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REVIEW

# Measuring the Effects of Interventions on Participation in Children with Developmental Coordination Disorder (DCD)

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## Abstract

**Purpose of Review** The 2019 International clinical practice recommendations for developmental coordination disorder" recommended setting goals, and targeting interventions, at the activity and participation level. This review will explore how clinicians can make a positive move towards participation focused practice by measuring the impact of interventions at a participation level.

**Recent Findings** Few studies have been published where the primary outcome measure is participation in activities which reflect child and family goals. The challenge of measuring the impact of participation focused interventions is setting goals and finding measures to capture both attendance and engagement from the child's perspective. The Canadian Occupational Performance Measure (COPM) is frequently used to set goals and measure outcomes but does not consider levels of attendance and engagement.

**Summary** Participation is a difficult construct to measure. There are tools available aimed at measuring participation, but they capture the parent/carer voice rather than the child's. The recent publication of national survey studies on the impact of DCD provides valuable data in support of the development of participation focused services in multiple countries. Future research should continue to explore ways of capturing the child's voice in measures of participation and continue to drive a better understanding of how participation focused practice can help mitigate some of secondary consequences reported in recent impact data.

**Keywords** Developmental coordination disorder · Intervention · Participation

## Introduction

International clinical guidelines for developmental coordination disorder (DCD) recommend that the goals of intervention should be directed at the child/young person's ability to participate in activities of daily living that are meaningful for them and their families [1]. Participation is defined as involvement in life situations [2] and "the ultimate outcome for health and educations outcomes" for all children with disabilities [2 p1093]. And, yet this outcome remains neglected in DCD research and not well translated in practice. This article considers this conundrum and suggests several future avenues to develop both research and practice, improving the health and well-being of these children via their full participation in life.

Children with DCD have significant difficulties with motor coordination which impacts on their ability to participate in activities of daily living and has a significant prevalence of 5–6% [3, 4]. It is well documented that activities of daily living frequently identified as challenging for children with DCD, by themselves and their parents/carers, include: self-care (dressing, personal hygiene, using cutlery); play and leisure (riding a bike, ball games, playing with peers) and academic participation (handwriting, using scissors, physical education [4]. These difficulties can lead to negative social, emotional and psychological consequences including social isolation, anxiety, depression and low self-esteem [4].

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Participation is a complex construct with two main elements, attendance and engagement [5]. It is much easier to measure attendance than engagement, especially in younger children, as it simply entails turning up and completing a particular activity in the community. Engagement cannot be observed but needs to be self-reported by the person participating—it is a subjective experience of being involved in the activity at different levels, whether psychological, emotional, and/or social. This may be why interventions are often targeted and measured at the activity level rather than the participation level. For example, there is evidence for the effectiveness of using goal-based interventions to teach bike riding for children with DCD [6, 7]. The outcome measured is usually whether the child can ride independently following the intervention i.e. they can do the activity. But participation in bike riding means riding a bike for leisure with family or friends, or as a means of transport. Dimensions of participation include frequency, diversity, level of involvement and desire for change and are influenced by the child's environmental context [8].

To measure the effects of interventions on participation, assessment must start with setting meaningful goals with the child and family. Recent research has shown child-led goal setting to be a complex process requiring six distinct steps: 1. Direct children to goal setting; 2, Elicit goal topics and priorities; 3. Construct a goal statement; 4. Indicate baseline goal performance; 5. Develop an action plan to address the goal; and 6. Evaluate goal progress after the intervention (DECIDE) [9]. Therapists may feel poorly equipped to set goals with children or perceive it as too time consuming [10]. Once goals have been set it is important to ensure they are reviewed with an appropriate outcome measure to establish whether they have been achieved and if the child's participation has improved.

Blank et al. identified several evidence-based participation-oriented interventions that are goal-based and task-specific, including Cognitive Orientation to Occupational Performance (CO-OP), Neuromotor Task Training, and others currently more confined to research. There is also some evidence for the effectiveness of assistive technology (like virtual rehabilitation) to facilitate skills training, mental rehearsal and school-based programs that target ball skills and team sport [1]. Although these interventions are participation based and have positive outcomes the effects at the participation level have seldom been investigated [11]. A sobering fact is the need for more, high quality research into the effectiveness of participation-based interventions for DCD [1, 12] and a need for greater awareness of the condition amongst health and education professionals to support participation [4]. Below, we explore how clinicians can implement participation focused practice via robust measurement and offer perspectives on potential enablers for increasing participation focused practice more broadly.

## Findings

### Ways to Measure the Impact of Participation Focused Interventions

1. *Capture Participation Itself*

The ease of implementing a participation focus within clinical practice can be hindered by the lack of tools available to implement this approach. Without robust measures to guide practice it can be difficult to consistently incorporate a participation focus into patient care. The Child and Adolescent Scale of Participation (CASP) [11] is one of the few measures that has a distinct focus on participation and can be used flexibly depending on the child's circumstances. It is a criterion measure which considers the extent of participation in the home (i.e. self-care, chores, socialising etc.), school (i.e. communication, moving around, socialising etc.) and community environments (i.e. leisure, structured events, moving around etc.). It was initially developed as part of a wider project to assess the needs of children and youth with traumatic and other acquired brain injuries following discharge from inpatient rehabilitation. However, it can be used more widely as a measure of participation before and after intervention in children including those with DCD. The CASP is freely available and can be self-administered or administered via a 10-min interview. It has versatile scoring options ranging from a total summary score to subsection or single item scoring. Items are scored using categories such as 'age expected', 'somewhat limited', 'very limited', 'unable', 'not applicable'. However, this approach to scoring focuses primarily on the level of difficulty or independence that a child has and does not fully align with the widely accepted definition of participation which includes both attendance (being there) and involvement (taking part) [13]. Nor does it take a strengths-based approach as scoring requires comparison to other children their age as a benchmark [1]. Furthermore, it is the parent rating their child's participation, although there is a youth version for older children to complete themselves. A closely related measure that incorporates both attendance and involvement is the Functioning Disability Evaluation Scale for Children (FUNDES-Child) [14], which expands on the CASP by including dimensions such as frequency of attendance and engagement. The FUNDES-Child was developed in Taiwan [14] and has been translated into Swedish [15] and English [16]. The Participation and Environment Measure for Children and Youth (PEM-CY) also measures the child's participation from the parent/carer's perspective and was used to find that children with DCD participate in fewer and less diverse activities than their typically developing peers [17]. The CAPE (Children's Assessment of Participation and Enjoyment) is a measure which captures the child's voice. Research using the CAPE suggests children with DCD participate less in physical, skill based and self-improvement domains but has not been validated for DCD [18]. However further work is needed to develop participation-based measures that capture both attendance and involvement, the child's voice and are applicable across diverse global contexts.

2. *Set Participation Focused Goals*

While standardised participation measures such as the CASP, PEM-CY, and FUNDES-Child provide valuable information about a child's level of participation in their everyday environments they do not inherently capture a child's priorities. For that reason, a participation measure such as the CASP can be used in conjunction with a goal orientated tool such as the Canadian Occupational Performance Measure (COPM) [19] or Goal Based Outcome Measure [20] to achieve a well-rounded overview of the child's participation. However, clinicians are often stretched for time and may not prioritise specific measures of participation in their practice [21]. In such cases goal setting plays an important role in ensuring that participation is embedded in the therapy process for the child and the family. Despite the absence of a formal participation measure, goals can reflect real-life participation such as involvement in self-care, school activities, play and community leisure. At the very least the use of goals to facilitate participation focused practice should remain central to the therapeutic process. Since parent and child goals often tend to differ significantly [22] it is important to ensure that measures which capture the child's voice are selected and this can be facilitated through the use of tools such as the CAPE [18], COPM (from 9 years) [19], Perceived Efficacy and Goal Setting System (PEGS) [23] (5–9 years), and the Paediatric Activity Card Sort (PACS) [24] (6 to 12 years).

## Contextual Influences on Participation Focused Practice

### A Chance to Reform Practice Through the Impact for DCD Movement

Governments in countries such as the United Kingdom [25] (UK Parliament, 2025) the Republic of Ireland [26] (Department of Education and Youth, 2025) and Australia [27] (Dept of Education, 2025) have acknowledged the inadequacy of the Special Educational Needs and Disabilities provision in mainstream schools and are proposing significant reforms to promote inclusion and participation. These reforms present an opportunity for clinicians and researchers to lobby for commissioning services whose success is calculated using participation-based outcome measures. In parallel, since 2019 over 10 countries have collected data using national survey studies to capture the impact of DCD on children and their families. These surveys are being progressively published by teams of researchers in various countries such as the USA [28], Canada [29], Australia [27, 30], Belgium and the UK [25, 31]. The data gathered highlight the significant participation restrictions in physical play, self-care and social activities that are experienced by children with DCD and offer robust evidence in support of the case for participation-based therapy at both national and local levels. For example, while parents reported that receiving a diagnosis was helpful within the *home* environment, many felt that the diagnosis had a limited impact on support in school, where awareness of DCD among teachers remained low in many countries. Promoting measures which capture the impact of DCD on school participation and raising awareness among teachers has potential to create more inclusive school environments. By lobbying for reforming services to embed participation focused goals in both clinical and educational environments, it may help bridge the gap in the lived experience between the home, school and wider community.

There is need to move more fully in the direction of participation focused practice and away from traditional interventions with a focus on improving body functions, such as coordination or balance which are not supported by evidence or recommended in the guidelines [1]. Much of the evidence for this move remains anecdotal and largely based on topics presented at national and international conferences. Recent work on developing an intervention to promote evidence-based practice, which supports participation as an outcome, found that children's occupational therapists need support for the "apply" phase of evidence -based practice [32]. They were aware of the need to set goals and consider participation-based outcomes but were unsure about how to implement them. The intervention facilitated evidence-based practice by identifying each team's training needs then delivering educational outreach based on these goals. The educational outreach was delivered by perceived experts. Following the intervention there was an increase in evidence-based behaviours and positive outcomes for service users [32]. Participants in this research also identified organisational barriers to providing participation-based interventions, e.g., staffing, electronic records systems that did not support recording of participation outcomes, and suggested middle managers needed to be empowered to address these barriers to evidence-based practice [33, 34].

## Discussion

It was surprising to find so few studies which used participation as a primary outcome measure since publication of the DCD international clinical guidelines recommend this approach [1]. However, we know that the knowledge translation pathway from research insights to implementation can take 15–20 years [35] and many interventions used in standard care for DCD are not participation based and lack robust evidence [36, 37]. Commissioners, policy makers and senior managers can shorten this through establishing key performance indicators that measure participation as the ultimate outcome of interventions. There is an opportunity to influence positive change in how services are measured using the government reforms surrounding special educational provision and the national DCD impact studies [25–32]. Ensuring that assessment includes a dedicated process of goal setting and that the goals are reviewed following intervention is an important step for a participation-based service. However, it is equally important that the meaning the child and family attribute to the skills acquired through intervention are understood to truly assess their impact on participation. For example, while the DCD impact studies indicated that children with DCD engage in physical activity and team sports there was a distinct mismatch between their engagement and their enjoyment of the activities [30]. This is important to note as while we need to measure both the attendance and involvement aspects of participation from the child's perspective. Interventions to facilitate participation also need to consider environmental factors such as physical, cognitive or social demands and levels of support provided as these have been shown to be a barrier to participation [19]. This includes not only the built environment but also the social environment, particularly friendships and peer relationships. Findings from the DCD impact studies highlight the importance of friendships and social interactions while also revealing the difficulties that children with DCD experience in navigating them [27]. A focus on participation may also need to support children with developing the skills to navigate their social environment to enhance participation outcomes.

Supporting therapists to make the move towards participation focussed practice can be facilitated by partnerships between practice and academia to deliver educational outreach and mentorship. Clinicians valued exploring theory and knowledge with experts to enhance their clinical reasoning which led to confidence in delivering more participation-based interventions [32]. Clinicians perceived the experts as granting them permission to make the changes in practice and enhancing their professional identity which facilitated positive behaviour changes in evidence-based practice [32]. This behaviour change can be further supported by endorsement from managers and commissioners.

## Conclusions

Children with DCD have the right to opportunities for enhanced health and well-being, and the potential to make significant contributions to society and avoid the secondary, negative, consequences of DCD when interventions focus on their participation. However, as participation is a difficult construct to measure researchers and clinicians may opt to measure outcomes at the activity, or even body function level. Many of the tools that do measure participation use parents/carers as proxies for their child. A participation-based approach requires time investment in goal setting with children and families, but this reaps dividends in the long run. It is also important to capture attendance, engagement and enjoyment from the child's perspective when capturing the impact of a given intervention. Service commissioners and policy makers are in a position to influence the use of participation-based measures which has the potential to improve the health and wellbeing with children with DCD. However, it starts with raising awareness about DCD as a condition that needs help. Only when commissioners and policy makers are aware of what DCD entails, will they be willing to use their influence to change current clinical practice.

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    - This guideline provides guidance for clinicians and researchers on assessing, diagnosing and delivering interventions for DCD.
- Steenbergen B, Valtr L, Dunford C, Prunty M, Bekhuis H, Temlali TY, van Abswoude F, Lust J, Warlop G, Augustijn M, Smits-Engelsman B and Wilson P (2024) Awareness about developmental coordination disorder. *Front. Public Health* 12:1345257. https://doi.org/10.3389/fpubh.2024.1345257

  - This article aims to raise awareness and understanding of the current issues facing children with DCD for the general public and health and education professionals. It identifies the key evidence and identifies ways in which children can be supported and helped to achieve their potential.

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  - This article identifies specific difficulties with participation in activities of daily living for children with DCD at school, home and the community. Self-care task and handwriting frequently occurred as well as difficulties with socialising and getting bullied.

- Tamplain, P., Miller, H. L., Peavy, D., Cermak, S., Williams, J., & Licari, M. (2024). The impact for DCD – USA study: The current state of Developmental Coordination Disorder (DCD) in the United States of America. *Research in Developmental Disabilities, 145*, Article 104658. https://doi.org/10.1016/j.ridd.2023.104658
  - This study reported that 92% parents found having a diagnosis useful. Parents reported children avoided motor actvities and they were concerned for their child's wellbeing.

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