

## **Developmental Coordination Disorder: A synthesis of evidence to underpin an allied health professions' framework**

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Children with Developmental Coordination Disorder (DCD) lack the motor coordination necessary to perform tasks considered appropriate for their age, given normal intellectual ability and the absence of other neurological disorders. DCD is a common childhood disorder that can develop into a long-term condition that has a significant impact on society. A key method of managing DCD is through the assessment and interventions of allied health professionals (AHPs). To date, no integrated AHP framework for the assessment and treatment of DCD exists. The present article illustrates the methods used to synthesise multiple data sources (policy, scientific evidence, service user views and AHP perspectives) by a multidisciplinary group of AHP researchers and practitioners. Through this process a series of principles of good practice were identified, and then developed into a framework for AHPs working with children with DCD. In this article the methodology used to enable synthesis from different evidence sources will be presented, as will the resultant framework. The findings will then be discussed within the current literature emphasising the importance of health/education partnership in the support and management of these children.

**Keywords:** allied health professions; child; Developmental Coordination Disorder; qualitative research; service delivery; systematic review

### **Introduction**

Developmental Coordination Disorder (DCD) is a motor skill disorder that often becomes evident in school-aged children (Dewey & Wilson, 2001). These children lack the motor coordination necessary to perform tasks considered appropriate for their age, given normal intellectual ability and the absence of other neurological disorders (Barnhart, Davenport, Epps, & Nordquist, 2003). DCD and DCD-like motor impairments are common problems in children. Prevalence is reported as between 4% and 19%, with a varying prevalence reported between countries (Tsiotra et al., 2006). However, it is important to note that reported prevalence is dependent on the criteria and measures used to identify the disorder, and that no “gold standard” test exists. Children with DCD may also have multiple difficulties, and it is likely that issues will be complicated by significant co-morbidity (Bax, 1999; Gillberg, 2003; Kaplan, Dewey, Crawford, & Wilson, 2001).

A child with DCD may demonstrate significant difficulty with self-care tasks (e.g., dressing, using utensils), academic tasks (e.g., handwriting, copying, organising set work, gym class), and/or leisure activities (e.g., sports, playground activities, social interactions) (Barnhart et al., 2003). Children with DCD usually have the same expectations placed upon them as their peers, as DCD is often a “hidden handicap” (Kadesjo & Gillberg, 1998). This

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can lead to repeated experiences of failure for children with DCD, causing a significant negative impact on their self-esteem, socialisation, behaviours and academic performance (Parmenter & Knox, 1991). Children with DCD may therefore be socially excluded (Hallum, 1995) because they engage in passive, solitary activities (Pollock & Stewart, 1990) and they rate themselves as particularly low in social acceptance (King, Shultz, Steel, Gilpin, & Cathers, 1993; Resnick & Hutton, 1987). Studies have also highlighted high levels of family stress, particularly during the time when parents suspect that their child has difficulties, but there is no diagnosis as yet (Larkin & Parker, 1998; Stephenson, McKay, & Chesson, 1990). Parents have reported that their child's DCD difficulties have resulted in a significant impact on family routines, siblings and daily activities (Chesson, McKay, & Stephenson, 1990; Stephenson et al., 1990).

While there are immediate effects, DCD can also lead to significant life-long consequences for children and families, and this creates a significant social impact. Studies have shown children do not "grow out of it", and move into adolescence and adulthood still trying to manage their difficulties (Cantell, Smyth, & Ahonen, 1994; Gillberg, Gillberg, & Groth, 1989; Hellgren, Gillberg, Gillberg, & Enerskog, 1993). For example, a long-term study has shown that 80% of the children diagnosed with DCD at the age of 7 were, by age 22, unemployed, had broken the law, were alcohol or drug misusers or had mental health difficulties (in contrast to 13% of the comparison group without DCD) (Rasmussen & Gillberg, 2000).

DCD is, therefore, a common childhood disorder that can develop into a long-term condition, which has significant impact on the individual, the family and society. The assessment and interventions of allied health professionals (AHPs) can provide coping strategies for the child and their families to attenuate the impact of DCD on their life.

### ***Developing a Framework***

The Allied Health Professions Clinical Effectiveness and Practice Development network was established in 2001 with the aim of promoting the use of evidence in practice, sharing best practice and building confidence in AHPs to engage with the clinical effectiveness and clinical governance agenda. To take this work forward, the National Health Service (NHS) Quality Improvement Scotland (QIS) Practice Development Unit began a process of engaging with AHPs to identify clinical improvement priorities within specific topic areas. One of the topics identified within the child-specific group was DCD.

There are multiple AHPs potentially involved with a child with DCD; these include physiotherapists, dieticians, podiatrists, occupational therapists, speech and language therapists, orthoptists and orthotists. These professions are aware that the Scottish Executive (2002a, 2005) has argued that NHS Scotland should have an AHP framework for implementing evidence into practice. This has not emerged for DCD services partly because there is a lack of summary information about evidence. There has not been a mapping of AHP scientific evidence for practice. Moreover, current standard and innovative practice has not formally been captured in a way that can be disseminated.

Increasingly, there is pressure from the general public, from professional bodies and the government, to set new standards and measure the quality of care (Department of Health, 2000; Scottish Executive 2002a, 2004, 2005). Developing an evidenced-based AHP framework for DCD through the gathering and synthesis of key information will provide stakeholders with the knowledge they need to improve services for children with DCD in Scotland. These improvements may include reviewing current service delivery and consideration of emerging practice. The presence of an evidenced-based framework will stimulate AHPs to complete "in house" re-designs in line with the framework's recommendations. It will provide focus and evidence to

argue for change, and provide an impetus to bring about changes to improve practice and assess the quality of DCD service delivery.

The present article illustrates the methods used to integrate several different evidence sources, which has developed a framework for AHPs working with children with DCD. It will present the methodology for the synthesis and the resultant framework.

### Study Aim

To synthesise a range of evidence sources to develop a framework for AHPs working with children with DCD.

### Method

Experimental studies and systematic reviews have traditionally been viewed as the gold standard of evidence for healthcare (Crotty, 1998). However, an important part in the development of any framework is to take account of the multiple and contrasting voices that permeate the healthcare landscape (Carter, 1998). As part of this process, scientific perspectives must be taken into account—but additionally the perspectives of healthcare providers as well as the perspective of services users and their families must be explored. Further, the policy agenda that underpins healthcare provision is an important source for consideration. Increasingly, the value of integrating this “qualitative” information with more quantitative approaches has been acknowledged (Dixon-Woods & Fitzpatrick, 2001). Therefore, to support the development of a context sensitive, evidence-based AHP framework, which takes into account service users’ and providers’ views, a bespoke methodology was developed.

### Evidence Sources<sup>1</sup>

Because of the complex nature of the interventions under investigation, and the multiple stakeholders associated with the care of children with DCD, a range of evidence perspectives were gathered. The evidence sources are now presented (see Table 1).

#### *Literature perspective on service delivery*

The evidence perspective included: parents’ and children’s views gained through review of qualitative research; clinically effective practice as identified by systematic review of quantitative literature; and good practice as identified by national policy. This was achieved through an integrative literature review of 50 quantitative studies, 10 qualitative studies and 10 key policy documents.

Table 1. Populating framework (child/parent journey) with evidence

Evidence source linked to synthesis questions	
Evidence source	Synthesis question
Literature perspective on service delivery	What does the scientific literature and policy suggest about effective practices?
Service users perspective on service delivery	What were patients/children experiences of each stage of their journey through AHP services?
Professional perspective on service delivery	What is current practice for children with DCD, and what form does innovative practice take?

*Service users' perspectives on service delivery.* This perspective included parents' and children's views gained through focus groups. Data were generated through six focus groups with 25 children with DCD and seven focus groups with 46 parents of children with DCD.

*Professional perspective on service delivery.* Clinically effective and innovative practice as defined by AHPs. This was captured through a national survey of 602 AHPs (this represents all individuals in the professions who work with children and 11% of the total Scottish AHP workforce). Follow up in-depth interviews were undertaken to understand innovative practice with 26 AHPs.

### ***Process of Evidence Synthesis***

Methods for developing the framework drew on guidance from other researchers who have successfully synthesised different types of information (e.g., Pawson, 2002; Popay et al., 2006) and constituted different phases of synthesis (see Figure 1).

*Synthesis team.* To develop the framework, findings from the data were synthesised by a multi-disciplinary group of AHP researchers and practitioners. This kind of skill mix within the research team allows research skills and advanced clinical skill to be simultaneously brought to bear on a given topic (Forsyth, Duncan, & Summerfield Mann, 2005; Forsyth, Melton, & Summerfield Mann, 2005; Forsyth, Summerfield Mann, & Kielhofner, 2005; Harrison & Forsyth, 2005).

*Stages in generation of the framework. Stage 1: Immersion, Summarising and Data Extraction.* Initially, the team immersed themselves in the evidence, which was read and re-read to gain a sense of its content, a process common to much applied qualitative research (Seale, 1999). Following from this, a means of systematically organising the evidence was developed. This involved summarising the evidence from each evidence source. However, this was not a data extraction process as would typically be carried out in a traditional systematic review; rather, its aim was to assist in the extraction of key ideas. This focus on extracting the key information crystallised the thinking of the team, and simplified the information, allowing the team members to interact with it more effectively.

*Stage 2: Developing an Organising Framework.* With continuing engagement with the data, an overall framework for understanding and relating the evidence became apparent. It was clear that the journey of the child/family was manifest in almost all aspects of the data. This "journey" was used as a tool to organise and give structure to the evidence. This was an appropriate step, given that the importance of child/family involvement in the rehabilitation of children with chronic conditions is universally acknowledged, and that current trends towards child/family-centred care are increasingly apparent in paediatric healthcare services (Franck & Callery, 2004; Hanna & Rodger, 2002). Also, research (Knafl, Brietmayer, Gallo, & Zoeller, 1992; Thorne & Robinson, 1988) has shown that parent/professional relationships pass through a series of stages, that these stages are qualitatively different from each other, and that child/family needs are different depending on which stage they are experiencing. Therefore, the following stages were used to delineate the boundaries of the framework (see Figure 2): early stages of a child's difficulties, assessment, intervention, and discharge.

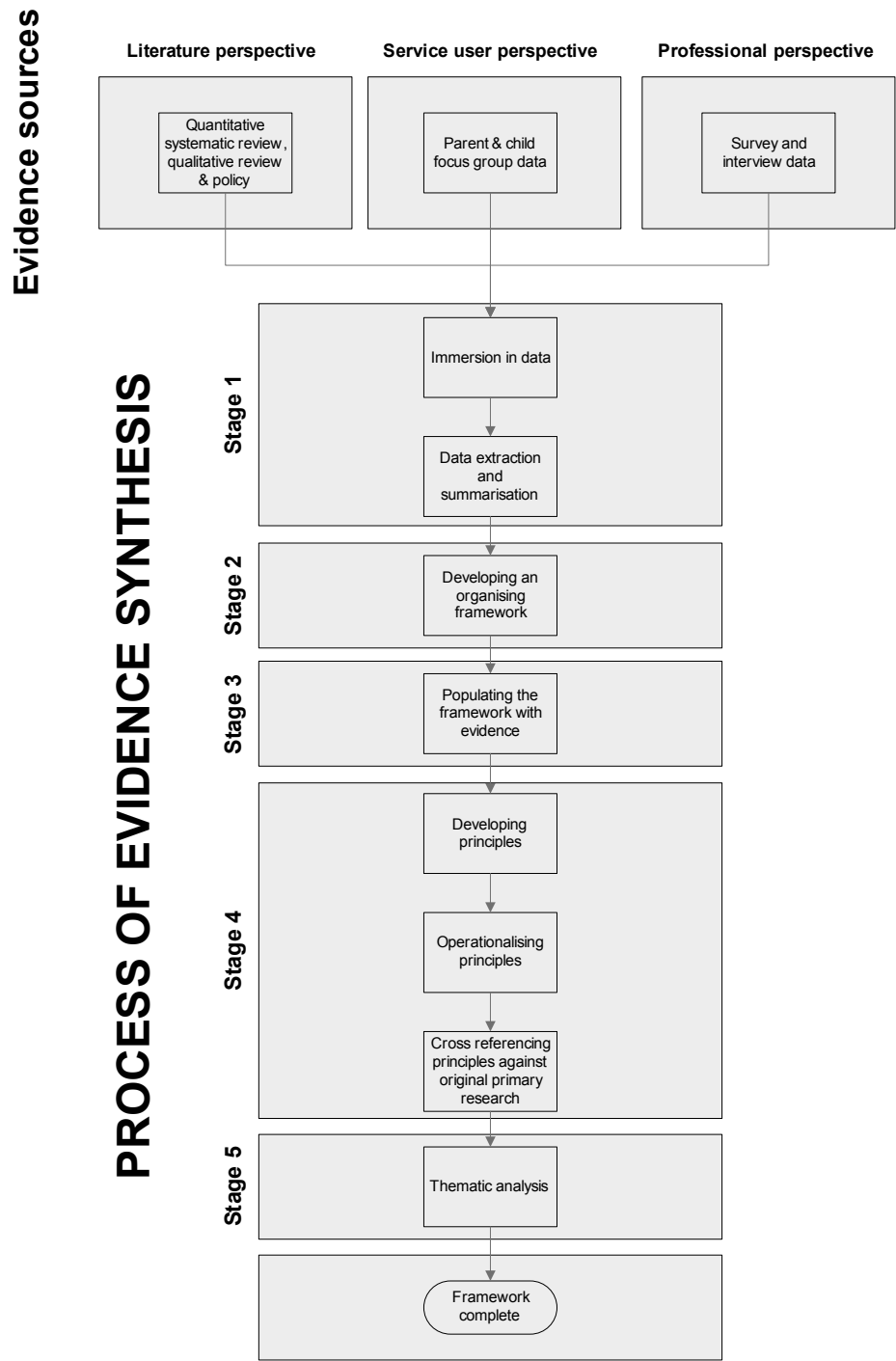


Figure 1. Process of evidence synthesis

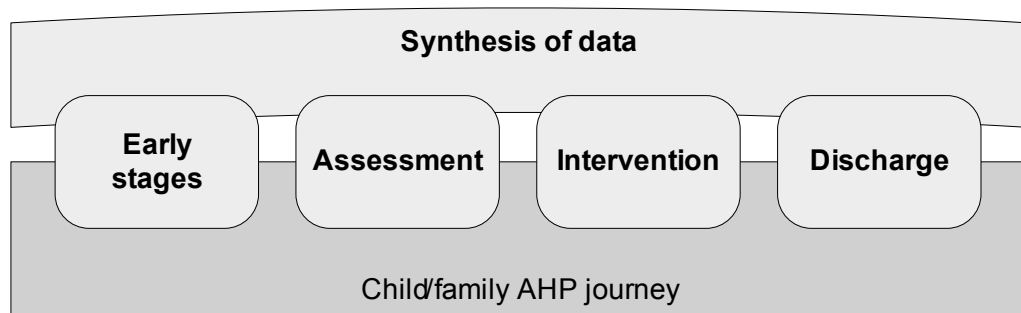


Figure 2. Developing an organising framework

*Stage 3: Populating the Framework with Evidence.* Having identified a framework, evidence was attributed/attached to one (or more) of the stages. Pawson, Greenlaugh, Harvey, and Walse (2004) discuss a process of “populating” evaluative frameworks with evidence in their guidance on evidence synthesis. Drawing on this idea, this process of attachment/attribution was achieved by reflecting on the evidence and asking the question of what phenomena (e.g., a parent’s experience of having a child with DCD), processes (e.g., the search for a diagnosis) or event/action (e.g., an AHP assessment) it reflected, and to which stage it therefore most strongly “belonged”. Because of the subjective nature of this activity, and therefore the possibility of introducing bias into the process (Silverman, 2000), all attributions were supported by a process of analyst triangulation (Whittemore, Chase, & Mandle, 2001), where regular debriefing exercises were carried out and attributions were finalised only when they had been endorsed by the whole team.

*Stage 4: Developing and Operationalising the Framework Principles.* After the framework was populated with evidence, the team took stock of the information within and across the stages, exploring: *how* the evidence related to the organising framework; *what* the evidence suggested; the *strength, rigour or trustworthiness* of the evidence; and the *key messages* from the evidence.

The outcome of this analysis was the development of individual evidence-based principles, which were written to provide tangible guidance for practitioners on service delivery within each stage of the child’s/families’ journey. The principles were reflective of the evidence attributed to the stage to which they belonged, drawing on parents’/children’s experiences, AHPs’ views, current practice, the scientific evidence and/or policy recommendations. The principles were operationalised by writing an underlying rationale for each principle, clearly identifying the nature of the supporting evidence, writing a key message for AHPs, and (where appropriate) including relevant quotes and/or examples of “smart working” (i.e., actual work taking place at present). In order to ensure that all the relevant information had been accounted for, a triangulation exercise was carried out where the original data streams were cross-referenced against the evidence included in the framework. No new evidence was included as a result of this analysis; however, this mapping exercise helped to identify the principles that were most “thickly” and “thinly” populated with evidence.

*Stage 5: Thematic Analysis.* In the last stage, a thematic analysis was made of the principles and their supporting evidence. The analytical process for developing the themes followed a number

of stages, using common qualitative techniques (Barry, 1998; Crabtree & Miller, 1992; Dey, 1993; Harden, 2005; Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998; Ryan & Bernard, 2003; Seale, 1999; Strauss & Corbin, 1998). The principles were read and re-read (immersion). Principles, their rationale and supporting evidence were then coded (i.e., marked up with a word or phrase that reflected their meaning or content) and then compared/combined to develop themes. Themes are defined as: a conceptualisation of the underlying patterns that are identified as being a substantive element of phenomena being studied (Boyatzis, 1998). These key themes of clinically effective practice permeated the principles/evidence.

## Findings

The framework has two elements: key themes of clinically effective DCD practice, and individual principles organised around the child/families' journey.

### *Key Themes of Clinically Effective DCD Practice*

The theme generation within the penultimate phase of the analysis yielded key themes that constitute the pathway. These are as follows:

*Health promotion.* Promoting community-based support for children with DCD prior to any involvement with AHP services requires additional support and education. AHPs have a critical role in the design and delivery of health-promotion strategies with referring agents allowing for community-based management of children possibly negating the need for more specialised services.

*Communication.* Effective communication transcends all aspects of AHP practice with children with DCD. In the first instance, good communication with parents and children ensures services are relevant and that all parties feel heard and understood. Secondly, effective collaborative work is initiated, maintained and developed by efficient communication.

*Child and parent involvement.* Structures and tools allowing children's and parents' voices to be heard should be an integral part of service planning and the child/family journey. Harnessing parental involvement alongside AHP practice is essential when integrating self-management as a key principle in the management of children with DCD.

*Working together.* Engaging with partners in education and developing an understanding of AHP roles will improve support for the child with DCD. Collaborative working and expanding current practice to include other agencies is essential in the development of an inclusive integrated model of service provision. Established clear pathways for entry and exit of services can assist in this process by clarifying roles and expectations for families, education and other involved professionals.

*Skills and Knowledge.* All AHPs require knowledge, training, and an understanding of current evidence for intervention. AHPs, in particular occupational therapists, have a pivotal role in the development and understanding of DCD and its impact on other AHP services and other agencies. This is essential not only for children engaged with AHP services, but also for other agencies



involved with children with DCD during pre-involvement and post-involvement with AHP services.

**The Framework Principles**

The phased approach to evidence synthesis yielded 19 individual principles: four were focused on helping children and families in the early stages, five were focused on AHP assessment, seven were focused on AHP interventions, and three were focused on AHP discharge (see Table 2). The principles will now be presented with reference to their supporting evidence.

**Helping Children and Families in the Early Stages: “Developing a supportive community where initial issues are resolvable with rapid access to AHP support when required”**

The first stage (“the early stages”) focuses on the stage before any contact is made with AHPs, when families and children may be aware of difficulties, but are perhaps receiving little or minimal support. This stage has four principles.

*Principle 1: Raising awareness within the community.* This principle was informed by parents’ views and policy documents, although several AHPs also commented on their potential role in increasing awareness. The principle reflects the notion that the long-term emotional consequences

Table 2. The Framework Principles

Helping children and families in the early stages: “Developing a supportive community where initial issues are resolvable with rapid access to AHP support when required”
Principle 1: Raising awareness within the community.
Principle 2: Supporting self-management within homes, schools and communities.
Principle 3: Increasing referring agents’ knowledge and understanding.
Principle 4: Optimising pre-assessment contact.
Assessment: “Contextual child and family centred assessment jointly with others, creating clear expectations and agreement on optimal courses of action”
Principle 5: Integrating views and expertise of parents/guardians and children.
Principle 6: Harnessing benefits of collaborative assessment.
Principle 7: Making assessment practices appropriate.
Principle 8: Structuring the diagnostic process.
Principle 9: Adopting an honest approach to outcomes and expectations.
Intervention: “Collaborative goal setting that embraces child, family and community contexts and supporting the child’s participation through shared expectations and responsibility within the change process”
Principle 10: Putting the child and family at the centre of care when goal setting.
Principle 11: Involving other AHPs and education staff in goal setting.
Principle 12: Enhancing participation of children with DCD.
Principle 13: The child is not the only focus for intervention.
Principle 14: Sharing expectation and responsibilities in supporting change.
Principle 15: Valuing formalised collaboration with others.
Principle 16: Using evidenced interventions that support change.
Discharge: “Supportive transitional pathways from specialist services to self-management within homes, schools and communities following evaluated outcomes”
Principle 17: Evaluating interventions and outcomes.
Principle 18: Providing strategies for self-management and making use of community resources.
Principle 19: Providing clear pathways for exiting services.



associated with DCD (such as low self-esteem) are shaped by the varied contacts a child experiences with others within society, and that, with a greater awareness of DCD within communities, there may be greater tolerance and positive action to support the child, which could alleviate some of the difficulties faced. This principle highlights that if others have greater understanding of DCD, they may be able to make a positive impact through their interactions. In particular, the findings suggest that information related to the prevention of difficulties could limit the impact of the condition for the child and their family, and potentially reduce the need for professional input at a later stage.

*Principle 2: Supporting self-management within homes, schools and communities.* This principle was informed by parents' views, AHPs' views, policy documents and the qualitative element of the systematic review. Its focus is the stage before any contact is made with AHPs; indicating that support, at this time, for the child from parents/guardians, those in education and/or those working in healthcare could reduce the impact of the condition, and may lessen the need for input in the future. In addition, providing parents/guardians with the knowledge and understanding could reduce the feelings of uncertainty, guilt and helplessness that parents/guardians report in the early stages, as well as reducing the strain that the whole family may experience.

*Principle 3: Increasing referring agents' knowledge and understanding.* This principle was informed by parents' views, policy, the qualitative element of the systematic review and the AHP survey. It proposes that early identification of difficulties and referral to appropriate services would help to ensure that difficulties are addressed as and when they arise, reducing the potential social, emotional and physical consequences of DCD. Also, that an increased awareness of professional roles would enable appropriate and timely referrals to be made, and that professionals should recognise that parents/guardians are often knowledgeable about their child's difficulties.

*Principle 4: Optimising pre-assessment contact.* The information for this principle came from AHPs' views and the AHP survey. From these data, it became apparent that gathering information and making contact with parents/guardians during the phase prior to face-to-face contact may be beneficial. (1) Parents/guardians have an early opportunity to engage with the therapist regarding the child's care, (2) it may avoid the need to discuss sensitive information while the child is present, (3) face-to-face assessments may be more appropriately structured to meet the child's and the family's needs, and (4) it may facilitate early access to services and care/support that is delivered by others.

***Assessment: "Contextual child and family centred assessment jointly with others, creating clear expectations and agreement on optimal courses of action"***

The second stage ("assessment") focuses on diagnosis and the assessment element of the child/families' journey. This stage has five principles.

*Principle 5: Integrating views and expertise of parents/guardians and children.* This principle was based on evidence from children's and parents' focus groups, interviews with AHPs, the qualitative element of the systematic review and national policy. Its focus was about the need to listen to parents/guardians and children in that it can help AHPs understand the kind of experiences, concerns and valuable knowledge that parents/guardians bring with them to initial assessment

sessions. The evidence strongly indicated that parents/guardians and children are knowledgeable about DCD and how it affects their lives. Further, that AHPs are critically positioned to engage with parents/guardians and children, to gather important information they can offer and to make them feel heard and understood, opening necessary channels of communication. Viewing parents/guardians and children as active contributors and providers of key information is important when developing intervention strategies.

*Principle 6: Harnessing benefits of collaborative assessment.* This principle was based on parents' views, AHPs' views, survey data and national policy. Its message concerns the fact that professionals should be mindful of negative parental perceptions of duplicated uni-professional assessments. Considering this, supporting parents/guardians and children to access professionals across health and education in an integrated manner is of key importance; it can also provide structure for integrated working throughout the patient journey. In addition to parents/guardians benefiting from collaborative working, there are also clear benefits for all professionals, including increased knowledge of others' roles and opportunities for peer support and evaluation.

*Principle 7: Making assessment practices appropriate.* This principle was based on parents' and children's views, the views of AHPs and survey data. From this evidence, it became apparent that AHPs are currently using tools to evaluate body functions (e.g., motor skills), and tend not to use tools that assess participation at home, school, or within the community. Parents/guardians and children, on the other hand, place value on successful participation in home, leisure or self-care activities. Accordingly, assessments addressing these facets of child performance may be beneficial. While not all components of assessment lend themselves to this orientation (e.g., some assessments require a clinic location), AHPs should also give consideration to conducting assessments within or with reference to different "natural" environments (e.g., school and home), addressing the child's participation in these environments. This would offer the AHP an insight into important aspects of participation as well as the opportunity to access the views of teachers and parents.

*Principle 8: Structuring the diagnostic process.* This principle was developed from parents', children's, and AHPs' views, as well as the qualitative systematic review and national policy guidance. Its focus is the diagnosis of DCD. There are multiple criteria related to the diagnosis of DCD; appraisal of these suggests that a multidisciplinary approach would ensure all criteria have been considered and fully assessed. In some cases, AHPs work alongside paediatric medical staff, helping to support the diagnostic process for children with DCD. However, in some sites this process lacks consistency and order, which may result in delays, which can be harrowing for parents/guardians. Having clear protocols for contributing to 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.

*Principle 9: Adopting an honest approach to outcomes and expectations.* This principle was derived from parents' views, the qualitative systematic review and policy. Fundamentally, it holds that acquiring an in depth understanding of parents'/guardians' and children's knowledge, understanding and expectations at the assessment stage may assist the AHP to discuss, openly, the planned therapy intervention and projected outcomes. This is important, because there is a professional consensus that DCD can be a lifelong condition. All those involved with the care of the child with DCD therefore require an awareness of this to ensure there is a shared expectation

of outcome. Open, honest communication from the earliest stages of involvement with AHP services will help to ensure parents/guardians, children and education staff have realistic expectations, and are suitably prepared for and capable of employing strategies to support the child not only at the time of discharge, but throughout their involvement with AHP services.

***Intervention: “Collaborative goal setting that embraces child, family and community contexts and supporting the child’s participation through shared expectations and responsibility within the change process”***

The third stage (“intervention”) directly addresses the content of therapy interventions for children with DCD, goal setting, engagement with parents and engagement with partner agencies, with a particular focus on education. This stage has seven principles.

*Principle 10: Putting the child and family at the centre of care when goal setting.* This principle was developed from children’s and parents’ views, survey data, qualitative and quantitative systematic review and policy. Helping children to achieve valued goals is an important element of AHP practice, and, for some, the ultimate objective of their interventions. When appropriate, making these goals functional in nature is beneficial for children with DCD. Actively involving children in this process ensures that the focus/outcome of intervention is based on the child’s view and may result in the child and family being more committed to therapy as it has relevance to their lives. Standardised tools are available that can support this process. Active involvement of parents/guardians in this process may help to make them feel heard and understood, and also allow them to provide valuable guidance on a child’s skills and abilities as well as areas of difficulty.

*Principle 11: Involving other AHPs and education staff in goal setting.* This principle was developed from children’s and parents’ views, survey data, AHPs’ views and policy. Setting goals with other AHPs and education staff ensures that there is a consistency of approach, which parents/guardians have frequently identified as important in the care of their child. If child-centred goals are shared across multiple health disciplines and education, they are likely to be more robustly addressed by all working with the child. In addition, the communication of goals within health disciplines, and with education, is likely to support more effective interaction between these groups.

*Principle 12: Enhancing participation of children with DCD.* This was the most strongly supported principle. This principle was developed from children’s and parents’ views, survey data, AHPs’ views, qualitative and quantitative systematic review and policy. Fundamentally, this principle proposes that focusing on participation (e.g., in home, school or community contexts) ensures that the emphasis is taken away from attempts to “fix” children’s coordination problems. Instead, consideration is given to the child’s engagement with their day-to-day life tasks, school, leisure and social interaction. This approach puts child and family needs at the centre of decision-making and care. It is important to note, however, that working on body functions (e.g., gait, balance, strength) or discrete activities (e.g., ball skills, jumping) may also support a child’s participation. Children also value improved performance in gross motor activities (e.g., football or rugby) involving their peers. A focus on improving skills around these areas may improve children’s sense of their competence within physical activities, encourage a life-long interest in exercise and facilitate greater engagement with peers in their community.

*Principle 13: The child is not the only focus for intervention.* This principle was developed from children's and parents' views, survey data, AHPs' views, quantitative systematic review and policy. Simply, this principle highlights the fact that the child should not always be the sole focus for intervention, recognising that modification of the physical, social or attitudinal environment of the child, through engaging with parents/guardians and teachers, and through health promotion, can provide a foundation on which to build enhanced participation. In addition, this principle includes the recommendation that explicit support of parents/guardians should be an important element of AHP practice, as they often require emotional, informational and/or practical support that AHPs are well placed to deliver.

*Principle 14: Sharing expectations and responsibilities in supporting change.* This principle was developed from parents' views, survey data, AHPs' views, quantitative systematic review and policy. These multiple sources tell us that there is a recognised need to involve the child, parents/guardians and education in any intervention and that the development of strategies for self-management, which can continue to be used on completion of therapy, should be a key focus of AHP practice. Shared goals and expectations across professions, involving parents/guardians and child, with an emphasis on self-management, may ensure that all involved feel prepared and supported to continue to implement strategies used when therapy ends. Effective communication is a fundamental component of this process, using structure and language that is accessible to all. Parents/guardians, in particular, have made clear statements as to the confusion professional jargon can cause.

*Principle 15: Valuing formalised collaboration with others.* This principle was developed from parents' views, survey data, AHPs' views and policy. Its focus is partner agencies, maintaining that engagement of these agencies, such as education, local authority and community groups in the delivery of community based intervention can provide the structure required to ensure a consistent approach to service delivery for children with DCD. Approaching service delivery strategically can also allow such initiatives to become embedded and integral within a school day, and implemented by school-based staff. AHPs may need to become increasingly aware of the need to adopt this approach to service delivery, in conjunction with partners in education, using activities that focus on engaging children in valued and meaningful activities.

*Principle 16: Using evidenced interventions to support change.* This principle is a reflection of the quantitative systematic review evidence. Findings related to this element of the study indicate that although further research is required in all areas, therapists should be aware of the current evidence base for their interventions. In terms of different therapies, the "active ingredients" of most interventions have yet to be identified. However, this does not mean they are ineffective; rather, this indicates that further work is required to identify the children most likely to benefit from intervention, and what those interventions should include. Reflection on current evidence, and integrating this into care, may contribute to the achievement of successful outcomes as well as helping to identify areas for future input.

***Discharge: "Supportive transitional pathways from specialist services to self-management within homes, schools and communities following evaluated outcomes"***

The fourth stage ('discharge') covers evaluation of outcomes, self-management and exit from services.

*Principle 17: Evaluating interventions and outcomes.* Based on child and parents' views, as well as survey data, this principle reminds AHPs that attaining personal goals and success are critical to the children and their carers. Indeed, many AHPs are already engaged in goal-setting and evaluation, a practice that places the child at the centre of care, and enables the therapist to critically review the effectiveness of interventions and outcomes observed. This process of review supports the development of clinical practice that is critically reflective and responsive to the improvements or lack of improvements observed.

*Principle 18: Providing strategies for self-management and making use of community resources.* When reviewing the parent data, AHP data and policy documents, it became clear that discharge from therapy can be a difficult and worrying time for parents/guardians of children with DCD. In light of this, and to support the move towards discharge, AHPs and other involved professionals must share their expectations of therapy with the child and carers and aim to provide (as best they can) strategies that can continue to be used by the family to support them through and beyond this stage. AHPs should endeavour to find and promote purposeful strategies, which will support the child and family in self-management. Such strategies may be implemented within the home and school or within the community.

*Principle 19: Providing clear pathways for exiting services.* This last principle was based on parents' views, policy and survey data. An awareness of the anxieties and concerns of parents/guardians around the time of discharge should assist AHPs in preparing and supporting the child and their family. If discussions around expectations, outcomes and discharge are initiated as early as possible, this would provide an opportunity for the child, parents/guardians and education to discuss needs and concerns, and ensure interventions and goals are appropriately aligned to meet the continuing needs of the child and family. Establishing and maintaining clear and open channels of communication between the child, parent/guardian and other professionals, such as education staff, to discuss their concerns prior to exiting the service could be critical at these times. Where intervention has been successful in empowering others to support the child's discharge, this may aid the success of transition out of therapy for all involved. Clearer pathways for re-referral could also alleviate anxiety around this time. A final recommendation is that discharge protocols could be used as a tool to support early discussion around expected outcomes and the discharge process.

## Discussion

As the awareness of DCD increases there has been an increase in demand for Allied Health Profession services. For example, one study identified that 61% of children waiting for assessment by an Allied Health professional were children with presumptive DCD, and that the median waiting time was 32–36 weeks (Dunford & Richards, 2003). One of the challenges in meeting the needs of these children is the review of current service delivery in order to determine whether services are focused on their needs and whether resources are being directed in the most efficient ways. An additional challenge for the development of any service is a common understanding of what constitutes best practice (Quality Improvement Scotland [QIS], 2007c). Good models of practice are usually underpinned by systematic review and clinical guidelines (National Association of Paediatric Occupational Therapists, 2000; Royal College of Speech and Language Therapists, 2005, 2006). There is now a range of such published guidelines, but these are usually derived from the literature and are thus very sensitive to the nature of that literature. There are

many gaps in the evidence base and, as a result, services commonly develop their own, more informal, guidelines reflecting custom and practice. If each service develops its own set of best practice criteria and uses its own technical language, this can make it very difficult for other professionals, those working alongside them, for parents and children, to understand the nature of the activity concerned and what to expect from their service (QIS, 2007a).

A seminal consensus statement for DCD in 1995 was produced through funding from ESRC, which involved a set of meetings with a range of professionals involved in DCD service delivery (Sugden, 2006). The statement has been pivotal in supporting a unified approach to these children nationally. This current DCD framework is viewed as an update of the consensus statement, which additionally focused on eliciting the views of children and families with DCD. Although there has been political pressure to advocate for public involvement in service delivery by seeking the service users' views (Scottish Executive, 2002b, 2005), this has been illusive in DCD services to date. A strong message articulated by children and young people during the consultation process for "Delivering a Healthy Future—An Action Framework for Children and Young People's Health in Scotland" (Scottish Executive, 2006) was that they did not feel heard and understood by services; this highlights that children should ultimately be at the centre of consultation on services and their views canvassed in a meaningful way. A framework that harnesses children and young people's voices and translating their opinions/needs has become an essential component of integrated children's services planning, ensuring that the needs of the child are at the centre of local service delivery (Scottish Executive, 2006). The child's voice resonates throughout all the principles, and specifically within Principle 5 "integrating views and expertise of parents/guardians and children", Principle 7 "making assessment practices appropriate", Principle 8 "structuring the diagnostic process", Principle 10 "putting the child and family at the centre of care when goal setting", Principle 11 "involving other AHPs and education staff in goal setting", Principle 12 "enhancing participation of children with DCD", Principle 13 "the child is not the only focus for intervention", and Principle 17 "evaluating interventions and outcomes". Parents are also essential stakeholders in the care of children with DCD. Parents' voices can be seen within Principles 2, 3, 5–15, and 17–19. It is widely recognised that participation of parents in the implementation of therapy is integral to the outcome and effectiveness of input. Parents can be, and many are, actively involved in supporting therapeutic strategies for their children, and possess valuable in-depth information about their children's skills and abilities. For example, qualitative research indicates that parents recognise motor learning difficulties in very young children with DCD or suspected DCD (Pless, Carlsson, Sundelin, & Persson, 2001; Rodger & Mandich, 2005). In many cases, parents are the first to identify their children's motor coordination problems and subsequently experience great difficulty and emotional trauma, struggling to access services to help and support their children (Mandich, Polatajko, & Rodger, 2003; Missiuna, Moll, Law, King, & King, 2006). Research has also shown that having a child with motor coordination difficulties in the family has a physical, emotional and social impact not only on the child but on the family as a whole; impacting on the lives of both parents and siblings (Stephenson, McCay, & Chesson, 1991). In line with the wider literature (e.g., Carter, 2002; Maciver, 2005), this body of work has also identified the impact of healthcare service characteristics on parents. Qualitative research, by allowing parents to describe, discuss and explain the factors that they find important, provides an evidence source to develop an understanding of the nature of living with a child with motor coordination difficulties. A framework with these insights can sensitise clinicians and other involved parties, leading to a situation where parents' motives, actions and worries are better understood; this will lead to better quality care (Maciver, 2005).

Developing an evidence-based framework that is organised around children's and families' journeys through healthcare services will allow AHPs to understand both the nature of their current practice and the scientific evidence available and will provide a powerful tool to support



effective practice (QIS, 2007a). The presence of an evidence-based framework will stimulate AHPs to complete re-designs in line with the framework's recommendations as it provides to argue for change and provide an impetus to bring about changes to improve practice (QIS, 2007b).

Principles 2, 6, 11, 13–15 and 18 illustrate the importance of the educational environment for children with DCD and follow the government philosophy of partnership working (Robinson & Cottrell, 2005). Teachers are increasingly challenged as they try and provide educational experiences for a broad range of children that will meet the unique learning needs of each child (Missiuna et al., 2006). Teachers are in tune with the unique learning needs of children with DCD and indeed, since the early 1900s, education has been aware of the existence of “able” children who experience motor coordination difficulties that affect their ability to cope with school life (Peters, Henderson, & Dookun, 2004). Children can become excluded and may employ strategies involving aggression or clowning to enter into social groupings (Evans & Roberts, 1987), causing challenges in the classroom. Teachers also observe more behavioural challenges; for example, poor concentration and disorganisation that affects participation in the class (Losse et al., 1991). However, it can go unnoticed, with some children hiding their feelings (Missiuna et al., 2006). These struggles may be misinterpreted or misunderstood by some teachers because of the disparity between the child's intelligence and their motor performance (Missiuna et al., 2006).

Schools are where students are supported to participate in developing life skills (Booth & Samdal, 1997). Full participation in school life is viewed as important to how successful the child is at learning (Finn, 1989) and increased involvement in social activities during early adulthood (Simeonsson, Carlson, Huntington, McMillian, & Brent, 2001). Children with physical difficulties can have challenges fully participating in school life (Mancinni, Coster, Trombly, & Heeren, 2000). Specifically, they avoid the playground and have less social interaction with classmates (Bouffard, Watkinson, Thompson, Dunn, & Romanow, 1996; Smyth & Anderson, 2000). Moreover, in school, sports are a public activity where peers and other team members can evaluate performance. Children can exert some control and withdraw from sports and the social opportunities it provides (Causgrove Dunn, 2000). With more boys being affected than girls (ratios up to 4:1) (Smyth, 1992), they may be at risk from emotional impacts as team sports are considered important in their masculinity (Wright, Sugden, Ng, & Tan, 1994).

With challenges in both the classroom and the playground, school may become a hostile environment for children with DCD challenges. The importance of an effective partnership with AHPs in both the identification of these challenges and in supporting the children engage with school life is critical.

The literature has identified some educational colleagues as being unsure of their specific responsibilities related to this group of children (Peters et al., 2004). AHPs are now, however, increasingly involved in delivering services in partnership with education. UNESCO's (1994) Salamanca Statement triggered a revision of services delivered to children with special educational needs (Ainscow, 1997), leading to a series of policy initiatives across the UK (Department for Education and Skills, 2004)—of which the most recent in Scotland has been the Education (Additional Support for Learning [ASL]) (Scotland) Act (2004). This Act aims to ensure that all children and young people are provided with the adequate support to facilitate their engagement in learning and, where possible, they should be included in their local school. The Education (ASL) (Scotland) Act also promotes a more integrated model of service delivery organised around the child's/young person's needs and collaborative working among all those supporting them and their families.

AHPs feed into this collaborative process of support for individual children with additional learning support needs. Although, historically, such professional groups, with their close



association with the health system, have tended to work with children outside the context of the school environment (i.e., within clinics or hospitals), this has been changing both within the NHS (Scottish Executive, 2005) and in terms of the interaction between other agencies. There remain groups of children with complex health needs who need focused attention from an individual therapist, but it is now assumed that, even for these children, best practice requires services to be delivered within the classroom (Carlin, 2005) and the playground (Wooley, Armitage, Bishop, Curtis, & Ginsborg, 2005). Inevitably such changes offer challenges, and this has led to the impetus to develop models of best practice that can be used in closer partnership with education.

Schools are also important agents in Principle 3 “increasing referring agents’ knowledge and understanding” and Principle 8 “structuring the diagnostic process”. Early diagnosis treatment and educational support are important. Failure to diagnose and address these challenges of motor impairment can have long-lasting effects (Rasmussen & Gillberg, 2000). Many children within mainstream school with coordination problems continue to find it difficult to obtain a clear diagnosis. Once a referral and assessment have been achieved, however, parents were satisfied with their intervention (Peters et al., 2004). The DCD *Diagnostic and Statistical Manual of Mental Disorders IV* criteria (American Psychiatric Association [APA], 2000) include a determination that the child’s challenges interferes with academic achievement (which could be achieved though the integration of child and parents views). Moreover, the onset is apparent in early years; however, it is not usually diagnosed before the age of five years (Zoia, Barnett, Wilson, & Hill, 2006), with 75% of children with DCD being referred during the first few years of primary school (McGovern, 1991). Some children find their way to occupational therapy and physiotherapy interventions for their movement and daily activities challenges directly from an educational source. However, most children go through long medical routes, which take longer to access the AHP intervention they required (Peters et al., 2004). Educational colleagues can be pivotal in providing a referral route for these children. However, children on the waiting list with presumed DCD may not actually have DCD.

It should be noted that diagnosis is an issue clouded by co-morbidities. DCD is associated with autism spectrum disorder (Mari, Castiello, Marks, Marraffa, & Prior, 2003), Attention Deficit Hyperactivity Disorder (Martin, Piek, & Hay, 2006), dyslexia (Ramus et al., 2003) and specific language impairments (Hill, 2001). DCD is not an isolated motor problem but is associated with affective problems; for example, anxiety (Rose, Larkin, & Berger, 1997) and lowered feelings of perceived physical efficacy (Trost et al., 1996). It is therefore a complex disorder that requires close relationships between health and education to support paediatric consultants with effective diagnosis.

## Summary

It is possible to place the child and family at the centre of an analysis that synthesises multiple evidence sources in order to develop a best practice framework. This AHP framework comprehensively covers the child and family journey through services, and highlights the importance of the allied health professions and educational partnership in supporting these children.

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## Note

1. Funder: NHS QIS. The data were therefore designed to be representative of every health board in Scotland (QIS, 2007a).

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