Reflections on using a Community-Based and Multisystem Approach to Transforming

School-Based Intervention for Children with Developmental Motor Disorders

Wenonah Campbell,* Ph.D., is an Assistant Professor in the School of Rehabilitation

Science and a Scientist with *CanChild* and the INCH lab at McMaster University, 1400

Main Street West, IAHS 414, Hamilton, Ontario, Canada. L9K 1E9

Email: campbelw@mcmaster.ca

Chantal Camden, Ph.D., PT, is an Assistant Professor in the School of Rehabilitation at

Sherbrooke University, 3001 12ᵉ Avenue Nord, Sherbrooke, Québec, Canada.

J1H 5N4

Email: Chantal.camden@usherbrooke.ca

Cheryl Missiuna, Ph.D., O.T. Reg. (Ont.) is a Professor in the School of Rehabilitation

Science, a Scientist with *CanChild* and the INCH lab, and holder of the John and

Margaret Lillie Chair in Childhood Disability, at McMaster University, 1400 Main Street

West, IAHS 412 Hamilton, Ontario, Canada. L9K 1E9

Email: missisuna@mcmaster.ca

*corresponding author

Abstract

Evidence-based management of Developmental Coordination Disorder (DCD) in school-age children requires putting into practice the best and most current research findings, including evidence that early identification, self-management, prevention of secondary disability, and enhanced participation are the most appropriate foci of school-based occupational therapy. Partnering for Change (P4C) is a new school-based intervention based upon these principles that has been developed and evaluated in Ontario, Canada over an 8-year period. Our experience to date indicates that its implementation in schools is highly complex with involvement of multiple stakeholders across health and education sectors. In this paper, we describe and reflect upon our team's experience in using community-based participatory action research, knowledge translation, and implementation science to transform evidence-informed practice with children who have DCD.

Introduction

Developmental coordination disorder (DCD) is a neuro-developmental condition that impacts negatively on a child's ability to perform everyday self-care and academic activities and to participate fully at school, at home, and in the community [1, 2]. Evidence about children with DCD has accumulated rapidly in the last decade and there is now a much better understanding of the natural history of DCD, the mechanisms underlying the disorder, its impact on daily functioning, and the effectiveness of different intervention approaches [3-5]. Although DCD is common, affecting about 5% of all children, it often goes unrecognized [6, 7]. Recent causal models have suggested that DCD is a primary stressor that leads to secondary negative outcomes over time (e.g., depression, academic failure, obesity, social anxiety, and low self-esteem) but that such outcomes might be mediated by factors in the environment [8]. Indeed, there is now sufficient evidence to suggest that earlier identification of DCD, a focus on self-management, and prevention of secondary disability need to become the focus of the way we work with children who have DCD [9].

Why transform school-based intervention for DCD?

Although researchers know a great deal about DCD, widespread translation of that knowledge to parents, professionals, and healthcare funders remains a challenge; indeed, there is considerable variation across countries in extent to which health and education systems are designed to provide appropriate services to these children [2]. Many children with DCD are not recognized as having motor coordination difficulties until they begin to struggle at school, at which point, they may be referred to occupational or physical therapists [10]. Unfortunately, in many jurisdictions, the waitlist

for school-based rehabilitation services is incredibly long [11]. For example, in Ontario, Canada, school-age children may wait 2 years or more for occupational therapy services that ultimately involve fewer than 4-6 individual sessions – most of these are utilized for individual assessment to document the child's motor impairment [12]. By the time children with DCD are seen, they have often developed secondary emotional and behavioural problems and their needs have become too complex for the length and focus of the intervention that is provided [13-15]. Despite multiple systematic reviews having shown conclusively that existing treatments do not "fix" the underlying motor coordination impairments of children with DCD [4], the emphasis of most school-based interventions continues to be on the assessment and remediation of the motor impairment rather than on successful participation [16].

To change the focus of school-based intervention, a multidisciplinary team from CanChild, an internationally renowned centre for childhood disability research, recognized that a fundamental paradigm shift was required in how rehabilitation services were conceptualized [17]. Specifically, we envisioned an innovative approach that would build on best practice for children with DCD by focusing on: (1) earlier identification of children with DCD; (2) creating enabling environments to support children's successful participation at school; (3) building the capacity of educators and parents to manage DCD; and (4) using a collaborative coaching approach to problem-solve about practical strategies to compensate for children's motor difficulties. The development, evaluation, and implementation of this type of intervention required a partnership between researchers, the health care and school systems, the therapists who deliver services, and the families of children with DCD. In recognition of this need for partnership, we called

the initial research project "Partnering for Change," a name which was eventually

adopted as the name of the intervention and service delivery model (see Figure 1).

What was our team's approach to starting this transformative research?

From the first pilot study of the Partnering for Change (P4C) intervention in 2008,

our team has embraced the philosophy and principles of ***community-based participatory***

action research (PAR). PAR is "a collaborative research approach…designed to ensure

and establish structures for participation by communities affected by the issue being

studied, representatives of organizations, and researchers in all aspects of the research

process to improve health and well-being through taking action…." [18, p.2]. Thus, from

the outset, there was recognition that research to transform school-based rehabilitation for

children with DCD would require meaningful and ongoing engagement with the

individuals, organizations, and systems who would be the ultimate end users of this

knowledge in the province of Ontario. Three Stakeholder Symposia were held between

2008 and 2010 to bring together over 60 stakeholders who were concerned about the

length of time that school-age children with DCD were waiting for services [19-21].

Representation came from: families, therapists, educators, school boards, provincial

government ministries, and healthcare funding decision-makers. These meetings helped

to identify what stakeholders viewed as the major challenges of the existing approach.

Stakeholders brought varying perspectives but all agreed that the length of the waitlist

was untenable; there was consensus that obtaining an accurate diagnosis was secondary

to providing early intervention and support to children, families, and educators –

especially when the children were first noticed to be struggling at school and at home.

The meetings also provided a forum in which to share ideas and to shape the research

agenda with respect to developing and evaluating a new approach to intervention. A pilot study was mounted in 2 schools and the intervention was discussed and refined at the symposia.

This participatory approach was pivotal in supporting the team to obtain research funding to conduct a demonstration project of the intervention – this time with 11 schools and 8 therapists [22]. The goals of this project were to: (1) determine the feasibility and challenges of training occupational therapists to deliver this new intervention; (2) examine the receptivity of educators and schools to an intervention focused on capacity-building and collaborative coaching; and (3) explore the extent to which parents and educators increased their awareness of the needs of children with DCD. The results of this successful demonstration project were published in a trio of publications that described the conceptual and research basis for the P4C intervention [17], documented the research outcomes of the demonstration project with 87 families [23], and explored therapists' perceptions of delivering services to children with DCD in this innovative way [24].

In addition to publishing the findings, we recognized the importance of continuing to engage the stakeholders who were very much invested in the goal of improving school-based interventions for children with DCD. Thus, our team obtained "knowledge translation" funding to focus on activities intended specifically to disseminate knowledge about DCD and the P4C intervention to a range of knowledge users [25]. ***Knowledge translation*** (KT) is a term that refers to the process of making research findings understandable to and usable by their intended audience, including children and their families, therapists, other professionals, administrators, policy makers, or health care

funders [26]. Thus, one of the key activities supported by this grant was the development of online workshops about DCD so that therapists, parents, and educators had access to high quality evidence about how to optimally support these children at home, at school, and in the community [27]. An expert team synthesized the literature and conducted focus groups with parents who had been involved in CanChild studies over the years [28]. Experienced parents and therapists helped to define and shape the workshop content which was subsequently evaluated by parents whose children were newly identified as having DCD [27]. Other activities focused on refining training materials for occupational therapists regarding the delivery of the P4C intervention; strengthening our partnerships with health and education stakeholders; and actively working with policy maker stakeholders to disseminate the research findings to different knowledge user groups, such as departments within the Ontario government involved in children's health and education services.

With stakeholder partnerships strengthened, we began to consider carefully the next steps in the research process and what would be needed to reach our goal of transforming school-based intervention for children with DCD. We had successfully demonstrated the feasibility of P4C: it was highly acceptable to therapists, educators, and families; training needs of the occupational therapists had been identified; and preliminary evidence showed a positive impact of P4C on parents' and educators' knowledge about DCD [23]. However, additional research was needed before P4C could be considered ready for widespread adoption. Specifically, we needed to evaluate the impact of the P4C intervention on relevant outcomes for children, families, and educators over time. We also wanted to identify and explore the factors that impacted the

implementation of P4C on a larger scale. In the feasibility study, conditions had been fairly ideal. The P4C intervention was offered in addition to the regular OT service provided by the health care agency in that region; the school board and 11 schools had subscribed; and the 8 OTs who were trained to deliver the P4C intervention had all volunteered their participation. The question remained about what would happen if the P4C intervention was delivered in conditions that were more variable. That is, what would outcomes look like if the intervention was implemented by a different group of OTs in schools having different characteristics from the ones in the demonstration project? And would it work if it was offered as the sole intervention in a school, rather than as an additional service? These questions, along with a focus on implementation, became the objective of the next research grant, which was funded by the Ontario Ministry of Health and Long-Term Care and the Ontario Ministry of Education from 2013-2015 [29, 30].

How did we approach the issue of "scaling up" for the next research study?

From 2013-15, our team studied the evaluation and implementation of the P4C intervention in 40 schools across three different school boards and two different health care regions within Ontario. As in previous studies, PAR was still the foundation from which we approached working with community partners. In particular, we adopted an approach called ***integrated knowledge translation*** or IKT, which is defined as a process that enhances research uptake by guiding researchers and knowledge-users to work together throughout the research cycle to ensure the questions, methods, and findings are highly relevant to the health system [31]. Specifically, we worked with healthcare and education stakeholders via a Steering Committee that provided strategic direction to the

overall research project and a Working Group that problem-solved challenges "on the ground" and generated solutions. In addition, each health care agency, school board, and school agreed to designate one or more staff members to be a liaison to the research project on behalf of their organization. These individuals worked closely with research staff to support implementation of the P4C intervention and to resolve any barriers along the way. For example, each school needed to be prepared for a completely new type of population-based service. Thus, our liaisons ensured that introductory letters explaining the P4C service and the role of the therapist were sent home to all families at the start of the school year. They also facilitated communication: staff and researchers from the research team routinely met with and delivered presentations to a wide array of stakeholder groups (e.g., principals, school psychologists, speech-language pathologists, special education resource teachers), especially during the first year of the study when the intervention was new. This groundwork was not a focus of the research study per se but was incredibly important to creating a receptive environment for the research project and the OTs who delivered the P4C intervention.

With respect to the research study itself, the evaluation aspect addressed the research questions related to various outcomes associated with the P4C intervention, such as describing the types and amount of services delivered by OTs; the numbers of children reached and a thorough description of those children who required individualized services; measuring pre-post outcomes for teachers and parents with respect to their capacity to manage DCD using a knowledge and skills questionnaire; and measuring pre-post outcomes for children with motor coordination problems in participation at school [Part 1 of the *School Function Assessment*; 32] and at home or in the community

[shortened version of the *Participation and Environment Measure for Children and Youth*; 33]. Initial findings were shared at the 11th International Conference on Developmental Coordination Disorder [34-37] and these are available in an open access online interactive Final Project Report [38; see www.partneringforchange.ca]. Peer-reviewed publication of the results of the evaluation of the P4C intervention is forthcoming.

Understanding issues related to the implementation of a new intervention involves appreciating the facilitators and barriers to its delivery in schools and the factors that would need to be addressed to sustain its use in the long term. To guide this aspect of the study, we turned to a relatively new field of research called ***implementation science*** (IS). IS has gained increasing recognition among health care researchers in recent years owing to mounting evidence that far too many treatments fail to be used in routine clinical practice, even after decades of research documenting their effectiveness [39]. Researchers, knowledge users, and funders have begun to seek out innovative research approaches that close the gap between research and practice more quickly [40]. IS focuses on the "scientific study of variables and conditions that impact changes at practice, organization and systems levels; changes that are required to promote the systematic uptake, sustainability and effective use of evidence-based programs and practices in typical service and social settings" [41].

Although many IS frameworks are available [42], we chose to modify a change management framework [43] that was based on organized action systems theory [44] and socio-constructivist approaches [45]. This provided an implementation science framework that incorporated key factors known to influence the implementation of new

interventions (e.g., knowledge, attitudes, and skills of therapists; features of the intervention such as its perceived benefits and feasibility; and organizational characteristics such as leadership and workplace culture) [46]. Specifically, the framework captured the many complex interactions between: the people involved in the implementation of the P4C intervention (e.g., therapists, educators, administrators, research team); the specific organizations involved in delivering the service (e.g., health care agency, schools); and the larger health and education systems in which our research study was unfolding. We wanted to understand how the interactions across people, organizations, and systems influenced the process of delivering the intervention and its perceived impact. Finally, we wanted to be able to describe how implementation of the P4C intervention changed over the two-year period of the study and to identify the factors that were pivotal to that process of change. A diagram of the framework and a complete description of its components are outlined in the Final Project Report [38; see www.partneringforchange.ca].

Consistent with implementation-focused research [47], interview guides based on this framework were used to conduct individual interviews and focus groups during the 2-year study. Focus groups were held with the occupational therapists who delivered the P4C intervention while in-depth interviews captured data from other stakeholders including education stakeholders (e.g. school board superintendents, principals, special education teachers); health care stakeholders (e.g. decision-makers, managers, clinical coordinators, occupational therapists); and research team members. A content analysis [48] of these data using NVivo 10 [49] is in progress and is being guided by the IS framework. In the spirit of PAR, findings from the first year of the study were shared

with our stakeholders, presented at a variety of conferences [50-52], and included in the Final Project Report (see www.partneringforchange.ca).

Although preliminary, we have learned many valuable insights about what will be required to transform school-based interventions for children with DCD and, ultimately, to sustain that transformation over the long term. For example, implementation of the P4C intervention required a fundamental shift in how therapists, educators, families, and funders viewed what service for children with DCD "looked like." This shift in thinking did not occur easily and required considerable time and effort on the part of all stakeholders. Several illustrative quotes are provided in our final report that will attest to this finding. Other lessons learned included the need for a transition period before full implementation of P4C to provide time for building partnerships with stakeholders and to allow organizations to make adjustments to their internal structures and processes. Without such a transition period, people and organizations were overwhelmed. As well, therapists strongly endorsed the need for ongoing training and mentoring to support their transition to a new approach to practice. The explicit inclusion of an IS focus allowed these insights to emerge and facilitated our understanding of the complex factors that will ultimately influence the "uptake and spread" of P4C into everyday practice. To learn more about implementation science and its use in clinical practice research, readers may wish to consult recent tutorial papers on this timely issue [40, 53].

What have we learned from this research "journey"?

Although it has been well-documented in the literature [54], it was nonetheless surprising to experience firsthand just how much time and personal investment it required for our team to build strong relationships with our community-based partners, especially

as the project evolved from a pilot study to large-scale evaluation. With each subsequent research project, an increasing number of stakeholders became involved in the implementation process and the relationships with each stakeholder group needed to be cultivated independently. This required taking the time to understand each stakeholder's needs and then crafting tailored materials and messages that were delivered in that group's local context. While some health care agencies already had strong partnerships with school boards, others did not; where previous relationships did not exist, it took much longer to begin implementing the P4C intervention. Moreover, even once school boards had committed to be part of the research study, some schools and occupational therapists found a transition to this intervention to be very difficult. Not all educators are used to collaborative engagement with a health care professional who is present in their classrooms; not all therapists are comfortable providing services that target whole classes of children. Consultations, mentoring, and presentations were ongoing as the research project evolved. Our team was able to be responsive to the needs of different stakeholder groups due to the collective expertise of a large interdisciplinary team (i.e., our team includes occupational therapists, physical therapists, speech-language pathologists, special educators, methods experts, and a health economist) and the support of highly skilled project coordinators. Nearly every member of the team has been involved in knowledge translation and relationship-building activities with our stakeholders and/or knowledge users. For those wishing to know more about this experience, the American Speech-Language-Hearing Association has created a series of six online videos that feature the first author describing key "lessons learned" about building stakeholder

engagement and using implementation science in the P4C evaluation and implementation study (http://cred.pubs.asha.org/article.aspx?articleid=2299978&resultClick=1).

In addition to investing in community-based partnerships, we also needed to be responsive to changes in the larger socio-political system in which school-based services for children with DCD are situated. Specifically, the province of Ontario in Canada is in the process of significant transformation regarding how rehabilitation services are funded and delivered to school-age children with disabilities, including children who have DCD. This transformation began while we were conducting the demonstration project and has evolved during the time period in which we conducted our evaluation and implementation study. As a consequence, the research team and our community-based partners have had to be sensitive to how the P4C intervention might be impacted by broader "system-level" changes. Organizations other than those who have been our partners for the last 8 years may ultimately fund and/or be responsible for delivering occupational therapy services in schools. This has posed a challenge for us as researchers because it is difficult to plan for future research projects and secure grant funding in an environment where there so much uncertainty. However, the fact that people, organizations, and systems are open to change and innovation right now provides an unprecedented opportunity for our program of research to inform the most significant transformation of Ontario's school health system in decades. Indeed, other researchers who have utilized IS and PAR have reported experiences similar to ours and describe the importance of being ready to pursue "emerging opportunities" [55].

As the P4C intervention moves closer to being ready to adopt as standard practice, we have become astutely aware of the need to have a mechanism to measure intervention

fidelity; that is, to be able to determine that the intervention being provided is indeed P4C and that the core or essential features of P4C are being delivered as intended. With that in mind, we used a consensus-building technique to identify 16 core features of P4C that distinguish it from other school-based interventions [56]. These 16 core features align with the four major principles of P4C: **capacity building** (5 features) through **coaching** (4 features) and **collaboration** (2 features) in **contex**t (5 features). For example, features related to coaching include therapists modeling strategies to support children with DCD in the classroom, explaining to educators why particular strategies were effective, and helping educators to utilize strategies by problem-solving and providing feedback. Next, we developed and trialed an observational checklist to document the extent to which the 16 core features of P4C could be observed in the school setting [57]. Based on this study, we determined that not all core features could be captured through observation (e.g., the ways in which therapists built capacity among families was not readily observable during the school day) and that other measures would likely be required to capture all 16 features (e.g., documentation review or parent report). We anticipate that developing a 'toolkit' to measure the fidelity of P4C will become increasingly important in future studies – especially in light of the growing recognition that sustainable interventions are those that can be adapted to local contexts, while still preserving those features that render them effective [40].

Conclusion

Evidence indicates that DCD is a life-long chronic health condition that is best managed when school-based services focus on early identification, self-management, prevention of secondary disability, and enhanced participation [9]. P4C is a novel school-

based intervention based upon these principles that has been developed and tested in Ontario, Canada over an 8-year period using a community-based participatory action research approach. From the very first pilot study, our research team recognized that transformation of school-based intervention for children with DCD could only occur through PAR, where there is true collaboration and partnership with the individuals and organizations who would be responsible for implementing and sustaining change. Moreover, decades of research have convincingly shown that the process of putting research evidence into everyday clinical practice is complex and can be frustratingly slow. New fields of scientific study, including knowledge translation and implementation science, offer innovative frameworks and approaches that can dramatically reduce the research-to-practice gap. By sharing the successes, challenges, and lessons learned from the P4C project over the past 8 years, we hope to spark a reflective discussion among the scientific and clinical community about how research approaches and methods could be shaped to better ensure that what is demonstrated to be 'best evidence' is also implemented as 'best practice'.

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**This tutorial article provides an overview of essential information concerning
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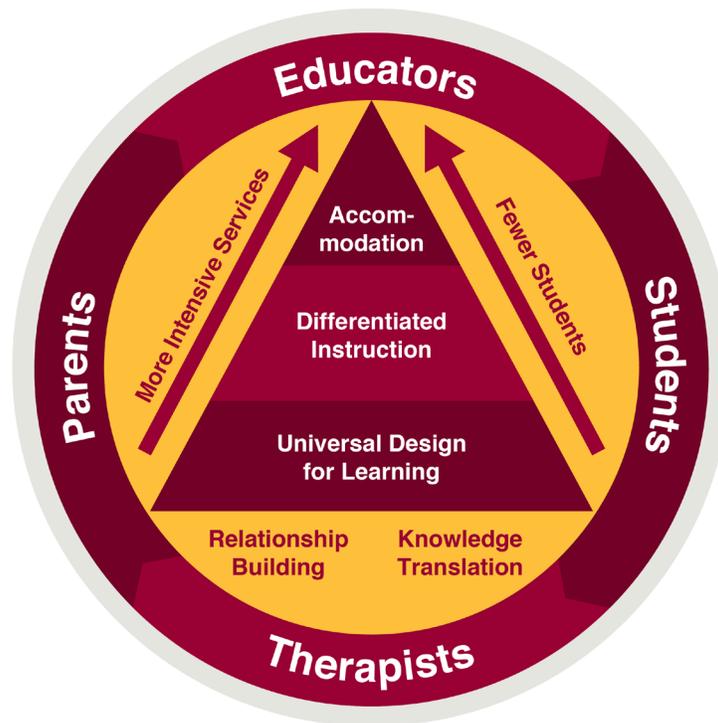
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PARTNERING FOR CHANGE: P4C
Building Capacity through Coaching and Collaboration in Context

Educators

Parents

Students

Accommodation

Differentiated Instruction

Universal Design for Learning

More Intensive Services

Fewer Students

Relationship Building

Knowledge Translation

Therapists

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Figure 1. Partnering for Change Model

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The Partnering for Change team used evidence from the literature to design a conceptual model that was tested in school settings and refined. This figure reflects the partnership that is needed between **therapists**, **parents** and **educators** to create environments that will facilitate successful participation for **all students**. Working from a foundation that focuses on **relationship building** and **sharing of knowledge**, these partners collaboratively **design environments** that foster motor skill development in children of all abilities, **differentiate instruction** for children who are experiencing challenges and **accommodate** for students who need to participate in a different way. While the school remains the target of intervention, allowing therapists to impact the greatest numbers of children, therapists are able to increase the intensity of the service that they provide as they coach educators and/or parents about individual students who have more complex needs. In this model, all collaboration and intervention occurs in the context of the school environment.