

# Best practice principles for management of children with developmental coordination disorder (DCD): results of a scoping review

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## Abstract

**Background** Developmental coordination disorder (DCD) is a prevalent health condition that is frequently unrecognized despite the substantial evidence that has accumulated regarding how it affects children's health, education and skills. Most literature focuses on measurement of impairment and description of intervention approaches for individual children; little is known about the principles that should guide best practice and service delivery for children with DCD as a population. The purpose of this study was to identify these principles.

**Methods** A scoping review was used to 'map' the information available to inform intervention and service delivery. Scholarly and grey literature written in English was identified in six databases, using a combination of keywords (e.g. guidelines, management, models and DCD); a 'snow-balling' technique was also used in Canada and the UK to access clinical protocols used in publicly funded health care systems. Over 500 documents were screened: 31 met inclusion criteria as they outlined practice principles for children with DCD as a population. Data regarding best practices were independently extracted by two reviewers and then compared with achieve consistency and consensus.

**Results** Two over-arching themes emerged, with five principles: (1) Organizing services to efficiently meet the comprehensive needs of children (e.g. Increasing awareness of DCD and coordination; Implementing clearly defined pathways; Using a graduated/staged approach); (2) Working collaboratively to offer evidence-based services (e.g. Integration of child and family views; Evidence-based interventions fostering function, participation and prevention).

**Conclusion** Numerous documents support each of the principles, reflecting agreement across studies about recommended organization of services. While these principles may apply to many populations of children with disabilities, this review highlights how essential these principles are in DCD. Researchers, managers, clinicians, community partners and families are encouraged to work together in designing, implementing and evaluating interventions that reflect these principles.

## Keywords

best practice, childhood disability, DCD, intervention, rehabilitation, service delivery

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## Background

Developmental coordination disorder (DCD) is a chronic neuro-developmental condition that significantly impacts a child's ability to learn and perform everyday self-care and academic tasks, and for which the prevalence is consistently reported to be approximately 5–6% (American Psychiatric Association (APA) 2013). A substantial body of evidence has accumulated and systematic literature reviews have described the activity and participation limitations of children with DCD (Magalhães *et al.* 2011), the impact of DCD on quality of life of children (Zwicker *et al.* 2013) and on children's fitness levels (Rivlis *et al.* 2011). Principal concerns of families are usually around the secondary consequences of motor incoordination (Missiuna *et al.* 2007), which include increased risk of depression, anxiety and childhood obesity, and decreased self-esteem (Cocks *et al.* 2009; Cairney *et al.* 2010a,b; Engel-Yeger & Hanna Kasis 2010; Piek *et al.* 2010; Missiuna *et al.* 2011).

To prevent secondary consequences and improve children's function, early identification is important. However, DCD is frequently unrecognized and undiagnosed (Missiuna *et al.* 2006b, 2007, 2013; Novak *et al.* 2012; Wilson *et al.* 2012); even when children are identified and referred, they often face long waiting times (Dunford *et al.* 2004; Peters *et al.* 2004) before receiving services that are often provided on a one-to-one basis (Wehrmann *et al.* 2006). In a recent meta-analysis of the efficacy of individualized interventions to improve motor performance in children with DCD, Smits-Engelsman and colleagues (2013) found interventions using task-oriented approaches had a significantly higher effect size than process-oriented interventions addressing children's impairments. This meta-analysis is useful to guide the choices of intervention approaches for an individual child with DCD, but does not provide guidance about how to organize health services. Some authors have argued that scant therapy resources might be used more strategically to build capacity among parents and teachers, rather than providing direct service to a smaller number of children (Stephenson & Chesson 2008). Missiuna and colleagues (2013) suggest that some interventions should target the population level, creating environments that facilitate the learning of motor skills, function and participation for all children. Similarly, recent guidelines for management of DCD in European countries (EACD 2011a,b, 2012; Blank *et al.* 2012) propose an algorithm for interventions that provides information and support to parents and teachers before moving to group or individual interventions. However, no synthesis of the evidence is available as yet to guide health service delivery for children with DCD. The purpose of this study is to identify principles that should guide service

delivery and to report the type of evidence available regarding the effectiveness of these principles.

## Method

Scoping reviews are used in health research to 'map' the breadth and depth of a concept within a certain field of research, particularly when there is a paucity of evidence to provide direction and bridge the knowledge-to-practice gap (Levac *et al.* 2010). Documents can be included from a variety of sources (empirical and non-empirical papers, and grey literature). The six iterative stages initially developed by Arksey and O'Malley (2005) to guide scoping reviews were further refined by Levac and colleagues (2010) and followed in this study.

Stage 1 serves to identify and refine the research question. In this study, we asked '*What current (2005–2012) written guidelines, protocols, decision tools and publications used in English-speaking countries with publically-funded health and education systems might inform best practice in the identification and management of children with DCD up to 16 years old?*'

Stage 2 involves identifying relevant studies. Scholarly literature published between 2005 and April, 2012 was searched using the databases of Medline, PubMed, Embase, Psycinfo, CINAHL and Academic Search Complete. Keywords used in various combinations included: Cost-Effective Models; Clinical Guidelines; Practice Guidelines; Interagency Working; Multi-disciplinary; Transdisciplinary; Health Education Partnerships; Multiagency Pathways; Service Delivery Models; Referral Pathways; Good Practice Guidance; Code of Practice; Management; Identification; Developmental Coordination Disorder; Dyspraxia; ADHD; Fine Motor Problems; and Motor Coordination Problems. The grey literature was also searched, including consensus and position statement papers, as well as the recently published guidelines and Guideline Clearinghouses. The second author (BW) screened over 500 titles and abstracts for their relevance to DCD, eliminating duplicates and non-English language articles. 'Best Practice' included the identification of DCD (awareness of key stakeholders), diagnostic process (e.g. assessment practices that consider contextual elements, but not specific measurement tools) and management (including partnership in schools). All questionable articles were discussed with at least two other authors (CC, CM) and consensus about inclusion was established; 86 articles remained. An email was sent to known experts in DCD across Canada and the UK seeking additional relevant service delivery protocols, pathways or agency procedures for DCD. A 'snow-balling' technique was followed whereby experts were invited to forward the request to other individuals; 13 new documents were identified.

Stages 3 and 4 (study selection and data charting) were iterative, with continual extracting and updating of the data charting form as the scoping team refined the scope of the review. The second author (BW) read the full content of all 86 documents. Some of these documents were excluded if they: (1) described or evaluated the effectiveness of *specific* interventions for individual(s) as these approaches have been well summarized in other publications (Polatajko & Cantin 2005; Wilson 2005; Blank *et al.* 2012; Smits-Engelsman *et al.* 2013); (2) addressed specific tests or assessment approaches focusing on individual children; (3) examined aetiology, underlying mechanisms, prevalence, co-morbidities and associated conditions, or the heterogeneity of DCD; or (4) provided no specific recommendations for service delivery. Finally, 31 documents focusing on children with DCD as a whole and providing population-level recommendations were retained.

In Stage 4, two team members (CD, BW) independently extracted and recorded the data of interest on a charting form including details about: (1) How the document met inclusionary criteria (presented a model of practice, a clinical care pathway, clinical guidelines or clear recommendations for practice); (2) The type of evidence (consensus/expert opinion, results from an empirical study, description of current service delivery or review of the literature); (3) The recommendations and best practice principles for management of children with DCD.

The two primary reviewers discussed the findings with the entire scoping review team at the beginning, middle and end of the review process to achieve consistency, consensus about inclusion and alignment of data extracted. Where two or more documents related to the same study or project (i.e. they represented one unique project), they were reviewed together.

Data analysis (Stage 5) is described below. Consultation (Stage 6) is in progress.

### Data analysis

BW reviewed all 31 documents and identified 37 statements of the best practice principles. Most statements were identified in more than one reference. CC carefully reviewed the documents that contained each of the statements to validate whether she had independently extracted similar concepts and to ensure rigour in the utilization of literature to support each statement. A perfect match was found on 109 occasions (65.7%). On 37 occasions, similar concepts were identified (22.3%) and there was disagreement on the main concepts in 20 occasions (12.0%). Discrepancies were discussed and consensus was reached on how each document supported key statements. These statements were

then clustered into themes and best practice principles and consensus was obtained with the larger study team.

## Results

Thirty-one references were included in this scoping review. A total of five best practice principles were identified and subsumed under two themes (see Table 1). To illustrate the strength of evidence supporting each best practice principle, references have been organized accordingly (consensus/expert opinion, empirical study, description of service delivery, review of the literature). Many documents focused on the difficulties experienced by children with DCD and their families, and provided recommendations to improve service delivery. A few empirical studies evaluated novel interventions, service delivery models or pathways: these particular references are marked with a cross (†) in Table 1.

### Numerical analysis

The 31 references represented 21 unique projects (see Appendix I); 12 references were from Canada, 15 from the UK, 3 from Germany and 1 from New Zealand. Although it is not necessary to appraise the quality of studies in a scoping review, it is of interest to note the extent to which any particular best practice principle has been researched or discussed. Table 1 presents the principles (references marked with an asterisk discuss each principle extensively) and the number of references suggesting each principle (ranging from 17 to 29). Nine documents described consensus and expert opinion (four from the same consensus process), 13 were based on empirical studies (of which five evaluated novel interventions, service delivery models or pathways), five were reviews/descriptions of service delivery and four were reviews of the literature. Each reference supported from one (Wann 2007) to five principles for best practice (e.g. Blank *et al.* 2012) (see Appendix I).

### Qualitative analysis

#### Theme 1: Organizing services to efficiently meet the comprehensive needs of children with DCD and their families

*Principle 1.1: Increasing awareness of DCD and coordination among all professional and community groups*

The need for increased awareness of DCD as a health condition by a wide variety of professionals was frequently described as essential to improve the identification of children with this disorder (Rodger & Mandich 2005; Missiuna *et al.* 2006b; Gaines &

**Table 1.** Best practice principles and supporting references

Principles	Consensus statements and expert opinions		Empirical studies		Review/description of service delivery		Reviews of the literature	
	No.	References	No.	References	No.	References	No.	References
			Theme 1					
		Organizing services to efficiently meet the comprehensive needs of children with DCD and their families (30 distinct references)						
1.1 Increasing awareness of DCD and coordination among professionals and community groups (29 references)	8	<ul style="list-style-type: none"> <li>Blank and colleagues (2012)</li> <li>Gaines and Missiuna (2007*)</li> <li>College of Occupational Therapists (2008, 2011)</li> <li>EACD (2011a,b, 2012)</li> <li>Sugden (2006, 2007)</li> </ul>	13	<ul style="list-style-type: none"> <li>Gaines and Missiuna (2007*)</li> <li>College of Occupational Therapists (2008, 2011)</li> <li>Maciver and colleagues (2011*)</li> <li>Missiuna and colleagues (2006b*, 2007, 2008*, 2011*, 2012a†)</li> <li>Reid and colleagues (2006†)</li> <li>Rodger and Mandich (2005*)</li> <li>Stephenson and Chesson (2008*)</li> <li>Wehrmann and colleagues (2006*†)</li> </ul>	5	<ul style="list-style-type: none"> <li>Forsyth and colleagues (2007*, 2008*)</li> <li>North Yorkshire County Council (2008*)</li> <li>Missiuna and colleagues (2012b)</li> <li>Salmon and colleagues (2006)</li> </ul>	3	<ul style="list-style-type: none"> <li>Kirby and Sugden (2007)</li> <li>Missiuna and colleagues (2006a, 2008*)</li> </ul>
1.2 Implementing clearly defined pathways to ensure access to diagnosis, evaluation and intervention (19 references)	5	<ul style="list-style-type: none"> <li>Blank and colleagues (2012*)</li> <li>College of Occupational Therapists (2008)</li> <li>EACD (2011a*, b*, 2012*)</li> </ul>	8	<ul style="list-style-type: none"> <li>Gaines and colleagues (2008†)</li> <li>Maciver and colleagues (2011*)</li> <li>Missiuna and colleagues (2006b*, 2011, 2012a†)</li> <li>Reid and colleagues (2006†)</li> <li>Stephenson and Chesson (2008*)</li> <li>Wehrmann and colleagues (2006*†)</li> </ul>	5	<ul style="list-style-type: none"> <li>Forsyth and colleagues (2007*, 2008*)</li> <li>Missiuna and colleagues (2012b)</li> <li>North Yorkshire County Council (2008*)</li> <li>Salmon and colleagues (2006*)</li> </ul>	1	<ul style="list-style-type: none"> <li>Kirby and Sugden (2007)</li> </ul>
1.3 Using a graduated/staged approach of assessment and interventions to foster capacity building and to efficiently address all the needs of children with DCD and their family (17 references)	4	<ul style="list-style-type: none"> <li>Blank and colleagues (2012*)</li> <li>EACD (2011a*, b*, 2012*)</li> </ul>	8	<ul style="list-style-type: none"> <li>Gaines and colleagues (2008†)</li> <li>Missiuna and colleagues (2006b, 2007, 2012a*†)</li> <li>Miyahara and colleagues (2009*†)</li> <li>Reid and colleagues (2006*†)</li> <li>Stephenson and Chesson (2008)</li> <li>Wehrmann and colleagues (2006*†)</li> </ul>	5	<ul style="list-style-type: none"> <li>Forsyth and colleagues (2007*, 2008*)</li> <li>Missiuna and colleagues (2012b*)</li> <li>North Yorkshire County Council (2008*)</li> <li>Salmon and colleagues (2006*)</li> </ul>	0	
			Theme 2					
		Professionals and families working together to offer evidence-based services fostering function and participation and preventing secondary consequences (30 distinct references)						
2.1 Integration of child and family views in assessment, goal-setting and intervention which recognizes the impact of DCD and the contextual life of the family, and ensures meaningful action (27 references)	8	<ul style="list-style-type: none"> <li>Blank and colleagues (2012*)</li> <li>College of Occupational Therapists (2008, 2011)</li> <li>EACD (2011a*, b*, 2012*)</li> <li>Sugden (2006, 2007)</li> </ul>	10	<ul style="list-style-type: none"> <li>Gaines and colleagues (2008†)</li> <li>Gaines and Missiuna (2007)</li> <li>Maciver and colleagues (2011)</li> <li>Missiuna and colleagues (2006b, 2007*, 2012a†)</li> <li>Miyahara and colleagues (2009*†)</li> <li>Rodger and Mandich (2005*)</li> <li>Stephenson and Chesson (2008*)</li> <li>Wehrmann and colleagues (2006†)</li> </ul>	5	<ul style="list-style-type: none"> <li>Forsyth and colleagues (2007*, 2008*)</li> <li>Missiuna and colleagues (2012b)</li> <li>North Yorkshire County Council (2008*)</li> <li>Salmon and colleagues (2006)</li> </ul>	4	<ul style="list-style-type: none"> <li>Kirby and Sugden (2007)</li> <li>Missiuna and colleagues (2006a, 2008)</li> <li>Morgan and Long (2012*)</li> </ul>
2.2 Interventions should be evidence-based, foster function and participation, and prevent secondary consequences (24 documents)	9	<ul style="list-style-type: none"> <li>Blank and colleagues (2012*)</li> <li>College of Occupational Therapists (2008, 2011)</li> <li>EACD (2011a*, b*, 2012*)</li> <li>Sugden (2006, 2007)</li> <li>Wann (2007)</li> </ul>	7	<ul style="list-style-type: none"> <li>Rodger and Mandich (2005)</li> <li>Missiuna and colleagues (2006b, 2007*, 2012a*†)</li> <li>Maciver and colleagues (2011)</li> <li>Stephenson and Chesson (2008)</li> <li>Wehrmann and colleagues (2006†)</li> </ul>	5	<ul style="list-style-type: none"> <li>Forsyth and colleagues (2007, 2008)</li> <li>Missiuna and colleagues (2012b*)</li> <li>North Yorkshire County Council (2008*)</li> <li>Salmon and colleagues (2006)</li> </ul>	3	<ul style="list-style-type: none"> <li>Kirby and Sugden (2007)</li> <li>Missiuna and colleagues (2006a)</li> <li>Morgan and Long (2012*)</li> </ul>

\*Documents discussing principles more extensively.

†Empirical studies evaluating novel interventions, service delivery models or pathways incorporating the best practice principles.

Missiuna 2007; Forsyth *et al.* 2008; Gaines *et al.* 2008; College of Occupational Therapists 2011; Maciver *et al.* 2011). As DCD often becomes more obvious when children enter primary school, educational staff need to be able to identify children, adapt their teaching methods and refer them to health professionals as needed (Reid *et al.* 2006; Salmon *et al.* 2006; Missiuna *et al.* 2012a,b). DCD impacts on multiple aspects of children's lives and many authors emphasized the need for health care and education professionals to collaborate to develop holistic evaluations and interventions (Rodger & Mandich 2005; Salmon *et al.* 2006; Sugden 2006, 2007; College of Occupational Therapists 2011; Maciver *et al.* 2011; Missiuna *et al.* 2012a,b). Salmon and colleagues stressed the importance of developing successful multi-agency collaborations with a consistent multi-disciplinary approach within a health care region (2006). They advised that exchanges among different disciplines increase professionals' expertise and knowledge.

Knowing where to refer children and how to obtain a diagnosis is also important (Rodger & Mandich 2005; Maciver *et al.* 2011). In many countries, only physicians and psychologists can give a diagnosis of DCD, using the criteria outlined in the DSM (APA 2000, 2013). Families and other professionals can provide information regarding these criteria to facilitate the diagnostic process (Sugden 2006, 2007; Missiuna *et al.* 2008; College of Occupational Therapists 2011) and to optimize the early contacts (Forsyth *et al.* 2007, 2008). When DCD co-occurs with other conditions, '[a] dual diagnosis of DCD and [...] should be given if appropriate' (Blank *et al.* 2012, p. 64). Population screening of children for DCD is not recommended, but heightened awareness and specific screening for the presence of motor challenges should occur in situations where children have conditions that are highly comorbid with DCD, such as speech and language delays and attention deficit hyperactivity disorder (Gaines & Missiuna 2007; Kirby *et al.* 2007; Missiuna *et al.* 2011; Blank *et al.* 2012).

Currently, many physicians reported unfamiliarity with DCD (Gaines *et al.* 2008). This was corroborated by parents who felt that physicians and health care professionals lack knowledge about DCD; parents feel anxious, do not know what is wrong with their child and perceived they need to fight the system to access services (Rodger & Mandich 2005; Missiuna *et al.* 2006b, 2007; Stephenson & Chesson 2008; Maciver *et al.* 2011). Increasing awareness of and knowledge about DCD could occur during the education of professionals, but also through continuing education (Wehrmann *et al.* 2006; Missiuna *et al.* 2012a,b). Effective strategies were described in the literature, including the simultaneous use of knowledge translation activities and knowledge brokering to physicians (Gaines *et al.*

2008). Reid and colleagues also reported positive outcomes following interventions to increase teachers' awareness (2006).

Raising awareness in the community at large was also recommended (Salmon *et al.* 2006; Forsyth *et al.* 2007, 2008). Authors believed that with 'a greater awareness of DCD within communities, there may be greater tolerance and positive action to support the child' (Forsyth *et al.* 2008, p. 161), and that can help families seek support from health care professionals (Stephenson & Chesson 2008). Raising awareness of health services funders has also been suggested as a strategy to improve services for children with DCD (Wehrmann *et al.* 2006). Education of all of these partners has the potential to offer more timely and effective services, to utilize resources better to decrease system level costs and to facilitate sustainability of the approach. Increasing awareness of DCD and building capacity of families, educators and health care professionals was an important component of most of the service delivery models identified (Forsyth *et al.* 2007, 2008; North Yorkshire County Council 2008; Missiuna *et al.* 2012a,b).

*Principle 1.2: Implementing clearly defined pathways to ensure access to diagnosis, evaluation and intervention*

Pathways are a sequence of actions, often including a single clear point of entry into services and a description of the roles of different professionals, that help improve coordination among different services providers involved in the child's life. According to the literature, pathways should be organized around different stages such as identification or diagnosis of DCD, assessment, intervention and discharge from specialized services (Forsyth *et al.* 2007, 2008; EACD 2011a,b, 2012; Blank *et al.* 2012); additional support may be recommended for transition periods (North Yorkshire County Council 2008). 'Having clear protocols for diagnosis may enable more focused and effective involvement and collaboration with all those involved in the child's life, and could reduce the time taken for a resolution to be reached' (Maciver *et al.* 2011, p. 426). Designating someone to coordinate services and help the family navigate the system has also been advocated (Sugden 2006, 2007).

The importance of clear pathways appeared to be an implicit but key theme for children with DCD, as so many studies documented the challenges families experience navigating the current system: '[uncertain] pathways followed by families as they sought to affirm their perceptions and obtain services for their child [...] The pathways followed by families were often convoluted and filled with contradictory and confusing messages' (Missiuna *et al.* 2006b, p. 12). Implementation of clear pathways are thus a recommended way to improve the delivery of services



that have been described as intermittent, patchy and uncoordinated (Rodger & Mandich 2005; Missiuna *et al.* 2006b, 2007; Maciver *et al.* 2011). The European Academy of Childhood Disability consensus project suggested two pathways (one for assessment and diagnosis, and one for intervention) that can be used to organize health and education services for children with DCD (EACD 2011a,b, 2012; Blank *et al.* 2012). Salmon and colleagues present a school-level pathway with the point of entry being teacher's expression of concerns (2006). Many described a graduated approach to intervention, recognizing that many children might only need adaptation, rather than individualized treatment. Hence, this was extracted as a separate best practice principle and is detailed further below.

*Principle 1.3: Using a graduated/staged approach of assessment and intervention to foster capacity building and to efficiently address all the needs of children with DCD and their family*

Graduated/staged approaches to service delivery described built on the following premises: (1) support begins with general, population-based interventions and accommodations (children can receive services even if they do not have a diagnosis), and (2) only children who do not respond well are referred to physicians or other health care professionals for individualized intervention. The assumptions outlined in these graduated/staged approaches are that scant resources 'would be better used to offer more support for families and teachers, rather than to attempt to provide direct therapy for a small number of children, as is the current approach' (Stephenson & Chesson 2008, p. 341). Sustainable approaches for DCD require knowledge translation and capacity building, so that generalization and accommodation can occur in the context of everyday activities (Kirby & Sugden 2007; Sugden 2007; Missiuna *et al.* 2012a,b). Many children with DCD will succeed at school without receiving individualized interventions (Salmon *et al.* 2006; Missiuna *et al.* 2012a,b). Self-management in different environments and capacity-building interventions should be promoted; the child should not be the only target of intervention (Forsyth *et al.* 2007, 2008). Population-based approaches and building capacity are postulated to ensure a more cost-effective response to children's needs and to create more sustainable health care systems (Kirby & Sugden 2007; Stephenson & Chesson 2008; Missiuna *et al.* 2012b). The literature also supports the use of a consultative model for children with DCD in occupational therapy school-based services (Reid *et al.* 2006; Wehrmann *et al.* 2006). These approaches move away from a medical model and consider the holistic needs of children with DCD, and not only health-related needs (Kirby & Sugden 2007; Sugden 2007).

The International Classification of Function from the World Health Organization (2001) was reported to be a useful model (Missiuna *et al.* 2006b; Maciver *et al.* 2011) to acknowledge the influence of environmental factors such as attitudes and health systems (Missiuna *et al.* 2007). In summary, support for this principle emphasized that the 'high prevalence and chronic nature of this disorder, as well as its long-term impact, requires a more sustainable type of service delivery to increase awareness, knowledge, and capacity among the adults who have a direct influence in the child's daily environment and who can support the child's development' (Missiuna *et al.* 2012b, p. 42).

Two emerging service delivery models were described that use a graduated/staged approach, beginning with population-based interventions where the school is the client and universal learning principles are used to help all children succeed. In Canada, Missiuna and colleagues (2012a,b) have studied a school-based occupational therapy model called 'Partnering for Change' that aims at building capacity in the child's environment and uses three progressive steps: universal design for learning, differentiated instruction and accommodation. Similarly, in the UK, the North Yorkshire County Council developed a school-based model using four 'waves': (1) general programmes fostering learning in class, (2) personalized individual programmes for skill development, (3) one-on-one specialist support in the school, and (4) occupational and physical therapy ongoing support in school or in clinic for children with severe needs (2008). Both models incorporate activities for knowledge transfer to parents. Access to information is perceived to be essential to empower parents (Missiuna *et al.* 2006a). Effective communication strategy can involve workbooks, DVDs, telephone consultations and blogs to share information with parents and children (Miyahara *et al.* 2009).

## **Theme 2: Professionals and families working together to offer evidence-based services fostering function and participation and preventing secondary consequences**

*Principle 2.1: Integration of child and family views in assessment, goal-setting and intervention which recognizes the impact of DCD and the contextual life of the family, and ensures meaningful action*

The literature accessed emphasized the importance of the child with DCD and the family being at the core of the management process (Forsyth *et al.* 2007; Sugden 2007). Using a family-centred approach was recommended to guide all interactions with families, 'since they have the breadth and depth of day-to-day experience' (Missiuna *et al.* 2006b) and are the ones who support the child in generalizing learning to daily activities

(Sugden 2006; North Yorkshire County Council 2008; Stephenson & Chesson 2008; Missiuna *et al.* 2012a). Families must participate in the identification of goals to ensure that recommendations are meaningful to them and responsive to their concerns. Care should also be taken to include children's goals, as they '*tend to choose functional activities such as bicycle riding while parents and teachers choose more generic goals such as improvement in coordination. The choice of goals should be a team effort with children having a major say in the choice*' (Sugden 2006, p. 470). Authors stressed the responsibility for collaboration in helping children and families to develop realistic expectations and to achieve their goals, with professionals in health care, rehabilitation and schools, as well as individuals in the community (e.g. coaches), sharing in this responsibility (Forsyth *et al.* 2007, 2008). Goals should encompass different dimensions of children's lives, including the development of learning and coping strategies, as well as support and strategies for transition towards adulthood (Forsyth *et al.* 2007, 2008; Missiuna *et al.* 2007).

Within current service delivery, with few exceptions, goals are planned by professionals without sufficient family or child input; interventions may also be focused more on remediation of impairment than on function (Forsyth *et al.* 2007, 2008). To increase family input into the planning of interventions, it has been recommended that professionals explicitly ascertain the impact of DCD on child and family life (Forsyth *et al.* 2007, 2008; Missiuna *et al.* 2008; College of Occupational Therapists 2011). Actively listening to parents' concerns was recommended as one way of decreasing parents' frustration, while awaiting access to services (Rodger & Mandich 2005). Identifying goals that are meaningful to children and families will move services away from an impairment-focus towards the final principle outlined below.

*Principle 2.2: Interventions should be evidence-based, foster function and participation, and prevent secondary consequences*

Many authors advocated using evidence about the effectiveness of specific interventions to guide the spectrum of services that are offered to children with DCD (Sugden 2006, 2007; Forsyth *et al.* 2007; College of Occupational Therapists 2011). Focusing on daily activities, teaching specific skills and fostering generalization of learning is recommended (Forsyth *et al.* 2006; Sugden 2006, 2007; Maciver *et al.* 2011; Missiuna *et al.* 2012b). As DCD is a life-long condition, opportunities need to be created to encourage participation and to ensure that '*children try out a range of sports and leisure activities until they "found their niche"*' (Rodger & Mandich 2005, p. 456). Making accommodations and providing trade-off between opportunities for

success and challenges and for learning are important to achieve a balance between independence and activity (Missiuna *et al.* 2006b, 2012a; North Yorkshire County Council 2008). Children also need to develop coping strategies to avoid the negative trajectories which begin with coordination difficulties and lead to social isolation and decreased self-esteem (Missiuna *et al.* 2007; Missiuna *et al.* 2006a; Sugden 2006; North Yorkshire County Council 2008; Maciver *et al.* 2011; Morgan & Long 2012). These negative outcomes are not believed by authors to be inevitable: developing protective cognitive strategies, facilitating positive peer interactions and encouraging health promotion are essential in the management of children with DCD, to prevent secondary mental and physical health conditions (Forsyth *et al.* 2007; EACD 2011a,b).

## Discussion

This scoping review identified two broad themes that encapsulate best practice principles to guide the service delivery of children with DCD as a population. The first theme, *organizing services to efficiently meet the comprehensive needs of children with DCD and their families*, refers to the structural elements that are required at the system/organizational level: individuals who are knowledgeable about DCD should collaborate (principle 1) within and across facilities, along clearly defined pathways that are well-established (principle 2), and deliver services within a model that grades the intensity of intervention (principle 3). The second theme, *working together to offer evidence-based services fostering function and participation, and preventing secondary consequences*, relates to the processes that happen at a more individual level: how families views and goals are integrated (principle 4) into the planning and the delivery of evidence-based interventions that encourage function, participation and prevention of secondary consequences (principle 5).

The principles identified seem intuitive as best practices for any group of children with disabilities. In fact, they align well with approaches and principles generally recommended in the literature. Integrating family and children's views is a central tenet of family-centred service which builds on child and family's strengths, fosters empowerment and recognizes families as partners in the decision-making process (Rosenbaum *et al.* 1998; Kolehmainen *et al.* 2012; Kuo *et al.* 2012). Family-centred service is also one of the six key principles recommended as the 'F-words' that should guide management of childhood disability: services should focus on Family, Fun, Future, Friends, Function and Fitness (Rosenbaum & Gorter 2012). Delivering services based on these principles would contribute to the prevention of secondary consequences in children with DCD, and

also decrease the negative impact DCD is reported to have on families (Novak *et al.* 2012).

Our results highlight the many authors recommending finding innovative ways to manage all of the children who have DCD (Wehrmann *et al.* 2006; Forsyth *et al.* 2008; Missiuna *et al.* 2012b); this is echoed in emerging literature in childhood disability that proposes guidelines to determine the optimal type and intensity of services (Palisano & Murr 2009), response to intervention approaches (McIntosh *et al.* 2011), school-based consultative models (Hutton 2009) as well as interventions and new models of service delivery to improve service accessibility and quality (Camden *et al.* 2010, 2013; Kolehmainen *et al.* 2012). The principles identified in this scoping review are not new in childhood disability, but the need for population-based interventions appears to be more critical in the DCD field. The high prevalence of DCD compared with other childhood disabilities, and the resultant stressors on health care resources, explain the greater emphasis on implementing graduated response care pathways which are perceived to be more cost-efficient (Wehrmann *et al.* 2006; Forsyth *et al.* 2008; Missiuna *et al.* 2012b).

The major contributions of this scoping review are to highlight that: (1) many studies have recommended best practice principles essential to manage children with DCD as a population; and (2) at this time, these principles are mainly built upon opinion, expert consensus and recommendations following studies of problematic situations rather than from empirical studies of the solutions. The next stage is to trial intervention models (Kirby & Sugden 2007) that incorporate the principles highlighted in this review. Many pathways and service delivery models reviewed lack evidence, at this point. The framework recommended by the Medical Research Council (MRC 2000; Craig *et al.* 2008) to guide evaluation of complex interventions has been used successfully (Missiuna *et al.* 2012b) as a framework to guide further research studies.

This study has several limitations inherent in the scoping review process. Despite an extensive search strategy, some relevant references might have been missed because they focused on interventions for individual children, although they might have contributed useful recommendations for the management of children as a population. Similarly, references describing specific assessment instruments were excluded but may have included information applicable to the identification of children with DCD, as a group. Likewise, principles for management of children with DCD might be found in the general literature in childhood disability, but this scoping review only included references specific to children with DCD. Identification of what constitutes a best practice statement may vary across individuals; however, the extraction of data and grouping of statements into themes and principles

followed a rigorous iterative process of independent coding, identification of and consensus on principles and themes. Finally, principles are not mutually exclusive, but the themes were formulated broadly and should encompass all best-practice principles outlined in the references of this review.

## Conclusion

Five important 'best practice' principles for management of children with DCD were identified in this scoping review. While the principles are applicable to many populations of children with disabilities, this review highlights what many studies see as essential for service delivery for children with DCD. Indeed, despite its high prevalence and devastating secondary consequences, DCD is still frequently unrecognized, families are struggling to access services and, often, service delivery models do not appear to be responsive to children's needs. The principles identified in this scoping review could guide future research and development of innovative approaches to management of children with DCD. Each principle was reiterated in numerous documents which reflects a movement towards agreement in the field. However, only five references described an actual evaluation of services that utilized these best practice principles. Researchers, managers, clinicians, community partners and families are encouraged to work together in designing, implementing and evaluating services that reflect these principles.

### Key messages

- A scoping review demonstrated that many studies identify best practice principles essential to guide the management of children with DCD as a population.
- Best practice principles focus on the need: (1) to organize services to efficiently meet the comprehensive needs of children with DCD and their families; and (2) for professionals and families to work together to offer evidence-based services fostering function, encouraging participation and preventing secondary consequences.
- Few current service delivery models adequately meet children's needs; best practice principles come from opinion, expert consensus and authors' recommendations following studies of problems, rather than from empirical studies of the solutions.
- Researchers, managers, clinicians, community partners and families are encouraged to work together in designing, implementing and evaluating services that reflect these principles.



## Acknowledgements

We wish to thank the many professionals and groups who sent us documents and who 'snow-balled' our request for practice documents to their colleagues. Chantal Camden is supported by postdoctoral fellowships from the Canadian Institutes of Health Research and from the Fonds de la Recherche en Santé du Québec, and by the career enhancement programme of the Canadian Child Health Clinician Scientist Program. Brenda Wilson is supported by the Waterloo DCD-UK Research Scholarship in Developmental Disorders, University of South Wales, Newport.

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## Appendix I

### Principles included within each document

Unique project No.	References†	Reason for inclusion‡	Type of evidence§	Country¶	Principles identified††				
					Theme 1: Organization of efficient services			Theme 2: Working together for participation	
					1.1	1.2	1.3	2.1	2.2
1	1. Blank and colleagues (2012). <i>European academy for childhood disability (EACD): Recommendations on the definition, diagnosis and intervention of developmental coordination disorder (long version)</i>	SDS	CEO	GER	+	++	++	++	++
	2. European Academy for Childhood Disability (2011a). <i>EACD recommendations: German-Swiss interdisciplinary clinical practice guideline. Definition, Diagnosis, Assessment and Intervention of Developmental Coordination Disorder (DCD) – pocket version</i>	SDS	CEO	GER	+	++	++	++	++
	3. European Academy for Childhood Disability (2011b). <i>EACD recommendations. Definition, Diagnosis, Assessment and Intervention of Developmental Coordination Disorder (DCD) – long version</i>	SDS	CEO	GER	+	++	++	++	++
	4. European Academy for Childhood Disability (2012). <i>EACD recommendations: German-Swiss interdisciplinary clinical practice guideline. Revised for the UK. Definition, Diagnosis, Assessment and Intervention of Developmental Coordination Disorder (DCD) – pocket version</i>	SDS	CEO	UK	+	++	++	++	++
2	5. College of Occupational Therapists (2011). <i>Diagnosis of developmental coordination disorder</i>	SDS	CEO	UK	+			+	+
	6. College of Occupational Therapists (2008). <i>Access to occupational therapy for children and young people with developmental coordination disorder</i>	SDS	CEO	UK	+	+		+	+
3	7. Forsyth and colleagues (2008). <i>Developmental coordination disorder: A synthesis of evidence to underpin an allied health professions' framework.</i>	SDS	SD	UK	++	++	++	++	++
	8. Forsyth and colleagues (2007). <i>Developmental coordination disorder. A review of evidence and models of practice employed by allied health professionals. Summary of key findings</i>	SDS	SD	UK	++	++	++	++	++
4	9. Gaines and Missiuna (2007). <i>Early identification: Are speech/language-impaired toddlers at increased risk for developmental coordination disorder?</i>	R-ID	ES	CAN	++			+	
5	10. Gaines and colleagues (2008). <i>Educational outreach and collaborative care enhances physician's perceived knowledge about developmental coordination disorder</i>	R-ID	ES*	CAN	++	+	+	+	
	11. Missiuna and colleagues (2008). <i>Enabling occupation through facilitating the diagnosis of developmental coordination disorder</i>	R-ID	RL	CAN	++			+	
6	12. Kirby and colleagues (2007). <i>Should children with ADHD be routinely screened for motor coordination problems? the role of the paediatric occupational therapist</i>	R-ID	ES	UK	++				
7	13. Kirby and Sugden (2007). <i>Children with developmental coordination disorders</i>	R-MAN	RL	UK	+	+		+	+
8	14. Maciver and colleagues (2011). <i>Services for children with developmental coordination disorder: The experiences of parents</i>	Consul/school	ES	UK	++	++		+	+
9	15. Missiuna and colleagues (2011). <i>A staged approach for identifying children with developmental coordination disorder from the population</i>	R-MAN	ES	CAN	++	+			
10	16. Missiuna and colleagues (2006a). <i>Parental questions about developmental coordination disorder: A synopsis of current evidence</i>	R-MAN	RL	CAN	+			+	+



## Appendix I Continued

Unique project No.	References†	Reason for inclusion‡	Type of evidence§	Country¶	Principles identified††				
					Theme 1: Organization of efficient services			Theme 2: Working together for participation	
					1.1	1.2	1.3	2.1	2.2
11	17. Missiuna and colleagues (2007). <i>A trajectory of troubles: Parents' impressions of the impact of developmental coordination disorder</i>	R-ID	ES	CAN	+		+	+	++
	18. Missiuna and colleagues (2006b). <i>Mysteries and mazes: Parents' experiences of children with developmental coordination disorder</i>	R-ID	ES	CAN	++	++	+	+	+
12	19. Missiuna and colleagues (2012a). <i>Use of the medical research council framework to develop a complex intervention in paediatric occupational therapy: Assessing feasibility</i>	Consul/school	ES*	CAN	+	+	++	+	++
	20. Missiuna and colleagues (2012b). <i>Partnering for change: An innovative school-based occupational therapy service delivery model for children with developmental coordination disorder</i>	Consul/school	SD	CAN	+	+	++	+	++
13	21. Miyahara and colleagues (2009). <i>A pilot study of family-focused tele-intervention for children with developmental coordination disorder: Development and lessons learned</i>	R-ID	ES*	NZ			++	++	
14	22. Morgan and Long (2012). <i>The effectiveness of occupational therapy for children with developmental coordination disorder: A review of the qualitative literature</i>	R-MAN	RL	UK				++	++
15	23. North Yorkshire County Council (2008). <i>Supporting children and young people with coordination difficulties</i>	R-MAN	SD	UK	++	++	++	++	++
16	24. Reid and colleagues (2006). <i>Outcomes of an occupational therapy school-based consultation service for students with fine motor difficulties</i>	Consul/school	ES*	CAN	+	+	++		
	25. Wehrmann and colleagues (2006). <i>Evaluation of occupational therapy school-based consultation service for students with fine motor difficulties</i>	Consul/school	ES*	CAN	++	++	++	+	+
17	26. Rodger and Mandich (2005). <i>Getting the run around: Accessing services for children with developmental coordination disorder</i>	R-MAN	ES	CAN	++	++		++	+
18	27. Salmon and colleagues (2006). <i>Development of multi-agency referral pathways for attention-deficit hyperactivity disorder, developmental coordination disorder and autistic spectrum disorders: Reflections on the process and suggestions for new ways of working</i>	Consul/school	SD	UK	+	++	++	+	+
19	28. Stephenson and Chesson (2008). <i>'Always the guiding hand': Parents' accounts of the long-term implications of developmental coordination disorder for their children and families</i>	R-MAN	ES	UK	++	++	+	++	+
20	29. Sugden (2006). <i>Developmental coordination disorder as a specific learning difficulty. Leeds consensus statement</i>	SDS	SD	UK	+			+	+
21	30. Sugden (2007). <i>Current approaches to intervention in children with developmental coordination disorder</i>	R-MAN	CEO	UK	+			+	+
	31. Wann (2007). <i>Current approaches to intervention in children with developmental coordination disorder</i>	R-MAN	CEO	UK					+

†References relating to the same study or project are presented together.

‡Initial reason for inclusion in the scoping review. SDS, systematically developed statement; R-ID, recommendations for identification of children with DCD; R-MAN, recommendations for management of children with DCD; consul/school, consultative and school-based model.

§Types of evidence. CEO, consensus and expert opinions; ES, empirical study; SD, review/description of service delivery; RL, review of the literature; ES\*, provide novel interventions, service delivery models or pathways incorporating these principles and the results following their implementations.

¶Country where the document was produced or where data were collected. GER, Germany; UK, United Kingdom; CAN, Canada; NZ, New Zealand.

††Principles identified. 1.1 Increasing awareness and coordination; 1.2 Implementing pathways; 1.3 Using a graduated approaches; 2.1 Integrating children and families' views; 2.2 Using evidence-based interventions, fostering function, participation and prevention.

+: reference identify/mention the principle.

++: reference discuss the principle in greater details.