Opening doors to participation of youth with physical disabilities: An intervention study

Favoriser la participation des adolescents ayant des handicaps physiques : Étude d’intervention

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Key words: Adolescent development; Leisure activities; Environmental factors; Occupational therapy; Parents.
Mots clés : activités de loisirs; développement de l’adolescent; ergothérapie; facteurs environnementaux; parents.

Abstract
Background. While participation in leisure activities is beneficial to youth’s health, little is known about effective intervention strategies to promote participation. Purpose. The aim of this study was to examine the effectiveness of environment-based interventions on participation of youth with physical disabilities. Method. Six adolescents ages 14 to 17 years participated in a 12-week intervention aimed at removing environmental barriers and coaching parents. An interrupted time series design was employed and a systematic replication of the intervention effect was examined across three individualized participation goals and across participants (17 goals overall). Goal performance was measured repeatedly using the Canadian Occupational Performance Measure and analyzed using visual inspection and a celeration line approach. Findings. A clinically significant improvement in performance scores (M = 4.5, SD = 1.77) was observed across all 17 goals, and a statistically significant treatment effect was replicated in 13 goals (76%). Implications. Findings support the effectiveness of environment-based interventions in promoting youth participation, but larger studies are required.

Abridged
Description. Bien que la participation à des activités de loisirs soit bénéfique pour la santé des adolescents, on sait peu de choses sur les stratégies d’intervention efficaces pour favoriser la participation. But. Le but de cette étude était d’examiner l’efficacité des interventions centrées sur l’environnement pour favoriser la participation des adolescents ayant des handicaps physiques. Méthodologie. Six adolescents âgés de 14 à 17 ans ont participé à une intervention de 12 semaines visant à éliminer les barrières à la participation et à encadrer les parents. Un modèle de séries chronologiques temporelles interrompues a été employé et une réitération systématique de l’effet de l’intervention a été examinée en fonction de trois objectifs de participation individuels et de l’ensemble des objectifs des participants (17 objectifs dans l’ensemble). Le rendement face à l’atteinte des objectifs a été mesuré à répétition à l’aide de la Mesure canadienne du rendement occupationnel, puis analysé à partir d’une inspection visuelle et d’une méthode d’estimation des courbes de tendance. Résultats. Une amélioration cliniquement significative des scores de rendement (moyenne = 4,5, écart-type = 1,77) a été observée pour l’ensemble des 17 objectifs et l’effet statistiquement significatif de l’intervention a été réitéré dans 13 objectifs (76 %). Conséquences. Les résultats indiquent que les interventions centrées sur l’environnement sont efficaces pour favoriser la participation des adolescents, toutefois, des études à plus grande échelle devront être menées.

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Participation in community leisure-based occupations—an important outcome of occupational therapy intervention—is significantly restricted among youth with various types of disabilities (Bedell et al., 2013; Engel-Yeger, Jarus, Anaby, & Law, 2009). To date, there is ample knowledge describing the factors that affect participation (Tonkin, Ogilvie, Greenwood, Law, & Anaby, 2014) with special focus on the environment as an influential factor (Anaby et al., 2013); however, little is known about effective strategies to promote participation.

Emerging therapeutic interventions suggest focusing on changing the environment and/or the activity demands, rather than directly changing the child’s abilities, as a useful approach for improving function and participation (Darrah et al., 2011; Kramer, Roemer, Liljenquist, Shin, & Hart, 2014; Law & Darrah, 2014). Within environment-based interventions, the therapist, youth, and family work together to identify environment-related barriers and/or facilitators (physical, social, institutional, activity demands) to participation in each activity. Through discussion and exchange of information, solution-based strategies to remove barriers are then proposed and implemented while building on youth/family strengths and supports. This process involves a coaching element (Graham, Rodger, & Ziviani, 2009) where the therapist engages and coaches both parents and adolescents on how to identify and apply effective strategies to improve the child’s participation. Such a collaborative approach can foster parental knowledge, problem solving, and self-advocacy skills and help develop strategies to overcome barriers autonomously.

Context therapy is an example of such an approach; it has been proven effective in improving performance of young children with cerebral palsy (Law et al., 2011) and was classified as a “green light” intervention—one that has demonstrated evidence of effectiveness and is considered recommended practice (Novak et al., 2013). A recent study successfully tested elements of this approach among six youth with physical disabilities in Ontario (Law, Anaby, Imms, Teplicky, & Turner, 2015). As participation levels are associated with contextual factors, such as policies, availability of services, attitudes, and culture and language (Anaby et al., 2013), the purpose of this brief research report is therefore to provide further evidence about the effectiveness of an environment-based intervention on leisure participation of youth with physical disabilities living in Québec. Such an examination will allow testing of the generalizability of this approach in different contexts or regions, a factor known to influence participation (Hammal, Jarvis, & Colver, 2004).

We hypothesized that a statistically and clinically significant effect of the intervention will be replicated across two out of three goals for each participant and across 75% of the overall goals (across all participants). Secondary hypotheses were also set, where differences in participation patterns and quality of life were anticipated between baseline and follow-up phases.

Method

Study Design
An interrupted time series design with multiple baselines (Shadish, Cook, & Campbell, 2002) was employed where the effect of the intervention on participation was examined across three leisure activities/goals within and across participants. The intervention was introduced at different time points for each goal (4-week delay), resulting in a 4-week baseline for the first goal, 8 weeks for the second goal, and 12 weeks for the third goal. Detailed information about this design specific to participation-based interventions has been described elsewhere (Anaby et al., 2014).

Participants
Once ethics approval was received from the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, youth with physical disabilities ages 12 to 18 years whose mobility is restricted (e.g., cerebral palsy, spina bifida) were recruited via two major rehabilitation centres in a metropolitan district of Québec, from both the Anglophone and Francophone communities. Exclusion criteria were youth diagnosed with progressive disorders and those within their 1st year following a severe brain injury. Youth with cognitive and/or communicative impairments were also included in the study; in these cases, parents took a more active role in the intervention.

Procedure
Participants were assigned to one of the four occupational therapists who delivered the intervention. A therapist worked with each youth individually in his or her home/community over the course of 12 weeks. At baseline, during the first session, occupational issues surrounding leisure were identified using the Canadian Occupational Performance Measure (COPM; Law et al., 2014), and these issues assisted in setting three desired activities or participation goals in which the youth would like to participate but finds difficult. Degree of performance in each leisure activity/participation goal was collected twice weekly (by phone/e-mail) using the performance scale of the COPM throughout each phase of the study: baseline, intervention, and follow-up (i.e., 4 weeks post-intervention for all three goals). A 4-week intervention was designated for each goal and involved four therapy sessions for a total of up to 12 sessions overall (4 sessions × 3 goals). Each intervention had the following steps: (a) Review baseline participation goals; (b) identify and evaluate environment-based barriers/facilitators to participation, including the setting in which these activities take place; (c) work together with the adolescent and parents to explore strategies to modify environmental barriers and/or activity demands and implement these strategies; and (d) engage and coach parents and adolescents and provide knowledge about useful strategies to search for information and advocate for the child’s inclusion.
Additional measures were administered pre- and post-intervention to assess changes in participation patterns (using the Participation and Environment Measure for Children and Youth [PEM-CY]) and quality of life (using the KIDSCREEN-27). Moreover, throughout the entire study, the intervention process (e.g., barriers, strategies, and special circumstances) was documented and evaluated by the therapists using a structured form. Finally, participants’ satisfaction with the program was measured post-intervention only (using the Client Satisfaction Questionnaire [CSQ-8]).

Measures
A standard demographic questionnaire was used to collect data about the youth and family, including information about the youth’s functional issues and health condition. The COPM, a semi-structured interview, guided participants to (a) identify three activity goals that were important to them yet were difficult to carry out and (b) rate their level of performance on a scale ranging from 1 (unable to perform) to 10 (performs extremely well). The COPM has demonstrated reliability and validity as well as an ability to detect changes in performance over time (Law et al., 2014).

Two measures were administered pre- and post-intervention. The PEM-CY, used to evaluate participation patterns and environmental barriers/supports, is a parent report tool that assesses children’s global participation in 25 activities across three settings: home, school, and community. Parents were asked to rate their child’s participation in terms of frequency (7-point scale), involvement (5-point scale), and whether a change in activities was desired. The PEM-CY also assessed environmental barriers and supports affecting participation in each setting. It has been shown to be a reliable and valid measure for children and youth ages 5 to 17 years, with and without disabilities (Coster et al., 2011). The KIDSCREEN-27 was used to measure five dimensions of quality of life: physical well-being, psychological well-being, autonomy and parents’ relations, social support and peers, and school environment. Using a 5-point scale, participants were asked to rate the extent to which different situations and feelings were experienced. Mean T values were calculated for each dimension ranging from 0 to 100 ($M = 50$, $SD = 10$), with higher values indicating better quality of life. The KIDSCREEN-27 has demonstrated sufficient validity and reliability (Ravens-Sieberer et al., 2007).

Post-intervention only, the CSQ-8 was used to measure level of satisfaction of a program or service using eight items rated on a 4-point scale. A summary mean score was generated ranging from 1 (minimal satisfaction) to 4 (maximal satisfaction). The CSQ-8 is a valid and reliable tool (internal consistency of 0.93) and was tested among families of children with physical disabilities (Attkisson & Zwick, 1982).

Data Analysis
For each participation goal, a series of data points that represent the level of goal performance, generated by the COPM, was plotted and analyzed to detect change. Visual inspection was conducted where an increase of at least two points on the COPM scale indicated a clinically significant change (Law et al., 2014). To detect changes that are statistically significant, the celeration line approach was used (Ottenbacher, 1986). This method calculates the proportion of data points falling above and below the line. If 50% are above the line and 50% below the line, this result indicates no treatment effect, whereas significantly more observations falling above the line indicates a change in goal performance. Finally, pre- and post-scores of quality of life generated from the KIDSCREEN-27, as well as participation and environment scores measured by the PEM-CY, were compared descriptively for direction and amount of change.

Findings

Sample Characteristics
Six youth (50% male; response rate 37%) ages 14 to 17 years ($M = 15$, $SD = 1.26$) participated in the study, and all attended a special education high school/class. Number of health conditions per participant ranged from 1 to 5 ($M = 3.16$, $SD = 1.6$); the majority ($n = 5$) had orthopedic/movement impairments as well as developmental delay, followed by intellectual delay, speech impairment, and specific learning disabilities (33%). Participants had a range of functional issues (between 6 and 10; $M = 7.7$, $SD = 1.5$), and all ($n = 6$) had a certain degree of difficulty moving around, using their hands to do activities, and communicating with others, followed by paying attention, reacting to sensations and managing emotions (83%), learning new information (67%), and controlling behaviour (50%). Specifically, three participants (Participants 1, 4, and 6) had relatively complex conditions illustrated by a number of functional issues and health conditions. Income and parental education varied.

Participation Goals, Environmental Barriers, and Strategies
Adolescents chose a range of activity types, including formal (e.g., dance classes, sailing, boccia) and informal (e.g., riding a bike, socializing with friends outside home/school). Various aspects of the environment were identified as barriers to participation, including lack of transportation; physical inaccessibility of community-based facilities, such as changing rooms; unsuitable activity equipment; unavailability of programs; poor access to information; lack of knowledge of community agencies/instructors/service providers about ways to adapt their program/activities; attitudes and availability of others; and the need for assistance/shadow services to accompany youth in activities. Therapists’ documentation of the process of the intervention revealed different solution-based strategies for removing environmental barriers (see Table 1). Strategies involved searching for local programs and contacting program
directors/instructors to explain participants’ needs. Collaborating with a range of service providers was also evident, which involved working with teachers, volunteer coordinators in the community, instructors/program directors, and rehabilitation technicians. For instance, therapists arranged for a volunteer to accompany the youth to art classes and provided education

<table>
<thead>
<tr>
<th>Environmental factors</th>
<th>Environmental barriers</th>
<th>Solution-based strategies</th>
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<tbody>
<tr>
<td>Social support</td>
<td>Participant needs an assistant/ supervisor/shadow to accompany them in activities</td>
<td>Therapist made arrangements with students from occupational therapy/physical therapy/adapted physical education programs</td>
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<td></td>
<td>Availability of friends for socializing</td>
<td>Therapist and teacher helped connect participant’s parents with contact information of peers</td>
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<td>Therapist worked with coordinator at rehabilitation centre</td>
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<td>Master’s student in field of adapted physical education to assist with bike riding</td>
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<td>Build on strengths/support: shared friends/activities with twin sister; supportive/resourceful family</td>
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<td>Discussion around potential social activities (e.g., photo camp)</td>
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<td>Physical/built environment</td>
<td>Lack of accessibility of community facilities</td>
<td>Contacted stadium and found accessible sections/appropriate pricing</td>
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<td></td>
<td>Unsuitable equipment</td>
<td>Visited yoga studio</td>
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<td></td>
<td></td>
<td>Therapist reviewed accessibility of football programs/stadium</td>
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<td></td>
<td></td>
<td>Verified accessibility of friend’s home</td>
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<td>Recommendations made for sitting in boat; therapist attended first lesson and adapted boat using straps.</td>
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<td>Team up with physical rehabilitation technician to adapt bike/boccia equipment</td>
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<td>Accessible bowling alleys found to practise alternate boccia</td>
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<td>Cultural</td>
<td>Language</td>
<td>Coaches/players provide English translation; one bilingual player specifically assists participant</td>
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<tr>
<td>Institutional</td>
<td>Access to information</td>
<td>Therapist provided resources; classes found through an inclusive arts and dance organization</td>
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<td></td>
<td>Adapted activities too costly</td>
<td>Therapist contacted art school directors to explain participants’ needs/get information about classes</td>
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<tr>
<td></td>
<td>Lack of availability of transportation services (especially weekends)</td>
<td>Therapist shared information with family about stadium’s accessibility/cost/transport options</td>
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<tr>
<td></td>
<td>Lack of availability of programs</td>
<td>Therapist provided resources about funding sources/study funds</td>
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<td></td>
<td></td>
<td>Therapist wrote letter of request advocating for transportation services on Sundays for swimming lessons</td>
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<td></td>
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<td>Therapist assisted with application for adapted transport</td>
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<td></td>
<td>Therapist found yoga classes that fit participant’s ability/level of experience</td>
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<td>Information on boccia associations in Montreal made available to family</td>
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<td></td>
<td></td>
<td>Therapist advocated for boccia activities via a physical activity centre for individuals with disabilities</td>
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<tr>
<td>Attitudinal</td>
<td>Friends are not fully aware of participant’s disability/needs</td>
<td>Work on communication with friends via technology (i.e., Skype, FaceTime, text, e-mail)</td>
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<td>Lack of knowledge of how to accommodate activity</td>
<td>Discuss how to sensitize friends about disability and needs and how they can be of assistance</td>
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<td></td>
<td>Therapist spoke with yoga instructor to suggest setting participant up near wall</td>
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<td>Build on strengths: Participant is open/accepting about disability, has good insight and initiative, is willing to connect/interact with friends and make new ones</td>
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<td>Activity demands</td>
<td>Activity is new</td>
<td>Adapt activity with high-visibility cues/props: highlighted arrows to locate balls/use of ramp</td>
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<td></td>
<td>Vision/focus/attention required</td>
<td>Therapist tried Wii yoga at home with participant</td>
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<tr>
<td></td>
<td></td>
<td>Build on strengths and supports: Participant and family developed homemade version of boccia kit by modifying baseballs, allowing her to practise</td>
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<tr>
<td>Other</td>
<td>Time and logistics, planning ahead, scheduling</td>
<td>Therapist listed friends, activities, locations and ways of achieving goal</td>
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<td></td>
<td>Well organized logistics: Plan made to reduce impact of school on Mondays; homework completed in afternoon, everything ready in advance to allow time for dance class</td>
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</table>
about participants’ needs and level of required assistance. Building on the youth’s/family’s strengths and resources/supports was another useful strategy to facilitate the goal of socializing with friends out of school. A close and trusting relationship between the youth and peers in combination with supportive family members and the youth’s willingness to connect helped enhance neighborhood interactions/outings.

The Effectiveness of the Intervention
An analysis of the 17 goals (3 goals × 6 participants; one youth set two goals only) indicated a clinically significant improvement in COPM performance scores, with a change in scores ranging from 3 to 9 (\(M = 4.5, SD = 1.77\)) across every goal following the intervention (see Figure 1). A statistically significant change was observed across 13 of the 17 goals/activities (76%), where all data points (100%) fell above the ceiling line post-intervention and strong, stable baselines were observed pre-intervention. Figure 1 illustrates the trajectory of each goal; change in performance score of Participant 2 across all three goals was not significant (6% to 50% of data points fell above the ceiling line), nor was it for Goal 2 of Participant 4 (all data points fell below the ceiling line).

Secondary outcomes for evaluating the intervention indicated that parents’ satisfaction measured by the CSQ-8 post-intervention was high (\(M = 3.5\) out of 4, \(SD = 0.6\)). Additionally, changes in PEM-CY scores in the community setting before and after the intervention were observed. On average, a small improvement in participation frequency was observed from 2.5 (range 1.6 to 3.1) to 3.1 (2.2 to 5.4) on a 7-point scale. While level of involvement, number of barriers, and number of supports remained relatively similar (from 3.8 to 3.9, 2.0 to 2.4, and 4.6 to 5.2, respectively), mean number of activities in which youth participated increased (from 45% to 58%), and mean number of activities in which parents desired change decreased on average (from 52% to 35%). Consistent patterns of change across participants before and after the intervention were observed in two of the five domains of quality of life: improvement in the autonomy (from 38.7 to 46.5) and physical well-being (from 35.4 to 39.1) scores.

Discussion
This brief report examined a relatively new occupational therapy intervention that aims to increase youth participation in leisure activities by changing only the environment. Our primary hypothesis was confirmed where a clinically significant improvement in COPM performance scores was evident in all 17 goals and the intervention effect was significantly replicated in just over 75% of the goals (i.e., 76%). There was one participant, however, with whom no goals were statistically significant. This participant (No. 2) was highly motivated, from a resourceful and supportive family, and eager to achieve goals (e.g., playing boccia) even before the intervention began. To illustrate, the family put together a homemade kit to practise bowling with siblings and friends. The occupational therapist reported that little guidance and support was provided to the youth to achieve this goal. While results of this specific participant are not significant, they are encouraging as they illustrate that in certain conditions, only minor, brief interventions are required and adolescents and their families can identify and implement solution-based strategies independently. For Participant 4, improvement in Goal 2 (socializing with friends) was evident before the intervention was introduced; however, during that time, a series of social events (e.g., birthday party, family gathering) took place, which could explain the timing to which chance occurred. This is not unusual in “real-life” studies, and hence documenting and evaluating the intervention process, as was done in this study, is important.

Our second hypothesis was partially confirmed, illustrating some improvement in participation patterns and certain aspects of quality of life. Change was mostly evident in number of activities and to a certain degree in level of frequency (quantitative aspect of participation) but not in level of involvement (qualitative aspect). This is not surprising as the intervention focused on increasing participation in three new community-based activities, whereas changes in involvement, which pertains to satisfaction and emotional engagement, may be exhibited only at later stages once youth gain more experience and become more familiar with the activity. Interestingly, the number of environmental barriers/supports remained quite similar; it is plausible that certain barriers were simply replaced by others, as engaging in new activities may evoke new barriers and aspects of the environment may become more salient to participants. Further larger studies are needed to better understand how the association between environment and participation changes over time.

Study Limitations
Inclusion of only six participants may be perceived as a limitation; however, we employed a rigorous design that resulted in the replication of the intervention effect across a range of different goals, circumstances, and conditions and thus can provide some evidence about the generalizability of the intervention. Furthermore, in conjunction with the results of Law et al. (2015) illustrating the effectiveness of this approach in Ontario, the study provides further support for the generalizability of this intervention in different locations/regions and offers an additional range of solution-based strategies. Testing the intervention with a larger, more diverse sample is still necessary; this would allow us to better understand for whom and under what circumstances this intervention is most effective as well as the optimal duration and amount of therapy required. Such aggregated data could shed light on the intervention’s cost-effectiveness and, consequently, inform policies related to practice. While the process of the intervention was documented, illustrating environmental barriers paired with solution-based strategies, fidelity was not systematically evaluated. Such an evaluation is recommended in future research; it can further reassure that the intervention was guided by the same
Figure 1. Changes in the Canadian Occupational Performance Measure scores within and across participants. Grey dotted line = performance scores; black vertical line = intervention starting point; grey solid line = celeration line; F = female; M = male.
principles across goals and across therapists. Finally, as is commonly done in practice and is typical in “real-life” studies, youth were not blinded to the time point in which the intervention began for each goal, which can result in a potential bias. Future controlled group studies using this intervention are needed.

**Implications for Occupational Therapy Practice**

Clearly, occupational therapists are well positioned to carry out this intervention as they specialize in modifying the environment and/or the activity by drawing on enablement skills, such as coaching, educating, and advocating (Townsend et al., 2013). This approach can redirect clinicians’ attention not only toward the concept of participation but can also shift the way therapy is delivered and packaged, toward community-based ecological practices that occur in real-life situations. Moreover, with appropriate knowledge translation strategies, this protocol can be easily incorporated into the clinical setting as it mirrors typical rehabilitation practice, one that is goal directed and family centered. Effective strategies for removing environmental barriers can also be disseminated to clinicians, youth, and parents and, consequently, can guide practice and empower families.

**Conclusion**

This study is one of the first to examine an intervention aimed at increasing leisure participation among this population; it lends further support to contemporary/emerging therapeutic approaches emphasizing the benefit of targeting modifiable factors within the environment rather than “fixing a deficit” within the child as leverage for inclusion. Further evidence about the effectiveness of this approach, among families of different backgrounds and contexts, is needed.

**Key Messages**

- Interventions at the level of the environment can promote participation in community-based leisure activities of youth with physical disabilities; however, further larger studies are needed.
- Examples of effective strategies for removing environmental barriers generated from this study can be relevant to occupational therapists, community-based service providers, and youth and their families.

**References**


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