

TITLE

Development and implementation of a new service delivery model for children with disabilities:
Implications for DCD

AUTHORS

Chantal Camden, France Léger, Julie Morel & Cheryl Missiuna

ADDRESS CORRESPONDENCE TO :

Chantal Camden

École de réadaptation, Université de Sherbrooke

3001 12^e Avenue Nord

Sherbrooke, Québec, Canada, J1H 5N4

chantal.camden@usherbrooke.ca

DECLARATION OF INTEREST SECTION

Authors don't have any interest to declare.

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ABSTRACT

There is a general consensus that new service delivery models are needed for children with developmental coordination disorder (DCD). Emerging principles to guide service delivery include the use of graduated levels of intensity and evidence-based services that focus on function and participation. Interdisciplinary, community-based service delivery models based on best practice principles are needed. In this case report, we propose the Apollo model as an example of an innovative service delivery model for children with DCD. We describe the context that led to the creation of a program for children with DCD, describe the service delivery model and services, and share lessons learned through implementation.

The Apollo model has 5 components: first contact, service delivery coordination, community-, group- and individual-interventions. This model guided the development of a streamlined set of services offered to children with DCD, including early-intake to share educational information with families, community interventions, inter-disciplinary and occupational therapy groups and individual interventions. Following implementation of the Apollo model, waiting times decreased and numbers of children receiving services increased, without compromising service quality. Lessons learned are shared to facilitate development of other practice models to support children with DCD.

KEYWORDS

DCD; Service delivery; Children with disabilities; Physical therapy; Occupational therapy; Intervention

Background

Developmental Coordination Disorder (DCD) is a chronic condition affecting 5-6% of school-age children (American Psychiatric Association, 2013). Coordination difficulties cause children with DCD to struggle in daily life activities such as buttoning, dressing, eating, writing and playing (Magalhães et al., 2011). However, it is the secondary consequences of coordination impairments, such as decreased fitness and low self-esteem (Cairney et al., 2010; Engel-Yeger and Hanna Kasis, 2010; Missiuna et al., 2011; Piek et al., 2010), that are the major concerns of families (Missiuna et al., 2007). Current evidence suggests that early intervention and support, in combination with education of families, can help children function successfully and might prevent secondary consequences (Camden et al., 2014; Missiuna et al., 2014).

Access to services and support is, however, often difficult for children with DCD and their families. Challenging factors include: 1) lack of recognition of DCD, resulting in families seeking assistance from multiple service providers to determine what is wrong with their child (Maciver et al., 2011; Missiuna et al., 2006; Rodger and Mandich, 2005; Stephenson and Chesson, 2008); 2) long wait times for services (Dunford et al., 2004; Peters et al., 2004); 3) the high prevalence of DCD which implies that many children may require services (American Psychiatric Association, 2013; Missiuna et al., 2014) and 4) children with DCD falling outside the mandate of many children's rehabilitation centers (Deloitte, 2010). Increasing professional and community awareness about DCD is leading to an increase in referrals but may not be sufficient for children to have access to timely services. In many situations, children with DCD received limited visits for one-on-one intervention focusing principally on impairments or single activities, with little work with adults in the children's environments (Wehrmann et al., 2006). Knowledge transfer and capacity building around the acquisition of specific functional skills in context are

nonetheless recognized as key chronic disease management strategies that are needed for children with DCD if we are to improve their long-term function and participation (Camden et al., 2014; Smits-Engelsman et al., 2012).

There is a growing consensus that we need to rethink how services for children with DCD are organized to address the issues around access to services and supporting children in their daily lives (Camden et al., 2014; Missiuna et al., 2014). Recently, a scoping review of all English literature pertaining to children with DCD identified several guiding principles for service delivery: increasing awareness of DCD; improving coordination of services; implementing clearly defined pathways for service; using a graduated/staged approach to service delivery; integrating children's and families views in assessment and intervention; and using evidence-based interventions that will focus on function, participation and prevention of secondary consequences (Camden et al., 2014). Missiuna et al. (2014), in a position paper on strategic management of children with DCD, identified similar principles: intervening at a population level to create environments that facilitate the learning of motor skills; direct teaching of life-long functional motor skills; and, accommodating for motor learning difficulties through changing the task or environment. Missiuna et al. (2014) stressed that therapists should work in schools, which are central environments in children's lives, and support teachers and families. Partnering for Change (P4C) is one example of a school-based, service delivery model building on these management principles in order to intervene at a population level. P4C is an occupational therapy model that uses a tiered approach to intervention including universal design for learning, differentiated instruction and accommodation (Missiuna et al., 2012a). P4C emphasizes the building of partnerships between therapists, educators and parents to transfer knowledge about DCD and facilitate capacity building. Collaboration and coaching of educators occurs where the

children are experiencing difficulties, in the context of the classroom and other school settings. While P4C has been shown to be a useful model for many children with DCD in school settings (Missiuna et al., 2012b), it offers less guidance for intervening with children with DCD with more complex needs or for those children who require support to transfer and generalize learning into home and community environments.

Around the world, many children with DCD are referred to community-based rehabilitation centers, so it is important to consider how best practices principles such as those described above could be implemented in such settings. Frameworks and guidelines have been proposed by Forsyth et al. (2008) and Blank et al. (2012) that integrate many best practice principles and could apply in community-based rehabilitation centers. However, to our knowledge, there are no published examples of community-based service delivery models based on best practice principles in DCD. Such examples would be helpful to guide therapists, managers and researchers wishing to redesign their services.

The service delivery model applied in one rehabilitation center in Québec, Canada, is an example of a program that implemented the best practice principles that are now identified in DCD literature (Camden et al., 2014). The goals of this case report are to: 1) describe the context in which the DCD program was created; 2) describe the Apollo service delivery model that guided service delivery; 3) outline the services provided; and 4) share lessons that were learned regarding the implementation of the best practice principles.

The Context

The Estrie Rehabilitation Center, in Southern Québec, Canada, is one of the 21 regional rehabilitation centers responsible for the provision of services fostering participation for individuals with chronic physical impairments. In most regions, these rehabilitation centers are the only public providers of rehabilitation centers to children with disabilities. Local health professionals refer children to the rehabilitation centers and must make the case that children's impairments are significantly impacting on their ability to perform everyday activities in order for children to gain access to services. When children are admitted in a Center, they received services through a specific program. In the Estrie Rehabilitation Center, the Center had a developmental (*e.g.* global delay), a motor (*e.g.* cerebral palsy) and a speech and language (*e.g.* language disorders) program, as well as a non-categorical teenagers' program (including children 12 to 21 years old). More than 1000 children receive interdisciplinary services at the Center, at home or in a community setting such as school.

The DCD program was created in 2003, when a developmental pediatrician in Sherbrooke started referring children to the Centre with a diagnosis of dyspraxia (which was the term used for DCD). The increase in referrals of children with DCD put additional pressure on the limited resources of the Centre that already had hundreds of children on a waitlist and some children were waiting over two years for service. The long waiting lists led managers, who agreed that children with DCD should be eligible for service in the Centre, to search for creative solutions. They created a special waiting list to capture all children referred with a diagnosis of DCD, developed a business case and lobbied the health Ministry at regional and provincial levels to get more funds to offer services to these children. The managers also partnered with a newly constituted provincial parent association for children with DCD. They acknowledged the limited public funds available for rehabilitation services but proposed that new types of services would be explored and

developed collaboratively. Special funds were eventually allocated to the Centre and the managers decided to use these funds to develop a specific program of services for children with DCD.

A decision was made early on to offer community-based groups and to restrict individual interventions for those children who were experiencing more severe impacts on their daily lives or who had complex needs. Community groups were developed in partnership as rehabilitation therapists from the Centre met with parents to explore the types of community-based groups that would best fit their interests and meet children's needs. Parents were particularly interested in their children having access to adapted leisure activities such as skiing, karate and swimming. In each case, therapists partnered with groups who were already offering classes in the community to develop and adapt classes for children with DCD. Classes were then advertised through the Centre and community organizations. About 8 children were included in each group that ran for 8 sessions and was offered either at a community pool or gym.

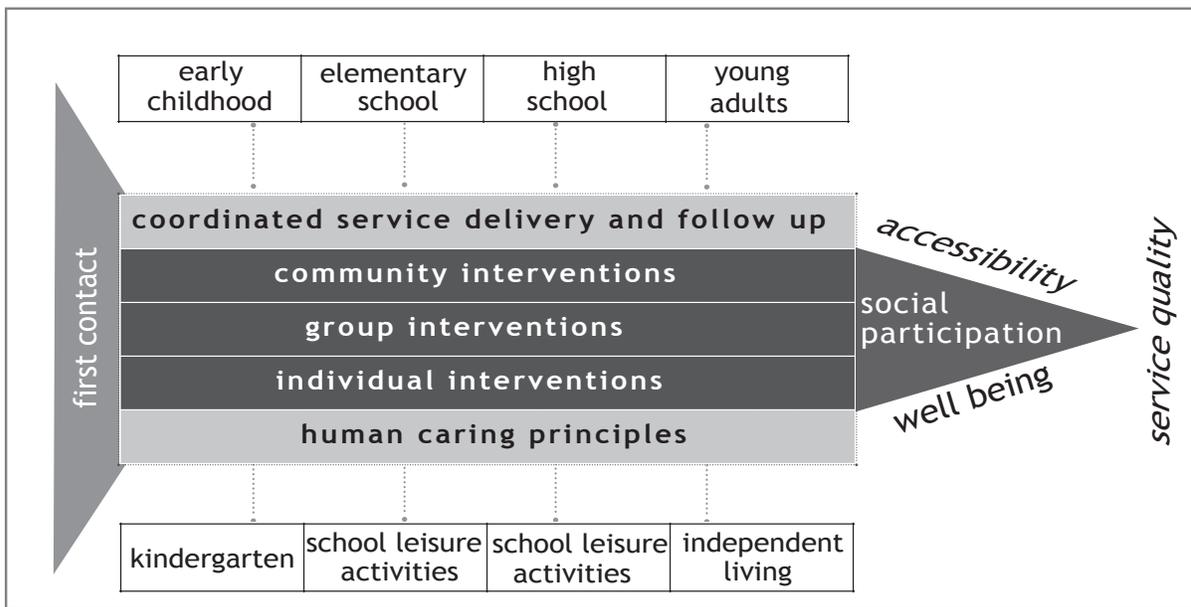
Another need identified by parents was to increase teachers' knowledge about DCD and skills to build capacity to manage children at school. Research grants were obtained in collaboration with the DCD parent association and the school board. In 7 schools, 9 educators from each school participated in six half-day sessions to learn about children with coordination difficulties (see Léger et al., 2009 for details). Teachers subsequently identified children with potential DCD and their parents were invited to participate in a one-day workshop on DCD.

Parents, teachers and professionals were highly satisfied with the new services. Teachers and parents reported an increase in their understanding and ability to manage children with DCD

following the school-based workshops (Pariseau et al., 2007). However, challenges were identified by the Center with the services offered: few criteria were available to guide decisions about whether to offer individualized services, groups were time-consuming to develop and difficult to sustain; and school training needed to be integrated better with the other services offered. A more integrated service delivery model was needed. A decision was made to reorganize childhood disability services more generally at the Centre level. The principles used to develop services for children with DCD (e.g., population-based interventions offered in partnership with the community) were used to develop a new service delivery model that would guide services for all children with disabilities in the Center. The development, implementation and evaluation of the new service delivery model, called Apollo, have been reported elsewhere (Camden et al., 2010; Camden et al., 2013a; Camden et al., 2009), but the way in which its implementation shaped the DCD program has never been described.

The Apollo Service Delivery Model

The Apollo service delivery model incorporates three levels of intervention: community-, group- and individual interventions (see Figure 1), These levels reflect a graduated approach, where consideration is given first to the most population-based interventions that would increase awareness, identification and management of children with DCD, and would facilitate participation and health promotion.



Population-based community interventions are illustrated first in the model since the team felt that the needs of many children, regardless of diagnosis and eligibility in the Center, could be met in the community. *Community* interventions were defined as interventions designed to increase the awareness or skills of individuals in the community who were likely to interact with children with disabilities (e.g., educators, coaches) regardless of whether they were or were not currently involved with children from the Centre. The goal of these interventions was to offer access to training, information and resources to individuals in the community in order to develop an inclusive community for children with disabilities, including the many children who have DCD. *Group* interventions were defined as activities that included two or more actual clients. Most of the time, groups involved children, but could also include parents and other adults involved in the children's lives to encourage generalization of skills learned and information provided. Groups were sometime offered in the community but were most often run at the Centre. Group goals varied from promoting strategies to maintain body function and structure (e.g., teaching

stretching exercises) to developing skills (e.g., interacting with others). Most groups were interdisciplinary and involved children with different diagnoses. Finally, *individual* interventions were offered only for those children who had specific needs requiring individualized attention or who had characteristics impeding their inclusion in groups (e.g., behavioral issues).

Two additional types of services were included to round out the Apollo model of service delivery. The *first contact* is a "one time" interview that offers personalized contact with the child's family. A social worker calls to interview the family and share information about the diagnosis, the Center and the community resources. This mechanism also allows for questions and for the collection of information on families' needs and priorities. This information is transferred to care coordinators who are rehabilitation professionals who facilitate access, coordinate services and ensure participation of children and their family in appropriate programs across the children's life span (*coordinated service delivery and follow up process*). Care coordinators are also responsible for ensuring smooth transition and integration among the interventions provided at community, group and individual levels.

Following implementation, the impact of the Apollo service delivery model on families of children with different diagnoses was evaluated and results revealed that service quality was maintained while the numbers of children receiving service increased and wait times decreased (Camden et al., 2010; Camden et al., 2013b) for all children in the Center, including children with DCD. Specifically for children with DCD, wait-times decreased following implementation from 214 days in 2007 to 63 in 2009, and the overall number of hours of services provided to each child ($p=0.93$) and the perception of service quality ($p>0.15$) remained stable over time (sub analysis reported in Camden et al., 2010). Parents of children with DCD reported appreciating

group interventions and the opportunities provided for their child to make friends and to learn new skills, even though some would have preferred access to more individual interventions (Camden et al., 2012). Enhancing community and group interventions increased accessibility and may have facilitated a move away from impairment-focused therapy toward interventions that promote participation. It was however not only the type of services (*e.g.*, group or individual) that was important to consider, but also the approach used to deliver the services. Graduated approaches based on scientific evidence and focusing on function needed to be embedded in this comprehensive service delivery model to respond to family goals.

Outline of the services now provided to children with DCD

Most interventions in the DCD program now use top-down approaches emphasizing learning of selected activities and identification of strategies to foster improved interaction between the child, the task and the environment (Blank et al., 2012; Levac et al., 2009; Smits-Engelsman et al., 2012). Therapists use principles of task-oriented, motor learning and cognitive interventions in all types of services they provide. For example, physiotherapists work with children in groups as they learn to break down bicycling and provide families with a flyer explaining the different activity-components needed to learn to cycle (*e.g.*, walking a bicycle and controlling the direction; pedaling while someone controls direction) as well as specific recommendations for their child. In occupational therapy, principles of Cognitive Orientation to daily Occupational Performance (CO-OP) (Polatajko et al., 2001) are used in group and individual interventions to engage children in problem-solving to find effective ways of performing life tasks. Successful strategies are shared with family members and, where possible, with teachers and community leaders to ensure generalization.

Development of life habits, which are defined as activities of daily living and social roles appropriate for a child's age (Noreau et al., 2002), serve as the overarching focus of the DCD program which helps therapists design interventions that impact on children's day-to-day lives. Since life habits are influenced by the child's age, the DCD team uses an age-based pathway to plan services across the life span (see Table 1). Lead disciplines are indicated but most groups are interdisciplinary. The pathway also presents the type of interventions that are designed to respond to DCD-specific needs or to needs that are common to most children with disabilities, including children with DCD. All children do not receive all services listed and age cut-offs are not strictly applied; the pathway only serves as a guideline for the planning of services over time. The Center tries to sustain community and group interventions but some have changed across the years, according to partners' and families' needs.

Table 1. Services for children with DCD in the Center

Level of Service	5 years old and younger	6-7 years old	8-9 years old	10-12 years old	Teenagers & Young adults
COMMUNITY		School and parent workshops			
		Swimming classes and learn to bicycle days			
GROUP (non-categorical)		Swimming 1 (PT)	Swimming 2 (PT)	Skating (PT)	-Cooking and budget management group -Getting ready for high-school group -Social skills group
		Cycling group (PT)			
GROUP (DCD only)	Information session for families with a newly diagnosed child with DCD				
	Information sessions for parents about daily living with a child with DCD (social workers)				
		- One group session for parents about children's independence - 2-3 group sessions promoting children's independence	- Typing or writing sessions (OT)	-3 group sessions promoting children's independence & homework skills (OT) - Summer camp (interdisciplinary)	
	- School skills (OT)		- Mathematics 1 (OT)	- Mathematics 2 (OT)	
INDIVIDUAL	Parental support and strategies as needed (by special education workers)				
	OT and/or PT if the child has complex needs				

Most community interventions involve partnerships with community organizations. Children with DCD benefits from non-categorical community interventions, such as swimming classes offered at the community pool with support from therapists. DCD-specific community interventions include learn to bicycle days offered in partnership with the DCD parents' association and training workshops for primary teachers around understanding and managing coordination difficulties (Léger et al., 2009). This latter example is a successful and sustainable

partnership that has expanded over the years. Regional school Boards have been so satisfied with the first training in 2005, it is now a recurring event for new teachers. Moreover, the Center's OT has now trained over 100 OT in other regions, in a “train-the-trainer” model. The DCD parent association has also hired the OT to give workshops for parents of school-aged children in two other regions, once a year.

Cycling, swimming and skating groups, as well as summer camps are groups that are not specific to diagnosis and that are available for children with DCD. For teenagers, the cooking and managing budget group includes many children with DCD. Groups that have developed specifically for children with DCD include mathematics, pre-school skills, skating and writing skills. Age-clustered groups targeting either parents or children have also been organized around fostering independence. Some groups are enhanced by individual follow up and education of others, for children who require it. Children having complex needs that are not fully addressed by community and group interventions may also have access to individual intervention. The DCD team has tried to develop community and group interventions in a systematic way, based on the needs of children at different ages. For instance, struggling at school is an important issue for children with DCD. The teachers training described above is a community intervention aiming at building capacity among teachers, so children with DCD are better supported. Children with DCD may receive group intervention to improve mathematics or handwriting. Finally, if needed, children can also receive individual cognitive intervention.

The DCD Program illustrates the operationalizing of best practice principles and partnerships with other pediatric programs in the Center and with community associations to support children with DCD. Future challenges include sustaining community interventions that are compromised

by the lack of primary health care services to support children with DCD. Primary health care professionals need not only to refer children with DCD to the Centre, but also to provide population-based, health promotion and prevention services. The Centre-based program can support community organizations but doesn't have the mandate and resources to mount and run groups in the community. The development of more population-based services would lead to greater system efficiency and decrease the need for referral to specialized rehabilitation centers.

Discussion

In the DCD field, there is a paucity of publications that describe program development and research of new service delivery models. The services outlined in this case report give one example of how the best practice principles identified by a recent scoping review (Camden et al., 2014) could be implemented in interdisciplinary community-based rehabilitation centers. To develop DCD programs, managers and decision-makers in rehabilitation centers have a key role in championing the needs of children with DCD; advocacy of managers is critical but that is very seldom mentioned in the literature (Wehrmann et al., 2006). Partnership with parents' associations to influence the development of new programs and services for children with DCD is rarely discussed in the literature. The importance of working with children and their families is described in great detail (Forsyth et al., 2008; Sugden, 2007) but it is usually in the context of providing service to individual clients. Parent involvement in the development of services could be very beneficial and could lead to more evidence-based services that target participation and prevention of secondary consequences, which are reported to be the real concerns of families (Missiuna et al., 2007) and should be the goal of services for children with DCD (Camden et al., 2014; Missiuna et al., 2014).

DCD programs should include pathways and coordination mechanisms to clarify stakeholders' role across the health and the education systems (Forsyth et al., 2008; Missiuna et al., 2006; Rodger and Mandich, 2005). Many pathways described in the literature begin with the identification of concerns about children with DCD by teachers (Campbell and Skarakis-Doyle, 2007; Missiuna et al., 2012a; Salmon et al., 2006). It is important, however, that primary health care providers can also recognize and refer children with DCD for support. Since only a small proportion of children with DCD need specialized rehabilitation services (Campbell and Skarakis-Doyle, 2007; Missiuna et al., 2014), it is not appropriate to refer all children with DCD to rehabilitation centers. Using a more graduated and population-based approach to service delivery seems appropriate for this population and could even provide resources and supports that are responsive to the needs of the many children with DCD who will never be diagnosed.

Graduated/staged approaches for children with DCD have been integrated successfully within a school-based (Missiuna et al., 2012ab) service delivery model. However, organizing supports only through schools could limit opportunities for home and community support; on the other hand, organizing DCD management principally through community-based rehabilitation centers could be costly and may not facilitate population-based and health promotion interventions.

Graduated/staged approaches could be used as a framework to organize services at a more macro level and to develop service delivery models that integrate primary-, home- school- and community-based care. Greater system efficiency could potentially be achieved while promoting participation for all children and increasing accessibility to rehabilitation services for the few children with DCD who have complex needs. Greater efficiency can certainly also be achieved by including children and families' views are foremost, and by ensuring that interventions focus on function and prevention of secondary consequences. Ideally, interventions at all levels will

foster resilience, develop self-esteem, promote healthy life styles and encourage participation in physical activities for children with DCD.

Conclusion

In this case report, we have shared our experiences developing and implementing services for children with DCD in a regional rehabilitation center for children with disabilities. We hope that this illustration will engage others in reexamining the principles being used to guide service delivery for children with DCD.

Declaration of interest section

Authors don't have any interest to declare.

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