Developmental Co-ordination Disorder

A review of evidence and models of practice employed by
Allied Health Professionals in Scotland

Summary of Key Findings

November 2007
NHS Quality Improvement Scotland (NHS QIS) is committed to equality and diversity. We have assessed this report for likely impact on the six equality groups defined by age, disability, gender, race, religion/belief and sexual orientation. For a summary of the equality and diversity impact assessment, please see our website at: www.nhshealthquality.org/nhsqis/2018.html. The full report in electronic or paper form is available on request from the NHS QIS Equality and Diversity Officer.
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Acknowledgements

We would like to extend thanks, first and foremost, to the families and children who gave their time to this research. Their passion for sharing their views and commitment kept the research firmly grounded in the experiences of service users. This perspective pervaded the work and provided a strong user focus to the research.

This research was also supported by a hard working steering group who were active throughout - piloting survey materials, identifying literature sources, reviewing reports, identifying experts in the field, providing access to participants, and encouraging the research team to maximise this opportunity afforded by NHS QIS.

Special thanks goes to those people who gave generously of their time to meet with the research team and provide valuable support and feedback throughout this research.

We would also like to extend thanks to the wider national community of AHPs. The remarkable level of help, support and interest received indicates that Development Coordination Disorder is an area of key interest to many AHPs. Their energy and commitment to quality of care was inspiring and we hope this research will provide them with a synthesis of knowledge to support innovation in practice.

ACHIEVE Alliance
Primary research team, consultative support and research assistants

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1 Introduction to the executive summary

The Allied Health Professions (AHPs) 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 NHS Quality Improvement Scotland Practice Development Unit (NHS QIS PDU) began a process of engaging with AHPs to identify clinical improvement priorities within specific topic areas. One of the topics identified within the Children’s Services Topic Specific Group was developmental co-ordination disorder (DCD). DCD is a motor skill disorder that often becomes evident in school-aged children. Children with DCD lack the motor co-ordination necessary to perform tasks considered appropriate for their age, given normal intellectual ability and the absence of other neurological disorders. DCD was identified for further work for the following reasons:

- DCD is a common disorder. Prevalence of movement difficulties in children has been reported as high as 19%. However, two studies undertaken in the UK reported a prevalence of 5% and 8.5% respectively1.
- Children with DCD may have other difficulties, and there are co-morbidities associated with attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and speech and language impairments.
- A key method of managing DCD is through the assessment and interventions of allied health professionals (AHPs). These include podiatrists, orthoptists, orthotists, speech and language therapists, occupational therapists and physiotherapists.
- To date, no synthesised evidence (professional, service user and scientific evidence) has been available in Scotland to support therapists to understand clinically effective practice for children with DCD.

Dr Kirsty Forsyth was commissioned by NHS QIS to complete a synthesis of evidence. This document provides a synthesis of evidence, organised around children’s and families’ journeys through healthcare services, and developed into a framework, with the intent of supporting therapists deliver effective practice for children with DCD.

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1 Reported prevalence is dependant on the criteria and measures used to identify the disorder.
2 Executive Summary of findings

2.1 Objectives and methods

The objectives included:

1. identify what evidence is currently available in relation to AHP intervention in the assessment and management of DCD (researched service delivery)
2. identify current service delivery by AHPs including areas of innovation, emerging practice and where possible information on impact and outcome (current service delivery)
3. identify a criteria or framework that would indicate clinically effective practice for AHPs (synthesis of data).

These objectives were achieved through the methods below:

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<td>Evidence Perspective</td>
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<td>Service User Perspective</td>
<td>Professional Perspective</td>
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The evidence gathered through these methods came from every health board in Scotland.

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2 An ethical opinion was received from the Multi-Centre Research Ethics Committee (MREC). Approval for subject recruitment was gained from the Multi-Centre Research and Development Committee (MRAD) as well as local NHS R&D offices. Honorary contracts and enhanced Discourse Scotland checks were gained.
2.2 Overall methods: how we collected our information

Because of the complex nature of the interventions under investigation, and the multiple stakeholders associated with the care of children with DCD, a diverse range of methodologies (including qualitative and quantitative methods) were included:

- **researched service delivery**
  - the evidence perspective
    - a review of 50 quantitative studies, 10 qualitative studies and 10 key policy documents

- **current service delivery**
  - the service user perspective
    - six\(^3\) focus groups with 25 children with DCD
    - seven focus groups with 46 parents of children with DCD
  - the professional perspective
    - a national survey of 602 AHPs\(^4\) (this represents all individuals in the professions who work with children and 11% of the total AHP workforce)
    - in-depth interviews to understand innovative practice with 26\(^5\) AHPs

- **synthesis of data**
  - findings from the above data were synthesised by a multi disciplinary group of AHP researchers and practitioners through a cyclical process of immersion, thematic analysis, idea webbing and conceptual clustering.

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\(^3\) Useful insights can be gained with three or four focus groups of 6-8 people.

\(^4\) OTs, PTs, orthoptists, podiatrists and orthotists were surveyed as their professional domain reflects the DSM IV criteria for diagnosing DCD. Manager networks and the NHS QIS Allied Health Professions (AHPs) Clinical Effectiveness and Practice Development network were used to identify AHPs in these professions who work with children. The total estimate of these AHP groups working with children was 602 and 100% of this population were surveyed. This represents 11% of the total AHP workforce (602/5476). AHP will be the term used in this document and refers to AHPs who work with children.

\(^5\) Saturation of information can be achieved with 12 interviews.
2.3 Short summary of findings

a. Researched service delivery: the evidence perspective

The literature review identified three and a half thousand international articles of which 50 quantitative studies, 10 qualitative studies and 10 key policy documents meet the inclusion criteria.

- The 50 quantitative articles were mainly focused on changing motor skills of children through individual clinic based therapy, delivered by qualified healthcare professionals.
- A summary of the highest quality evidence is presented below, for a full outline of the quantitative review please see the full report document.
- Eighteen percent (9/50) of the included studies were high quality randomised controlled trials studies, which indicated:
  - perceptual motor training and sensory integration (traditionally used by occupational therapists and physiotherapists) show benefit compared to no treatment and comparable effectiveness with each other in improving motor skills. However, the unique contribution of these therapies, or the pre-eminence of either approach over the other is not clear.
  - comparing kinaesthetic training with other approaches showed comparable/greater effectiveness in improving motor skills and kinaesthetic perception/memory; however, other studies indicated no effect relative to no treatment.
  - fatty acid supplementation can improve reading, spelling and behaviour.
- Overall, the quantitative evidence is insufficient to provide firm guidelines for practice. There are forms of care which appear promising, but all current approaches to the intervention of children with DCD require further clinical trials and outcome studies.
- Of the 10 qualitative studies sixty percent (6/10) were high quality, these indicated:
  - parents’ perspectives:
    - parents value therapy that enables a child to engage in school, home or social activities. Parents have an acute awareness that their child has significant social, emotional and physical difficulties and they were able to clearly articulate their own and their child’s difficulties. However, they felt that their concerns were trivialised by health
professionals. In particular, the process of attaining a diagnosis is difficult for parents.

- children’s perspectives:
  
  - children are able to identify a range of activities that they are not competent in and can formulate therapy goals in relation to personally important aspects of performance, eg leisure, self-care and productivity.
  
  - Further rigorous qualitative research is required in this area, and should focus on parents’ and children’s experiences of healthcare and/or education. In particular, accessing children’s voices should be an integral part of future AHP research.
  
  - Ten Scottish Executive and professional policy documents from 2000 to present were reviewed and indicated:

    - services should promote a preventative approach with early intervention and clear referral pathways to improve access to care and deliver timely care. Services should be close to where people live and have a competent workforce (with an appropriate skill mix) to promote child and parent involvement. Services should collaboratively work across boundaries of different agencies in a whole systems approach through strategic planning arrangements to ensure the involvement of key stakeholders. There should be a strong focus on the inclusion of functional activities in therapy with goals based on the daily life of the child.

b. Current service delivery: the service user perspective

- Parent focus groups identified: that parents need clear routes for entry/re-entry into ‘the system’; comprehensive and timely care/support available locally; knowledgeable and skilled professionals (health and education); communication between professionals; and professionals and parents/carers that is effective, ‘care for the carers’ to support them enable their child and raising the profile of DCD within society was viewed as important.

- Children focus groups identified that children saw therapy as being an enjoyable experience, however, some children recalled that their first visit to therapy was less than agreeable; this was evident from descriptions of initial assessment sessions with some children explaining that the first sessions were embarrassing and/or upsetting. Children were able to talk with ease about personal goals or aspirations and each
child presented a range of activities important to them. Schoolwork became a particular focus when discussing areas where they required assistance.

c. Current service delivery: the professional perspective

- AHP survey had a 65% response rate. Over half of respondents stated they saw children with DCD.

The majority of AHP referrals are received from community paediatricians, GPs and school doctors with half of these being mostly appropriate. Seventy percent of AHPs did not receive referrals from parents. Assessment is primarily carried out in a hospital location, with parents present, by senior staff, using assessments focused on the child’s capacity. Joint assessment was viewed as effective practice; however, there was little consistent evidence of this happening. In ascending order of frequency, AHP professionals provide feedback to parents, children, education and other AHPs following assessment. However, some methods of feedback were viewed as effective and not pursued. AHPs most involved in the diagnostic process are OTs, physiotherapists, and orthoptists. A greater percentage of these professions felt it was important to be involved than were actually involved. AHPs carried out goal setting with children and parents all or most of the time and found it very or mostly effective. Thirty percent identified that goal setting with education staff was an effective practice, however, it was infrequently carried out.

AHP professions are focused on different aspects of the child. OTs primarily focus on engagement in daily activities, physiotherapists focused on physical stability, orthoptists focus on visual motor skills, orthotists primarily focus on gait pattern and foot position, and podiatrists primarily focus on gait analysis and feedback and footwear advice. These AHPs expect to see changes most of the time for the above interventions.

Interventions were mainly individual and hospital based. School and home environments were seen as effective treatment locations by fifteen to twenty percent of AHPs, however, they only used these locations infrequently. The most frequent skill mix for implementing individual interventions was therapists and parents; this was identified as mostly effective. In regards to the evaluation of goals, the majority of AHPs use feedback from parents and children most frequently and found this practice very or mostly effective.
AHP interview identified a range of innovations including: using children’s perceptions of therapeutic change as primary outcome measures; using specialist tools to identify child goals and greater use of community interventions focused on children engaging with physical activities with peers. Innovative engagement with parents was demonstrated by some services, eg facilitating ‘parent to parent’ support and structuring child interventions to include specific parent focused group sessions. There were also areas where collaborative opportunities were pursued by accessing non-traditional sources of funding. Some specialist services are developing in areas of orthoptics and dietetics.

d. Synthesis of data

There were two outcomes of this analysis:

1. **Five key themes of clinically effective practice.** These themes permeate the data and represent an overall synthesis of the core values inherent in the framework.

   **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 developmental co-ordination disorder. 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 and post involvement with AHP services.

2. Individual principles were developed and organised around the child/family journey to give them cogency. Accordingly, they engage with the early stages of a child’s difficulties, assessment, intervention, and finally discharge. For each principle:

- the supporting data from our research is presented;
- a key message for AHP clinicians is given;
- quotes from parents, AHPs or children are presented where appropriate;
- examples of smart working (ie actual work taking place at present) related to the principle are presented where appropriate.

These principles provide guidance for practitioners on service delivery for children with DCD and their families and represent the substantive contribution of this research to current AHP practice.
Figure 1: Data synthesis

Data to inform framework

- Researched service delivery
  - Literature review
  - Evidence perspective
- Current service delivery
  - Child focus groups
  - Parent/guardian focus groups
  - Service user perspective
- Current service delivery
  - AHP survey
  - AHP interviews
  - Professional perspective

- Policy
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Synthesis of data

- Early stages
- Assessment
- Intervention
- Discharge

- Health promotion
- Communication
- Child and parent involvement
- Working together
- Skills and knowledge

"Child journey"
<table>
<thead>
<tr>
<th>Stages of the child and family journey</th>
<th>Helping children and families in the early stages</th>
<th>Assessment</th>
<th>Intervention</th>
<th>Discharge</th>
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<tr>
<td>Developing a supportive community where initial issues are resolvable with rapid access to AHP support when required.</td>
<td>Contextual child and family centred assessment jointly with others, creating clear expectations and agreement on optimal courses of action.</td>
<td>Collaborative goal setting that embraces child, family and community contexts, and supports the child’s participation through shared expectations and responsibility within the change process.</td>
<td>Supportive transitional pathways from specialist services to self management within homes, schools and communities following evaluated outcomes.</td>
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### Partnership through shared expectations

#### Principles

- Raising awareness within the community.
- Supporting self management within homes, schools and communities.
- Increasing referring agents’ knowledge and understanding.
- Optimising pre-assessment contact.
- Integrating views and expertise of parents/guardians and children.
- Harnessing the benefits of collaborative assessment.
- Making assessment practices appropriate.
- Structuring the diagnostic process.
- Adopting an honest approach to outcomes and expectations.
- Putting the child and family at the centre of care when setting goals.
- Involving other AHP and education staff in the goal setting.
- Enhancing the participation of the child with DCD.
- The child is not the only focus of intervention.
- Sharing expectation and responsibilities in supporting change.
- Valuing formulised collaboration with others.
- Using evidence interventions that support change.
- Evaluating interventions and outcomes.
- Providing strategies for self management and making use of community resources.
- Provide clear pathways for exiting services.
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.*

- Raising awareness within the community.
- Supporting self management within homes, schools and communities.
- Increasing referring agents’ knowledge and understanding.
- Optimising pre-assessment contact.

Assessment

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

- Integrating views and expertise of parents/guardians and children.
- Harnessing benefits of collaborative assessment.
- Making assessment practices appropriate.
- Structuring the diagnostic process.
- 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.*

- Putting the child and family at the centre of care when goal setting.
- Involving other AHPs and education staff in goal setting.
- Enhancing participation of children with DCD.
- The child is not the only focus for intervention.
- Sharing expectation and responsibilities in supporting change.
- Valuing formalised collaboration with others.
- Using evidenced interventions that support change.

Discharge

*Supportive transitional pathways from specialist services to self management within homes, schools and communities following evaluated outcomes.*

- Evaluating interventions and outcomes
- Providing strategies for self management and making use of community resources.
- Providing clear pathways for exiting services.
Helping children and families in the early stages

‘I know there’s something not quite right’ [parent]
**Principle: Raising awareness of DCD within the community**

**Evidence for principle:**
Parents/guardians felt DCD was a condition not well understood within society. Related to this, parents/guardians expressed the need for all individuals working with children, eg in schools or leisure facilities, to have a basic knowledge and understanding of the condition. They expressed a desire for an increased public awareness of the difficulties experienced by their children, along with greater accessibility to advice on basic approaches that could be used to support them. Policy documents support the use of a preventative approach, and suggest the need to develop a learning culture which focuses on education, training, development and planning (at national, regional and local levels) to integrate children’s service plans.

**Key message:**
The long term emotional consequences associated with DCD, such as low self-esteem, may be shaped by the varied contacts a child experiences with others within society. With a greater awareness of DCD within our communities, there may be greater tolerance and positive action to support the child, which could alleviate some of the difficulties faced. If others had greater understanding of DCD, they may be able to make a positive impact through their interactions. Information related to the prevention of difficulties could limit the impact of the condition for the child and their family and reduce the need for professional input at a later stage.

**Exemplars of evidence:**
*A parent discussing awareness raising at a school:* ‘…one of the OTs went to school and did a whole awareness raising thing with most of the staff and that was really, really useful […] I think that how other people react to a child really influences that child’s self-esteem.’

*Some parents gave examples of teachers who demonstrated an understanding of their child’s difficulties:* ‘she [child] absolutely adores it [dancing] and we have videos of the whole chorus going to the left and she goes to the right, but she has a dancing teacher that never ever picks her up on that, who will go up to her and stroke her arm or her leg to give her the sensory feedback to say which part of the body she’s got to move.’

*Several AHPs commented on their potential role in increasing awareness, putting information out into the community, a podiatrist comments here:* ‘the other thing, probably, my profession needs to do, and haven’t done, is produce some form of health promotion material […] the main points to look for when you buy a pair of shoes.’
Evidence for principle:
Parents/guardians expressed feelings of guilt that when their child’s difficulties first became apparent, they had not recognised these or known how best to help their child. From a professional perspective, AHPs indicated that they felt they could play a greater role regarding health promotion at the pre-referral stage working with education and other health professionals. The qualitative review also highlighted the emotional strain felt by families and feelings of guilt that parents/guardians experience in the stages prior to entry into support services and/or pre-diagnosis. Policy documents support the need for a preventative approach for these children and for AHPs to become supporters of self-care and self-management.

Key message:
At the stage before any contact is made with AHPs, support for the child from parents/guardians, those in education and/or those working in health care could reduce the impact of the condition, and may lessen the need for input in the future. Providing parents/guardians with the knowledge and understanding to do this could reduce the feelings of uncertainty, guilt and helplessness that parents/guardians report, as well as reducing the strain that the whole family may experience during these early stages.

Exemplars of evidence:
Smart working – a dietetics service has been established which works directly with schools in a health promotion role: ‘A lot of the out-reach work I do tends to be going into schools […] sometimes to discuss specific children, but sometimes it’s quite often a general enquiry from the school about how they support kids with particular difficulties when it comes to diet.’

Smart working: a service has developed an internet resource, which provides easily accessible information and support for parents/guardians and health professionals involved with children with co-ordination difficulties.
**Evidence for principle:**
Parents/guardians identified that accessing AHP services could be difficult, confusing, and lacking in a clear referral pathway. At this stage, many parents/guardians felt that ‘something’ was ‘wrong’ but that these concerns were sometimes not listened to or recognised by health professionals or education staff, leading to a delay in their child accessing help. Parents/guardians explained that some professionals appeared to lack awareness of possible signs of DCD, or knowledge about who could provide further advice and guidance. This left parents/guardians feeling anxious, confused, alone and unsupported. They felt that all professionals working with children should have an awareness of DCD, and have sufficient knowledge regarding management to direct them to a relevant professional for further guidance. From the survey, most AHP services accept referrals from other health professions but only a few accept referrals directly from parents or education. The majority of referrals are received from community paediatricians, GPs and school doctors with half of these being ‘mostly appropriate’. AHPs found referrals from other AHPs ‘very appropriate’; however, referrals from this source were less frequent. The qualitative review supports the findings from the parents/guardians focus groups with regard to the difficulties expressed, and that parents/guardians are aware that their child is not developing normally and may experience a lack of support from health or education in the early stages. Policy documents support the need for early intervention and clear referral pathways to improve the ease of access to care. They place a heavy emphasis on listening to parents/guardians and children when designing and delivering services.

**Key message:**
Early identification of difficulties and referral to appropriate services would help to ensure difficulties are addressed as and when they arise, reducing the potential social, emotional and physical consequences of the condition. An increased awareness of professional roles would enable appropriate and timely referrals to be made, and professionals should recognise that parents/guardians are often knowledgeable about their child’s difficulties. Parents and guardians however, cannot currently self refer to the majority of services.

**Exemplars of evidence:**
*A parent discusses their early experiences: ‘…if you [health professional] listen, because the parent knows. I think what we’ve experienced is that our suspicions and our concerns have been proved right. And if they had listened and given a little bit more consideration instead of just giving lip service you know, we could have been further down the road than we are.’*

*Smart working: in one location, health, education and social work teams, in partnership with parents, have developed a regional resource folder with guidelines for the management of children with DCD. It is used as a reference for parents, professionals and voluntary groups and provides information on DCD as a condition, the numerous issues involved and the role of different interagency team members.*

*An orthoptist discusses the importance of raising awareness of their role to others to facilitate referral to the right people at the right time: “…and just raising the profile as well, educationally to say, “these children are having specific problems”. I would like to somehow to get involved with training of, teacher training [teaching them]; “these are things I would look for, are quite specific, are quite obvious and this is how you get these kids to us for assessment”.*
Evidence for principle:
AHPs indicated that gathering information about the child and family in a pre-assessment phase afforded them the opportunity to gather sensitive information prior to the parent/guardian attending with their child. Some AHPs gathered this kind of information via telephone interview. Professionals reported that this pre-assessment contact with parents/guardians allowed them the opportunity to help structure the assessment around the child’s needs. In addition, some therapists made use of a paper-based checklist (ie the movement ABC checklist) which was completed by staff at an education site. This type of information was used to provide an opportunity to identify children who could benefit from community based intervention prior to any further therapy services involvement. The survey indicated that occupational therapists were most likely to gather information prior to face-to-face assessment, often from school and home sites. Physiotherapists and orthoptists were the professionals that predominantly gathered verbal information from schools. Very few professionals were making use of early diagnostic tools (eg the DCD questionnaire).

Key message:
Gathering information and making contact with parents/guardians during the phase prior to face-to-face contact may be beneficial for a number of reasons: (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.

Exemplars of evidence:
An occupational therapist discusses the benefits of pre-assessment contact: ‘...we can try and get information before we actually see the child and we try and tailor our assessments much more now because we are having a conversation with the parent pre-assessment…I think staff feel already engaged with the parent by the time they attend […] for the child it is less intimidating as long conversations with parents on the day are avoided.’

Smart working: an occupational therapist working within a remote and rural community used the movement ABC checklist to help identify children within remote areas who had movement difficulties. These children were then offered access to education based motor skills sessions. This proactive assessment of children referred to the occupational therapist enabled the AHP to engage with current educational legislation and work with partner agencies to provide school-based intervention prior to any AHP involvement.
Assessment

“The first time [I came to therapy], I felt a wee bit embarrassed…” [child]
Evidence for principle:

From the parents'/guardians’ narratives, the stage prior to referral was an emotionally challenging time. They had often waited for lengthy periods during which they experienced feelings of guilt, uncertainty, confusion, anxiety and frustration. They were also concerned about the impact of perceived delays upon their child. Parents/guardians are also keen observers of their child’s difficulties, a finding which is supported in much of the qualitative literature. Some parents/guardians wanted a diagnosis for their child, as they viewed it as something which may enable them to gather more information about the condition and was perceived, by some, to be an important tool in accessing support and understanding from education and other professionals. Children were able to talk about the activities and skills at which they would like to get better, and explain the range of things with which they still needed help. Parents and guardians reported that they valued those AHPs and other professionals who appeared to tailor care and support distinctly, to support the individual needs of the child and family. From a professional perspective, AHPs interviewed indicated that assessment could provide a useful means of gathering the children’s and parents'/guardians’ views. Many highlighted the importance of listening to the parent or guardian, as a means of gathering vital information as well as being the first step to engaging them in supporting the child. Policy documents support the importance of listening to parents/guardians/children and the duty health care professionals have to be alert to the needs of the child.

Key message:

National policy gives guidance about the need to listen to parents/guardians and children. The evidence presented here is important 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. Parents/guardians and children are knowledgeable about DCD and how it affects their lives. Allied health professionals 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.

Exemplars of evidence:

A parent discusses the difficult feelings associated with gaining a diagnosis: ‘from the minute you know something’s wrong till you finally get a diagnosis you go through this most harrowing, awful experience in which you reduce yourself to nothing; to this worthless, neurotic, terrible parent.’

Smart working: an occupational therapist discussing the importance of listening to parents: ‘I think its listening to parents, and appreciating what to them are the fundamental issues and most important to them, they are key to understanding what the main issues are. I suppose I see them as much as clients as the children.’
Principle: Harnessing benefits of collaborative assessment

Evidence for principle:
Parents and guardians expressed a clear desire to have an integrated approach to the care of their child. They were able to give examples of what they perceived to be good and bad practice in terms of cooperation and joint working regarding assessment. Frustration was experienced by some as a consequence of repeated questioning or assessment of their child; this was associated with an assumption that there was insufficient information sharing and collaboration between professionals. Parents/guardians reported that this wasted time and raised their concern that professionals were not working in a united way to support their child. From a professional perspective, AHPs made repeated reference to the value of joint assessment and sharing knowledge and expertise, in particular with other AHP colleagues. They suggested the child and parent/family avoided repeated visits for assessment and would be able to observe a collaborative approach to assessment. In addition to this, AHPs were able to share skills/knowledge and work together to enhance the care of the child. The findings from the survey highlight that for many AHPs working collaboratively at the assessment stage remains an aspiration rather than a reality. Where joint assessment was carried out (and this was rated as: ‘infrequent’) AHPs indicated that joint assessments were carried out alongside occupational therapists and perceived this to be ‘very effective.’ Joint assessments with occupational therapists and physiotherapists; physiotherapists and orthotists; podiatrists and physiotherapists and orthoptists and ophthalmologists were all viewed as ‘effective,’ although they were only conducted ‘some of the time’ or ‘none of the time.’ Policy documents support the need to develop integrated approaches to service delivery between local authorities and NHS Scotland, collaboratively working across boundaries of different agencies in a whole systems approach.

Key message:
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 benefitting from collaborative working, there are clear benefits for all professionals, including increased knowledge of others’ roles and opportunities for peer support and evaluation.

Exemplars of evidence:
A physiotherapist describes the benefits of assessing children with an occupational therapist: ‘…the therapists can chat amongst ourselves and decide what we think the problems are and where we think we should go with these problems. They [the children] are actually probably getting a better assessment because we have got that peer review, that peer support there. Then we also feel that their treatment now is much more tailored to their actual needs, rather than receiving two different types of treatment.’

Smart working: occupational therapists and physiotherapists have piloted a change to service delivery where children with DCD and co-ordination difficulties are assessed by both professionals. As part of this process, occupational therapists and physiotherapists were involved in gathering and sharing information from parents/guardians through home visits and assessments were carried out in a variety of community based locations. Once children’s needs were identified, collaborative work with education meant children were included in school based intervention carried out by trained education staff.
Evidence for principle:
Parents/guardians value improvement in the child’s active engagement with age-appropriate participatory activities, eg playing on bikes with peers. They reported in focus groups that this was important as they observed the child’s self-confidence and general well-being to improve as a consequence of such developments. Children reported in focus groups that they wanted to improve in skills and activities which related to participating in play with others, eg being able to play basketball better. From a professional perspective, collectively, assessment tools used by AHPs primarily address issues of body functions. In contrast, there is little use of assessments which address issues around the child’s active and successful participation in meaningful and valued activities at home, school or in the community. Also, some professionals felt there was a need to move away from the hospital setting for assessment, although it was recognised that there were advantages when using standardised measures to being in a clinical setting. Survey data supports these findings. Firstly, most professions (excluding OTs and orthoptists) used non-standardised assessment tools, and very few used tools that assess the engagement of the child in their home, school or community environments. Secondly, AHPs appear to carry out the majority of assessments in hospital based locations. The next most frequently used location for assessment was school. This latter finding varied between professions with a higher incidence of assessments being carried out in schools by some professions (eg physiotherapists, occupational therapists) and rarely being carried out by others (eg orthoptists, orthotists and podiatrists).

Key message:
From the evidence gathered, AHPs are currently using tools to evaluate body functions, and tend not to use tools which 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 (for example, some assessments require a clinic location) AHPs should also give consideration to conducting assessments within or with reference to different ‘natural’ environments, (eg 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.

Exemplars of evidence:
A parent gives their view on the optimal place for child assessment: ‘I think the assessment could be more user friendly because these children are usually in their school or playgroup where you can watch them at play seeing as many things as you can.’

The quotations below from two different therapists highlight the arguments related to having assessments in the right place for the child and in relation to the assessment: ‘…it’s wrong to try and medicalise these children too much and bring them into hospitals, ’cause quite often they’re taking a whole day out of school for a one hour appointment.’

‘Sometimes they occur in schools, if logistically it’s going to work better to do it in a school […] but it’s better […] if they can come to us at the clinic […] because with access to the equipment and you’ve got some control of your time from a standardised assessment point of view.’
Evidence for principle:
During AHP interviews, participants discussed the complexities of diagnosis and the possible benefits of using a structured multidisciplinary process to assist professionals. Some AHPs were able to describe such collaborative practice with medical colleagues that enabled a uniform approach when moving towards a diagnosis. The development of diagnostic protocols was perceived positively as a tool that could ensure a cross boundary approach towards gathering evidence required during this process. The survey indicated that community paediatricians were the professional group most frequently involved in the diagnosis of DCD. Of the AHPs surveyed, occupational therapists were the most frequently involved AHP group in the diagnostic process, with others being involved less frequently. The majority of AHP departments did not have a recognised protocol for supporting diagnostic process. Evidence from the parent/guardian focus groups and qualitative review would suggest that the period before and during diagnosis can be difficult and stressful.

Key message:
There are multiple component parts related to the diagnosis of DCD, as listed in the DSM-IV criteria. 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 colleagues, 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.

Exemplars of evidence:
An occupational therapist talks about her concerns about the lack of a systematic approach to diagnosis for children with DCD: ‘I just feel that developmental co-ordination disorder or co-ordination difficulties children “float about”. I think they go from one professional to another and I think it depends on your luck on who you get if something is going to happen [...] I just think, [if] you get an OT who thinks you have DCD, you can get checked out by the doctor and the doctor will confirm that, or the doctor will say, “yeah, they’ve got it”, but there’s no multi-disciplinary assessment in this area. I can’t speak for anyone else, but I feel it’s really missing.’

Another occupational therapist reports on the diagnostic process in which they are involved: ‘The occupational therapists come together, have a discussion about what they’ve seen and done [...] once they’ve done their assessments, they maybe chat to the parent, they maybe chat to the school again, then for the third appointment they’ll bring in the doctor, who does his neural examination, and at that point the diagnosis is made. So, on the third appointment we would look at making a diagnosis. There are some children [for whom] a diagnosis won’t be made […] and we would make a decision to do a bit more assessment.’
**Principle: Adopting an honest approach to outcomes and expectations**

**Evidence for principle:**
Parents/guardians were clear that they highly valued AHPs who were open and honest regarding the future for their child. They felt that, at times, therapists were not completely open in presenting their views of the child’s likely progress or the challenges ahead. When asked about discharge, parents/guardians reported that they found discharge from AHP services difficult and upsetting, often being perceived as an abrupt ending, leaving parents feeling alone and without support. The review of the qualitative literature draws attention to the uncertainty and anxiety that parents and guardians report during the initial stages of caring for their child, when they have no access or support from services. These may be feelings that return with the approach of discharge. Policy documents support AHP practice in enabling the self management of conditions which are long term.

**Key message:**
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. There is professional consensus that DCD can be a lifelong condition. All those involved with the care of the child with DCD 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, education and others 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.

**Exemplars of evidence:**
A parent talks about the moment when she confronts a healthcare professional about the longer term outcomes of therapy, she has to take a direct approach to getting an answer ‘I even got to the point where I had to say “are you actually going to cure it, or are you just going to help it?” And he said, “Oh no, no, we’re just helping it along.” And I thought, “Oh, what a fundamental thing that I should have known”.

A parent explains that they felt the need to know, even roughly, how things were likely to progress or not: ‘I know it’s a fine line that you walk between “it won’t” or “it will”, but I think you do need to know the parameters of what you’re looking at. That, you know, you’re not failing parents, they [the child] may never eat neatly.’
Intervention

‘Therapy is fun!’ [child]

Standing on the Platform
Evidence for principle:
During the parent focus groups, participants had a clear view of their child’s strengths and difficulties, and felt well placed to provide input to professionals on important goals for their child. Children were able to demonstrate a clear ability, using basic language and drawing, to articulate skills that they aspired to develop, and tasks within the home and school with which they needed help. Difficulties in school were often the primary focus of their discussion, although children often aspired to improve in valued leisure activities such as football, karate or rugby. Children were also able to reflect on and imagine success, expressing how it must ‘feel’ to achieve a particular goal or ambition. From a professional perspective, AHPs also indicated that setting goals with the child and family was a valuable activity. Findings from the survey indicated that AHPs carry out goal setting with children and parents/guardians, ‘all or most of the time.’ Occupational therapists were the only profession who reported using standardised tools to assist with this process. Considering the qualitative review, this literature also describes children as having a definite awareness and opinion regarding their own skills and abilities, and that parents/guardians are key stakeholders in understanding a child’s difficulties. Considering the quantitative review, although use of child-centred outcome measures is not common, some evidence of efficacy of AHP intervention is available regarding improvements in child self-selected goals. Policy documents advocate listening to the child’s wishes, enabling them to choose priorities, establish targets for success and engage them in monitoring their own progress.

Key message:
Helping children to achieve valued goals is an important element of AHP practice, and for some, the ultimate objective of their interventions. When appropriate, considering the nature of the AHPs’ practice, 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 which 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.

Exemplars of evidence:
An occupational therapist talks about the usefulness of having the child set their own goals: ‘I think what I found really quite helpful, is actually having the children setting their goals. Especially when they come in the groups; I use it as a means of focussing them. Some may be coming for a few weeks and it’s good just to re-focus them back, “This is the reason you’re coming and you wanted to get better at going on your bike.” Kind of re-focus them and re-integrate them into why they’re actually coming. I think that’s really good, children setting their goals.’

Smart working: in one location, therapists are using a child-focused reflective tool as a therapy outcome measure. They measure the child’s perception of their abilities before and after intervention and use the child’s perception of change to formally judge if therapy was effective for that child; this leads to the focus and outcome of intervention being based on the child's view.
Principle: Involving other AHPs and education staff in goal setting

Evidence for principle:
Children clearly articulated the importance of personal educational goals (eg improving reading, writing and spelling). Parents and guardians consistently highlighted that they wanted quality, comprehensive health care services (medical care and therapies) and supporting education-based care provided locally. They gave examples of good and bad practice in terms of co-operation and joint working involving education and health sector based professionals. They also reported that where there were good lines of communication and shared child-centred goals between the educational and health sites, then care was more effective. From a professional perspective, interview respondents indicated the importance of setting goals with education staff and other AHPs; although survey findings indicate only half the AHPs carried out goal setting with education staff ‘some of the time’ and found this process ‘mostly effective.’ Policy documents suggest interventions should include activities that are functional and that goals should be based on the daily life of the child.

Key message:
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, and across to education, is likely to support more effective interaction between these groups.

Exemplars of evidence:
An orthoptist discussing future plans for greater collaborative goal setting: ‘… some kind of getting together with all the therapists to lay down one goal for this child to work towards, or one report, so we know where we’re going with that person, that the teachers will understand and everyone else involved.’
Principle: Enhancing participation of children with DCD

Evidence for principle:
Children identify the need for help with curricular activities (e.g., writing) and their ‘muscles’ and ‘balance’, however, the focal point of children’s aspirations for improving skills centred on activities at a participation level, and on gross motor activities (e.g., rugby, football, karate) that facilitated engagement with their peers. In addition, parents and guardians do not identify motor co-ordination difficulties as their primary concern. Instead, they want to see their child improve at home (e.g., dressing, using cutlery), school (e.g., keeping up academically with peers, concentrating in class) and leisure activities (e.g., riding a bike, swimming) along with greater social inclusion (e.g., having friends, being accepted by peers). They also valued their child’s sense of confidence, self-esteem, and general perceived ‘happiness’. From a professional perspective, AHPs focus on a number of different issues, with different professional groups having a different emphasis in their intervention approach. Survey findings also indicate this. Considering the qualitative review, parents/guardians and children value therapy input that enables a child to engage in school, home, or social activities. Considering the quantitative review, although the evidence is sparse, there are some findings which indicate that improved participation is a potential outcome of AHP intervention. Policy documents suggest in addition to improving motor skills, school and leisure based activities, that AHPs should also aim to improve other attributes such as self-esteem and confidence.

Key message:
Focussing on participation ensures that the emphasis is taken away from attempts to ‘fix’ children’s co-ordination 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.

Exemplars of evidence:
A child discusses how he would feel if he achieved his goal of scoring a try at rugby: ‘How would you feel if you scored a try?’ [moderator] ‘There was this thing on the radio, you phone up and you can get a fanfare for the first time you’ve done something in your life!’ [Child]

The focus group moderator and child discuss the moment when the child could successfully tie his own shoe-laces: ‘How did that make you feel?’ [moderator] ‘Kind of nice […] ’cos when I couldn’t do it I needed other people to help me, and by the time there was me with two other boys I could tie my shoe laces’ [child] ‘how did that make you feel?’ [moderator] ‘Excited!’ [child].

Smart working: in one location, an occupational therapist and a physiotherapist, working with a cycle coach and local authority staff, supported children to gain experiences of success by teaching them to ride a bike alongside peers in the community. These children entered the group with no or very poor bike skills. At the end of the group, all were able to ride bikes. In addition, children cited examples of having more opportunities to cycle with friends, and parents/guardians provided positive feedback about their children succeeding where they had previously failed.
Evidence for principle:
Parents/guardians valued those professionals (eg AHPs, teachers and support workers) who appeared to be genuinely interested in the child’s welfare and sought to tailor care/support/advice in ways which effectively supported the child and family. This ‘genuine’ interest in the child appeared to be linked to parents/guardians perceiving the professional to be focussing upon the child’s/family’s needs and having a positive attitude towards the child and the child’s care. In addition, parents/guardians valued being empowered by AHPs to support their children in the best possible manner. From a professional perspective, AHPs demonstrated knowledge of why parents/guardians required support, and how to support them; they also appreciated the important role parents/guardians played in supporting the child. Similarly, AHPs recognised the importance of working with teachers, providing guidance and education where necessary. Lastly, some AHPs discussed their role in terms of general health promotion, focusing not on individual children, but on groups of children and their environments. Survey findings indicate that although some AHPs are working in a service delivery model which encompasses a range of the elements described above, most still provide individual interventions to children as their primary focus. Considering the quantitative review, research has shown that parents, teachers and support staff have an important role to play in providing services and can provide direct services to children under the supervision of therapists. Policy supports innovative cross boundary approaches to AHP involvement in health promotion, assessment and intervention.

Key message:
The child should not always be the sole focus for intervention. It is recognised 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, explicit support of parents/guardians is an important element of AHP practice, as they often require emotional, informational and/or practical support which AHPs are well placed to deliver.

Exemplars of evidence:
A speech and language therapist discusses strategies to involve parents: ‘…usually we engage the parent in whatever we’re doing and encourage them to take it on board, rather as role-modelling, we’ll get them to think of ideas as well.’

‘An orthoptist discussing her role in working with parents/guardians and teachers: ‘sometimes parents need a suggestion of “take them to karate”, or “teach them to swim” just these kind of things that […] the parents are so overwhelmed by the problems that their kids have, that they don’t think of these.

A dietician describes the importance of parents for helping children with DCD, and the importance of supporting and engaging parents: ‘when it comes to diet the most effective thing for children with DCD is that the parents actually feel better informed and more confident. And, so what I am saying is actually the broad range of psychological benefits for the family having mulled around these things for ages, being told by half, “do nothing”, by the other half, “do everything”, and being made to feel guilty for either option, at last having somebody that they can discuss it with, that’s somewhere between the two, I genuinely think has major psychological benefits for the family that allow them just to get on with things.’
Evidence for principle:
Parents/guardians want to be involved in their child’s management, and make effective contributions to their care. However, this is at times blocked by ineffective communication, with failure to provide sufficient information on the child’s management and/or outcomes. The use of professional jargon left parents/guardians feeling confused and distanced from the management of the child. Lack of communication between professionals resulted in a disjointed provision of support. The need to involve parents/guardians and education was a strong theme from the AHP interviews with an identified need to shape parents/guardians expectations of their responsibilities and the expected outcomes of intervention. Professional terminology/jargon was also recognised as a barrier to effective communication with parents/guardians. Survey findings highlight that feedback to parents/guardians and other professionals from AHPs is commonplace, and therefore an important consideration. There is emerging evidence from the quantitative review that parents/guardians and education staff can be effective in the delivery of some interventions. Involving parents/guardians and children in delivering care and developing strategies for self management is supported by policy documents. Policy also endorses interagency working and the inclusion of education in a whole systems approach to the management of the child.

Key message:
There is a recognised need to involve the child, parents/guardians and education in any intervention. 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.

Exemplars of evidence:
A parent explains how difficult it can be to make sense of some communications from health professionals: ‘the report came forward on that assessment, I did not find [it] user friendly at all either. It was […] you know, there was an appendix at the back that was all of these formal assessments and it wasn’t […] that wasn’t meaningful to me and I don’t think it would be meaningful to a lot of people.’

A parent talks about what they observe happening at school, in terms of support, and how things can appear to ‘break down’ from one year to the next: ‘and I think you get things set up in school and then it comes to end of term and it all falls apart again. That’s what I’ve found. You have to keep going back to school.’

Smart working: in one location, therapists have set up a carers clinic where at the first session of a block of group therapy parents/guardians are involved in viewing their child participating in activities. The therapists will use this as a method to engage parents/guardians in the intervention process and as a way to aid communication about what they are doing and why.
Principle: Valuing formalised collaboration with others

Evidence for principle:
Parents/guardians perceived the care of their child to require a team approach and believed that where good lines of communication, child-centred goals and shared expectations were developed between education and health, care would be more effective. From a professional perspective, AHPs were able to highlight examples of effective collaborative working with partner agencies to deliver interventions based within community locations. They emphasised a need to develop regional and strategic approaches to the management of DCD with formal collaboration between multiple agencies across local authorities. In providing and delivering, for example, motor based interventions alongside education a strategic level approach was considered more effective than engaging with individual schools. Although there were many examples of intervention being delivered within local communities few were structured in such a way as to engage formally with the local authorities concerned. Policy recommends that strategic planning arrangements are established to ensure the involvement of key stakeholders and effective and efficient delivery of services by therapists.

Key message:
Engaging partner 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 allow such initiatives to become embedded and integral within a school day, and implemented by school based staff. Allied health professionals 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.

Exemplars of evidence:
A physical education specialist describes the strategic, regional route they took to setting up support in schools: ‘it’s amazing, I think, through all of the various different background contexts, it’s amazing how many different regions and schools and clusters of schools have something […] small motor programmes […] however, they were going about it in the opposite direction from where we were, in regards that they were starting very much from occupational therapy and physiotherapy and then trying to go in through each individual school. Whereas we were going the opposite way. It was coming from the region itself. And I think that’s [the later] always going to be a far more successful route.’

An occupational therapist describes, as an authority wide initiative, training for staff to run motor interventions based in schools: ‘we ran one training morning for the learning assistants on kind of DCD and difficulties that these children have and why, what we were going to do to help them, and then we did individual, one hour sessions with the assistants who were running the groups, and went through the programme, so they knew how the programme ran. And then after that, they get weekly visits from ourselves.’
Principle: Using evidenced interventions to support change

Evidence for principle:
High quality randomised control trials have indicated that (1) sensory integration and perceptual motor training (traditionally used by occupational therapists and physiotherapists) are more effective than no treatment, but no more effective than each other at improving motor skills (2) that fatty acid supplementation can improve reading, spelling and behaviour and (3) that kinaesthetic training shows comparable/greater effectiveness in improving motor skills, kinaesthetic perception and kinaesthetic memory in some studies; but in other studies shows no effect relative to no treatment. More recently developed interventions, eg task specific approaches or CO-OP (a goal orientated, problem solving approach which teaches children cognitive strategies to deal with motor problems) have yet to robustly demonstrate their efficacy. Due to the small number of studies using suitable outcome measures, there is limited evidence to support or disprove the value of any intervention in terms of a child’s wider participation (eg self-care, leisure, play and school work). Due to a lack of quality research, the effectiveness of orthoptic and podiatric interventions for children with DCD is uncertain. Overall, the quantitative evidence is insufficient to provide firm guidelines for practice. There are forms of care which appear promising, but all current approaches to the rehabilitation of children with DCD require further clinical trials and outcome studies.

Key message:
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.

Exemplars of evidence:
A therapist described a journal club, which routinely met to review literature and reflect on how this would change their current practice and protocols. ‘it is good to get together and have support to review literature […] it can be hard going if you are doing it on your own […] we all want to be evidence based and it is helpful to have summaries of evidence available to pull from.’
Discharge

‘...and it was like “Right, we’ll you see you at Primary 7!”’

[parent]
Evidence for principle:
Children were able to reflect upon times when they had experienced success and recall the feelings associated with that. It was notable that children had strong positive feelings associated with times of achievement and that they were able to talk extensively about goals they aspired to achieve in the future. Parents and guardians also talked about the importance of their child achieving personal goals. In relation to goal setting, more than half of the AHPs surveyed set goals. Parents were commonly involved in goal setting and when evaluating these, the majority of AHPs again involved parents/guardians and children. That said, 65% of AHPs did not have established protocols/frameworks for follow-up or review. Policy guidance for the care of children with DCD supports interventions that are relevant to the needs of the child and family and those that are evidence based.

Key message:
Attaining personal goals and success are critical to the child and their carers. Many allied health professionals are already engaged in goal setting and evaluation, a practice which 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.

Exemplars of evidence:
*An occupational therapist talks about the importance of focusing upon effective clinical practice and talks about her desire to see more research to support this: ‘If it was me […] I would be taking much more time to research the impact of intervention and make sure we were developing good, occupation focused outcomes and measures and make sure, in an ideal world,[interventions] come down to the kinds of children that we are really effective at working with […] because I think that’s there and we probably should be making sure that we focus on interventions that […] and change [we need to] just put our focus on what we do best.’*
Principle: Providing strategies for self management and making use of community resources

Evidence for principle:
Parents/guardians identified that discharge can be a challenging time, associated with ongoing concerns about the future for their child. They valued having strategies to support the child, which they were able to continue implementing when therapy contact ceased. These strategies could involve activities or approaches which could be implemented within the home, school or the community setting. Interviewed allied health professionals reported that they valued having approaches to support the child, which could be continued with ease and incorporated into daily life, both at home, in the school and within the community on completion of therapy. Policy documents support the promotion of self management of conditions and involving the child, parent and other agencies in the provision of care.

Key message:
Discharge from therapy can be a difficult and worrying time for parents/guardians of children with DCD. 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 which can continue to be used by the family to support them through and beyond this stage. Allied health professionals 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.

Exemplars of evidence:
The quotation below is from a parent who is explaining the benefits of taking her child to kick-boxing classes – these were recommended by a therapist: ‘That’s why I go to kickboxing because it’s exercise […] and it works for them all [the children]. They’re going to have fun. Plus they’re getting the added bonus of doing all these exercises. They don’t even relate to [therapy] […] it’s kick boxing and it’s fun and they’re doing all these exercises that’s great for them, you know for muscle tone, everything’.
**Principle: Providing clear pathways for exiting services**

**Evidence for principle:**
Parents/guardians reported apprehension and worry in relation to the future life for their child and voiced concern regarding discharge from therapy. Some services offered continued support via a telephone contact, and parents/guardians appeared to value this opportunity, finding this reassuring around the time of discharge. From the survey it was noted that the majority of AHPs do not have a protocol for discharge.

**Key message:**
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. Discharge protocols could be used as a tool to support early discussion around expected outcomes and the discharge process.

**Exemplars of evidence:**
*A parent describes worrying about their child’s future:* ‘that’s where my worry is as well. My daughter’s at the high school and you’re thinking “How are you going to cope with that?” I don’t even want [name] to walk up to the school, let alone go to the school.’

*A parent talks about her experience of discharge:* ‘they have discharged [child’s name] but said if ever there’s any problem or we need to talk to them […] and we did. A teacher at the end of last year […] she had a really good teacher who thought she could foresee problems arising and so we contacted the OT department and they’ve seen her and reassessed her and you know, they’ve been fantastic to us […] for us.’
Improving the quality of DCD service delivery: a framework

Early stages
- Raising awareness of DCD in communities
- Supporting self management within homes, schools and communities
- Increasing referring agents' knowledge and understanding
- Optimising pre assessment contact

Assessment
- Structuring the diagnosis process
- Integrating views and expertise of parents/guardians and children
- Harnessing the benefits of collaborative assessment
- Making assessment practices appropriate

Intervention
- Putting the child and family at the centre of care when goal setting
- Enhancing participation of children with DCD
- Valuing formalised collaboration with others
- Sharing expectations and responsibly in supporting change
- Using evidenced interventions that support change
- The child is not the only focus of intervention

Discharge
- Providing strategies for self management and making use of community resources
- Evaluating interventions and outcomes

Communication
- Health promotion
- Child and parent involvement
- Working together
- Skills & knowledge

Improving the participation of children with DCD
- Providing strategies for self management and making use of community resources
- Evaluating interventions and outcomes
- Clear pathways for exiting services

Health promotion
- Communication
- Child and parent involvement
- Working together
- Skills & knowledge

Improving the quality of DCD service delivery: a framework

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Developmental co-ordination disorder
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- in large print
- on audio tape or CD
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- in community languages.

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