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## Enabling physical activity participation for children and youth with disabilities following a goal-directed, family-centred intervention



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### ABSTRACT

**Background:** There is a paucity of research demonstrating the optimisation and maintenance of participation outcomes following physical activity interventions for children and youth with disabilities.

**Aim:** To evaluate changes in physical activity participation in children with disabilities following a goal-directed, family-centred intervention at a healthsports centre, and to identify factors influencing participation following the intervention.

**Methods and procedures:** A mixed methods pre-test post-test cohort design was applied. Recruitment occurred over a 12 month period during standard clinical service provision. The Canadian Occupational Performance Measure (COPM) was administered to children and parents pre (T1) and post-intervention (T2), and at 12 weeks follow-up (T3). Goal Attainment Scaling (GAS) was applied to assess outcomes at 12 weeks follow-up (T2–T3). Qualitative inquiry described barriers to goal attainment at T3.

**Outcomes and results:** Ninety two children with a range of disabilities (mean age 11.1yr; 49 males) were included in the study. Statistically significant and clinically meaningful improvements in parent ratings of COPM performance and satisfaction of participation goals were observed following intervention. Ratings at 12 weeks follow-up remained significantly higher than baseline, and 32% of children attained their COPM-derived GAS goal. Environmental factors were the most frequent barrier to goal attainment following intervention.

**Conclusion and implications:** These results provide preliminary evidence for goal-directed, family-centred interventions to optimise physical activity participation outcomes for children with disabilities.

### What this paper adds

Children and youth with disabilities participate in alarmingly low levels of physical activity. In contrast to previous research attempting to optimise physical activity outcomes, the intervention model in this study is centred on a participation- and environment-focused approach. Our findings indicate the potential for goal-directed, family-centred interventions to improve physical activity participation outcomes in children and youth with disabilities. Additionally, this study provides insight into factors that may

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influence the sustainability of physical activity behaviours acquired from interventions, particularly in relation to the environment. To our knowledge, this is one of the first studies to evaluate participation as the primary outcome measure in a physical activity intervention in children and youth with disabilities. Future studies using randomised, controlled designs are needed to provide higher level evidence for the effectiveness of this approach.

## 1. Introduction

Enabling participation in physical activity is an important goal for children and youth with disabilities, parents and health professionals. It is widely acknowledged that children and youth can experience health and psychosocial benefits from regular participation in physical activity. However, children and youth with disabilities are more restricted in their physical activity participation than their typically developing peers (Maher, Williams, Olds, & Lane, 2007; Van den Berg-Emons et al., 1995), and are less active as they become older (Claridge et al., 2015; MacDonald, Esposito, & Ulrich, 2011). The need to identify strategies that facilitate meaningful involvement in physical activity is recognised as an urgent priority (Peterson, 2015).

A range of environmental, personal and activity-related factors affecting physical activity participation in children and youth with disabilities have been identified (Kang, Zhu, Ragan, & Frogley, 2007; Lin et al., 2010; Shields, Synnot, & Barr, 2012; Verschuren, Wiart, Hermans, & Ketelaar, 2012). Recently, emphasis has been placed on the importance of the environment in enabling a child's participation (Anaby, Law, Feldman, Majnemer, & Avery, 2018; Darrach et al., 2011; Law, Anaby, Imms, Teplicky, & Turner, 2015); increasing accessibility, decreasing negative attitudes, and ensuring staff are adequately trained to adapt activities for children and youth if required (Verschuren, Wiart, & Ketelaar, 2013). Furthermore, it has been suggested that attempts to increase children's activity should target the whole family (Timperio, Salmon, & Ball, 2004; Willis et al., 2017), and engage communities and municipalities (Gorter, Galuppi, Gulko, Wright, & Godkin, 2017).

There is a strong evidence base in the paediatric rehabilitation literature that supports the efficacy of goal-directed and family-centred interventions to enhance outcomes across all domains of the International Classification of Functioning, Disability and Health (ICF) (Novak et al., 2013). Combined use of the Canadian Occupational Performance Measure (COPM) and Goal Attainment Scaling (GAS) has been suggested as beneficial in the assessment of outcomes in paediatric rehabilitation interventions, as they provide different but complementary information about goal progress (Cusick, McIntyre, Novak, Lannin, & Lowe, 2006; Keenan, King, Curran, & McPherson, 2014). These measures enable the development of personalised outcomes, with the COPM also able to be utilised as a self- and proxy-report measure. The COPM and the GAS have previously been employed as outcome measures in interventions targeting leisure participation in children and youth with disabilities (Imms, Mathews, Nicola Richmond, Law, & Ullenhag, 2015; Law et al., 2015).

While exercise programs for children with disabilities have become a contemporary focus of intervention, limited studies have demonstrated improvements in the participation outcomes of participants. Recent systematic reviews concluded that training interventions and body function-focused approaches demonstrated little effect on participation (Adair, Ullenhag, Keen, Granlund, & Imms, 2015; Bloemen, Van Wely, Mollema, Dallmeijer, & Groot, 2017; Reedman, Boyd, & Sakzewski, 2017). These reviews also reported that few intervention studies have focused on participation as a primary outcome measure (Adair et al., 2015). Although we know that exercise programs can be beneficial in children with disabilities, training interventions alone are not enough for them to stay physically active (Gorter, 2017). Currently, there are limited studies that demonstrate the optimisation and maintenance of an individual's physical activity participation at a community level, and in the long-term (Van der Ploeg et al., 2006; Van der Ploeg et al., 2007).

The purpose of this study was to evaluate change in physical activity participation following a goal-directed, family-centred intervention in children and youth with a disability immediately post-intervention and at 12 weeks follow-up. We hypothesised that i) the intervention will increase perceived (parent and child) performance and satisfaction of individual physical activity participation goals post intervention (T2) and at 12 weeks follow up (T3); and ii) children will attain goals relating to physical activity participation in their local community set post-intervention (T2). Additionally, we aimed to explore the factors affecting goal attainment in a child's local environment following intervention (T2–T3), as reported by the parent.

## 2. Methods

### 2.1. Study design

A pre-test post-test cohort design was used to determine changes in physical activity goal attainment, performance and satisfaction following a child's participation in the Local Environment Model (LEM) intervention at Beitostolen Healthsports Centre (BHC), and to determine whether participation outcomes achieved from the intervention could be transferred into the child's local community. This study was an evaluation of a clinical program that has longitudinal outcome measurement embedded within it. Ethics approval for this study was obtained from the Norwegian Regional Committee for Medical and Health Research Ethics, section South-East C (S-08658a 2008/18016), and The University of Western Australia (RA/4/1/8263).

### 2.2. Participants

Recruitment occurred over a 12 month period using consecutive sampling during standard clinical service provision at BHC. Children were eligible to participate in this study if they were a) participating in a stay at BHC in a Local Environment Model group,

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