Law et al., 2006). Families reporting annual incomes less than \$30,000 were found to experience lower levels of participation overall (Law et al., 2006). For single-parent families, total participation intensity and levels of participation were found to be lower than for single-parent families with children or youth without disabilities (Law et al., 2006). Finally, one study proposed that a greater household income was related to a more gradual decline in recreational participation (King et al., 2009).

Parental stress was found to be a barrier to participation (LaVesser & Berg, 2011; Majnemer et al., 2008; Parkes, McCullough, & Madden, 2010) and was related to decreased enjoyment of activities (Majnemer et al., 2008), increased difficulties with engagement in activities (LaVesser & Berg, 2011), and decreased participation in community groups (Parkes et al., 2010). Finally, having a support person who is able to bring the child to his or her activity was found to

promote the participation of children and youth with disabilities (Heah et al., 2007).

Environmental factors. Since components of the environment interact with the child's or youth's functional abilities to facilitate participation, the environment was often identified as a mediator of successful participation (Hammal et al., 2004; Harding et al., 2009; Heah et al., 2007). For successful participation to occur, children indicated that they wanted to feel interconnected with their environments as this provoked feelings of happiness, excitement, freedom, and acceptance (Harding et al., 2009). Children identified that the need to negotiate their environment hindered their participation, and it was in these contexts that they felt anger, fear, or annoyance (Harding et al., 2009). Children often saw the environment as being more disabling than their condition itself (Harding et al., 2009).

Children and parents stated that the greatest perceived barriers were in the natural and built environments. Physical barriers in the environment were associated with lower participation of children with physical disabilities (King, 2006; Law et al., 2007). General attitudes at home and in the community were rated as having the lowest impact on participation (LaVesser & Berg, 2011; Michelsen et al., 2009, Parkes et al., 2010). The social environment within community activities had a large influence on participation. "Adolescents with an ASD were significantly more likely never to see friends (43.3%), never get called by friends (54.4%), or never be invited to activities (50.4%) compared with adolescents from all other groups" (Shattuck et al., 2011, Findings, para. 2). For children with ABI, increased levels of participation were found to be associated with fewer environmental barriers, resulting in greater participation in the home and somewhat in very limited community participation (Galvin, Froude, & McAleer, 2010). The following factors were identified as impacting successful participation: bullying, stigma, policies, the nonuse of sign language, unnecessary assistance from adults, and time pressures (Mihaylov et al., 2004). For parents, restricted information, lack of consultation, poor support for caregivers (i.e., adequate supervision; Buttimer & Tierney, 2005; Forsyth, Colver, Alvanides, Wooley, & Lowe, 2007; King et al., 2009; Mihaylov et al., 2004), community program design (i.e., accessibility of program/information), and the costs associated with sport and leisure facilities (Klaas et al., 2010; Mihaylov et al., 2004) were all identified as impacting successful participation.

Discussion

This scoping review examined perceptions and influences of participation as well as patterns of participation of children and youth with disabilities. Results indicate that participation is a complex phenomenon that is influenced by a multitude of factors, including those associated with the child, the family, and the environment. Children and youth with disabilities enjoy similar activities as their age-matched peers but experience significantly lower levels of participation in these activities. Their participatory preferences are influenced by development stages, but personal and environmental factors may impact their ability to participate in preferred activities. Children and youth with disabilities were found to be particularly limited in active-physical participation, an important finding as limited physical activity has been linked to negative health outcomes, such as obesity, hypertension, and diabetes (Kurpad, Swaminathan, & Bhat, 2004). Given current knowledge about adapted sports and recreation, such limitations are not necessary.

The results highlight the value of the ICF as a framework to analyze and understand the participatory experiences of children and youth with disabilities. While participation is influenced by the personal factors of age and gender, other factors, such as child and family preferences, social support, and environmental supports and barriers, are very important as well. Parental planning and oversight is more prominent at a young age, when parents sought to ensure a proper "fit" between the activity, the environment, and the abilities of their child. In adolescence, when youth begin participating beyond the context of their home and school environments, environmental barriers had a greater influence on participation. Findings indicate that patterns of decreased social participation and increasing social isolation develop as youth move through adolescence. Qualitative interviews with children and youth also highlighted the importance of a proper "fit" between activities and environments in relation to their abilities to promote feelings of mastery when engaging in an activity.

The interplay between environment and participation has been identified as one of the most important factors influencing successful participation for children and youth with disabilities (Colver et al., 2011; King et al., 2003; Law et al., 1999; Lawlor et al., 2006). For example, there is evidence that the effect of personal and environmental factors on participation varies across activity types (Anaby et al., 2012; King et al., 2009). Both children and youth experience more frequent participation in activities that are informal, such as recreational activities. Activities that are organized and more formal can require a specific set of personal abilities as well as specific environmental supports to enable children and youth with disabilities to participate.

Parents, communities, institutions, policies, and children's own choices mutually shape involvement in out-of-school activities. Family values, preferences, cohesiveness, and resources play a vital role in determining children's participation. When these elements are analyzed together, it appears that participation is best supported when a child lives in a region with accessible and supportive community-based programs, when his or her family has specific participation preferences and can provide social support, and when a child's functional abilities fit well with the skills required from an activity. Policy and intervention efforts that are ecological, integrated, and family centred and that deliver practical, coordinated services and information will likely support children's participation by supporting family processes and easing the stressors associated with caring for a child with a disability.

Implications for Practice

Research indicates there are numerous possible pathways to positive, health-promoting participation (Mahoney, Larson, & Eccles, 2005). The findings of this scoping review provide knowledge for occupational therapists designing programs for children and youth with disabilities. Occupational therapy can enable the selection or redesign of an array of occupations for children that are meaningful and support well-being. Occupational therapists are skilled in analyzing the transactional relationship between the child/youth, environment, and occupation (Law et al., 1996). Using this approach, occupational therapists can determine areas of poor fit and subsequent targets for intervention. Personal factors, including factors of the child or youth and the family, are more stable than variables of the environment and occupation. Therefore, focus can be placed on modifying the latter two to enhance levels of participation. This is particularly evident in the SPARCLE study (Fauconnier et al., 2009; Hammal et al., 2004; Michelsen et al., 2009), which demonstrates the impact that inclusive programs and policies can have on the participation of children and youth with disabilities. Therapists can use a strengths-based approach to enhancing the participation of children with disabilities. Such an approach focuses intervention first on addressing modifiable environmental and family level factors that support participation. Intervention to improve a child's functional abilities is then focused on enabling performance at the activity and/or participation level in the ICF model, rather than focusing on changing the child.

Health care providers, teachers, and families of children and youth with disabilities can work together to improve participation in meaningful occupation by moving beyond diagnostic categories and addressing activity and environment factors that have been found to influence participation (Law et al., 2004). Clinicians can work toward client-centred goals whereby children are provided with choice, thereby promoting individualistic development and feelings of self-efficacy. Occupational therapists are uniquely positioned to play a significant role in promoting participation due to their emphasis on meaningful occupation, the link between one's functional abilities, one's environments, and the effect that these interactions have on the health and well-being of their clients.

Future Research

Future areas of research on the participation of children and youth with disabilities should take into greater consideration the impact of environmental and occupational factors, examining the effect that adapted settings make in enhancing levels of participation. This scoping review clearly shows the need for additional research to examine the impact of cognitive impairments on participation. Research focused on children and youth with cognitive and/or emotional disability is needed since the vast majority of studies have been with children and youth with physical disability. Likewise, more studies should be conducted across regions so that rates of participation of children with disabilities can be compared. With this, factors that are supporting participation on a macro level can impact change globally. Finally, physical inactivity and its association with chronic conditions of children with disabilities should be further explored, as participatory experiences of these children are unique and could potentially have different supports and barriers.

Limitations

Several limitations of this review should be noted. Only studies that could be retrieved in the English language were included, although several translated articles were included. Due to the quantity of peer-reviewed literature retrieved, grey literature was excluded. The review focused exclusively on participation in activities outside of formal academics, which excludes the body of literature on school participation. Finally, many studies utilized a variety of measures of participation; lack of standardized measurement may limit consistency when comparing results across the studies.

Conclusion

Children with disabilities face a number of barriers to participating in meaningful activities and life situations due to their functional abilities and the interaction between these abilities, and their social and physical environments. Taking part in everyday activities for children with disabilities, like their typically developing peers, is paramount to a sense of belonging within the community, and an adapted environment can facilitate this (McManus et al., 2008). At the community level, particular attention to improving social and institutional support has the potential to enhance participation. Missed opportunity to support a child's occupational development and participation in meaningful life situations, at any stage in his or her developmental cycle, could have a profoundly negative impact across the life span (Law, 2006).

Key Messages

- Participation outside of school is a complex phenomenon that is influenced by many factors, including those associated with the child, the parent, the environment, and the occupation.
- Children and youth with disabilities participate more in informal activities and are particularly limited in active-physical participation. They participate more often with family than with peers.
- Occupational therapists can facilitate children's participation through their skills in analyzing the transactional relationship between a child's occupations, skills, and functioning and the environment in which he or she lives.

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