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Adaptation and extension of the European recommendations (EACD) on Developmental Coordination Disorder (DCD) for the UK context.

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Abstract

Background. Developmental Coordination Disorder (DCD) affects the learning and performance of everyday motor skills. It commonly co-occurs with other developmental disorders and a range of associated psycho-social impairments. Recent evidence-based guidelines on diagnosis, assessment and intervention provide valuable information for practitioners. However these are directed primarily at German-speaking countries and focus on work with children.

Aim. The aim of this project was to consider the application of these guidelines in the UK and to extend them for use with adults with DCD.

Methods. Individuals with DCD, parents and professionals from a wide range of disciplines were invited to two workshops to discuss and debate the guidelines, to adapt them for the UK and produce dissemination materials.

Results. A working definition of DCD was agreed, minor revisions were made to the guidelines to reflect the UK context, an extension for adults was compiled and a series of leaflets was produced to disseminate this information to health and education professionals, parents and employers.

Conclusions. This work will raise awareness of the condition across different professional groups. It provides information to help those working with children and adults with DCD in the UK to assist in the process of diagnosis, assessment and intervention.

Key words: DCD, diagnosis, assessment, intervention, guidelines, consensus statement

Introduction

Developmental Coordination Disorder (DCD) is a condition characterised by significant difficulty in the acquisition and performance of a range of fine and/or gross motor activities. This affects everyday life skills and participation at home, in leisure and in education and/or employment (Kirby, Edwards, & Sugden, 2011; Poulsen, Ziviani, & Cuskelly, 2007). Children with DCD typically present with difficulties with self-care (e.g. toileting, washing, dressing), handwriting, riding a bike, catching a ball and playing games and sports as well as other educational and recreational activities (Dunford, Missiuna, Street, & Sibert, 2005; Geuze, 2007). These motor difficulties are usually recognised in early childhood and occur in the absence of a general medical condition, intellectual, sensory or neurological impairment.

In the past children with DCD have been referred to as ‘clumsy’ (APA, 1987; Henderson, 1977) or ‘physically awkward’ (Wall, McClements, Bouffard, Findlay, & Taylor, 1985), emphasizing the behavioural features of this condition. Indeed they tend to take longer to learn motor skills and motor performance is often slow, awkward and inaccurate (Missiuna, 1994; Wilmut, Byrne, & Barnett, 2013). The term ‘developmental dyspraxia’ is also sometimes used (Steinman, Mostofsky, & Denckla, 2010; WHO, 1992, 1993), although it is often unclear whether this actually refers to the same diagnostic category (Henderson & Barnett, 1998). Sometimes it is used interchangeably with the term DCD but it can have different connotations for different professionals, leading to confusion and miscommunication. To aid consistency and make clear reference to the formal diagnostic criteria, DCD remains the preferred term. This has been the recommendation in international consensus statements and formal diagnostic manuals (APA, 2000, 2013; Sugden, 2006).

In addition to the motor difficulties, a considerable body of research demonstrates common co-occurrence with other developmental disorders such as Dyslexia/Reading Disorder, Attention Deficit Hyperactivity Disorder, Specific Language Impairment and Autism Spectrum Disorder (Dewey, Kaplan, Crawford, & Wilson, 2002; Hill, 2001; Kaplan, Wilson, Dewey, & Crawford, 1998; Piek & Dyck, 2004) and a range of associated non-motor difficulties. These include social and emotional difficulties which can also have serious negative impacts on daily life and have been recognised from a young age (Piek, Bradbury, Elsley, & Tate, 2008). For example, children with DCD have been reported to have a low self concept (Poulsen, Johnson, & Ziviani, 2011), high levels of anxiety (Pratt & Hill, 2011) and difficulty maintaining friendships (Piek, Barrett, Allen, Jones, & Louise, 2005) compared to their age peers without motor difficulties. Some reports also indicate a higher incidence of more serious psychological and psychiatric disorders (Cantell & Kooistra, 2002; Cantell & Kooistra, 2002; Green, Baird, & Sugden, 2006; Lingam et al., 2012) extending into adult life (Hill & Brown, 2013; Kirby, Williams, Thomas, & Hill, 2013).

DCD has long been recognised and has been included in formal classification schemes since 1987 (APA, 1987). It is described in the DSM-5 (APA, 2013) and also referred to in the ICD-10 (WHO, 1992) where it is labelled using the term ‘Specific Developmental Disorder of Motor Function’, which is largely equivalent to DCD. Despite this formal recognition of the disorder, DCD remains poorly understood by many healthcare and educational professionals (Missiuna et al., 2008), particularly compared to other developmental disorders. As DCD is one of the more prevalent developmental disorders, this is a cause for concern. Prevalence rates vary depending

on the population sampled and the methods of assessment used, but range from about 2% in a UK population investigation (Lingam, Hunt, Golding, Jongmans, & Emond, 2009) to 5-6% reported in DSM-5 (APA, 2013).

Inclusion of the condition DCD in the international classification schemes of the APA and WHO is useful in terms of acknowledging and describing the condition and setting out the diagnostic criteria. However, these schemes are broad in scope and designed for an international audience. They do not therefore provide the information required by practitioners/clinicians and researchers regarding application of the diagnostic criteria or guidance for the assessment and management of individuals with DCD either generically or within the context of an individual's service or national health care/education system.

Concerned by this lack of information, experts from around the world have met to discuss the formal diagnostic criteria and agree on how these should best be translated and operationalised for clinicians and researchers working in the field. In 1994 an international consensus meeting was held in Ontario, Canada, culminating in the publication of a working definition and practical guidelines (Polatajko, Fox, & Missiuna, 1995). Over ten years later a similar meeting was held in Leeds, UK resulting in an updated document (Sugden, 2006). Both of these meetings brought together experts working across different disciplines including medicine, psychology, allied health (occupational therapy and physiotherapy) and education. Drawing on their own practice and knowledge of the literature, issues relating to terminology, assessment, diagnosis and approaches to intervention were discussed and debated.

More recently a consensus document has been produced by a working party from the European Academy of Childhood Disability and published in the journal *Developmental Medicine and Child Neurology* (Blank, Smits- Engelsman, Polatajko, & Wilson, 2012). As with the production of the previous guidelines, this involved bringing together expert opinion to consider the main issues. Importantly, however, this time the consensus process was grounded from the start by a thorough review of the relevant literature by a panel of international experts. This ensured that later discussions and decisions were clearly informed by the available research evidence on DCD. The resulting EACD document represents the most detailed and robust guidelines to date, which are likely to be influential in informing research and clinical practice around the world.

The EACD recommendations have been written in both an extended format (Blank et al., 2012) 2012) and a shorter ('pocket') version (EACD, 2011). Both focus on four aspects of DCD: definition, diagnosis, assessment and intervention and have been adopted by The Association of the Scientific Medical Societies in Germany (Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften or AWMF), which is equivalent to the National Institute for Clinical Excellence (NICE) in the UK. This publication should be welcomed by all those working in the field of DCD, as it provides a thorough and evidence-based document to guide the work of clinicians and researchers. One limiting factor to the widespread use of these guidelines, however, is that they have been compiled principally for those working in German-speaking countries, particularly Germany and Switzerland. The only assessments referred to in the document, therefore, are those applicable to these countries, either established in the German language or with German translations. Furthermore, since the recommendations were initiated by medical practitioners in Germany, they are framed within the medical model of the

German health system. This is quite different to the approach to DCD taken in the health and educational context in the UK and possibly in other countries both within and outside Europe. It was therefore important to ensure that the EACD recommendations are appropriate for the medical and educational settings in other countries.

A further limitation to the EACD recommendations is the exclusive focus on children. This is despite the large body of longitudinal work which has established that the condition typically persists into adolescence and adulthood (Cantell & Kooistra, 2002). Early studies have tracked development into the teenage years, showing continued difficulties with hand skills, balance, and ball skills. Although somewhat hampered by the lack of normative data on standardized tests for older children, reports by class and Physical Education teachers confirmed continued motor problems in adolescents, who had been identified at the age of 5-6 years. The detailed and regular follow up of particular cohorts has provided information on the developmental course of the condition from early childhood into young adulthood (Losse et al., 1991). While some children do seem to show improvement, the majority continue to have motor difficulties compared to their peers. Indeed DCD continues to have a negative impact on everyday life skills (e.g. self-care, handwriting), education and employment (Hill, Brown, & Sorgardt, 2011; Kirby et al., 2013). Learning new skills, such as driving or sports also continues to be problematic (Kirby, Sugden, & Edwards, 2011). Perhaps most concerning is the persistence of psycho-social difficulties associated with DCD in adulthood and an increased incidence of quite serious psychiatric disorders associated with the condition in later life (Rasmussen & Gillberg, 2000). With increased recognition of the persistence of DCD through the life course, there is a growing need for the guidelines on DCD to be relevant beyond childhood.

This paper summarises the process of checking the EACD recommendations to ensure that they reflect the health, educational and social context of the UK. Simultaneously, the guidelines were extended to consider the diagnosis and assessment of DCD in adults. This process has been coordinated by ‘*Movement Matters*’, an umbrella group representing all organisations in the UK concerned with children and adults with DCD¹.

The process

Two workshops were organised by the *Movement Matters* Group to bring together representatives from the widest possible range of health care and education professions and professional bodies with an interest and expertise in DCD (see Table 1 for a list of the organisations included). Also involved in the meetings were parents of children with DCD and adults with the condition, who represented user groups in the UK. Key groups were contacted and invited to send one or two delegates to contribute to these workshops. If unable to attend they were invited to submit comments that were circulated and discussed at the meetings.

Insert Table 1 about here

The four main aims of the workshops are outlined below.

¹*Movement Matters* represents the following groups: DCD-UK, The Dyspraxia Foundation, The Developmental Adult Neuro-diversity Association (DANDA) and the National Handwriting Association (NHA).

1) *Agree on a working definition of DCD*

A working definition provides a succinct overview of the condition using everyday language. This is necessary for use by different professionals and lay people in order to allow for common understanding and consistency in communication. A working definition of the condition had previously been drafted and agreed by the *Movement Matters* Group. This was brought to the first meeting for discussion and agreement.

2) *Adapt the 'pocket' version EACD recommendations for children in the UK.*

The objective for the workshops was made clear to delegates at the outset; the intention was not to re-write the EACD recommendations any more than necessary to adapt them to the context of the UK. A very important element of the existing document was the strong evidence base and this was to be retained. This work reflects what has been recognised as an important part of Knowledge Transfer (KT) principles. In the health domain, the KT model has been defined as 'a cross-cutting approach that covers various domains in health. It is a complex, non-linear process that involves not only recent research findings but also the dynamic interaction of producers and users to bring about change.' (WHO, 2006) (p.12). Similarly, Davis (2005) uses the definition of Knowledge Transfer as an 'iterative, timely and effective process of integrating best evidence into the routine practices of patients, practitioners, health care teams and systems, in order to effect optimal health care outcomes and to maximize the potential of the health care system' (p.128).

3) *Draft a 'pocket' version of guidelines for adults*

The objective here was to use the existing framework and format of the EACD document for children. It was agreed from the outset that the work on DCD in adults lacked the evidence base available for establishing detailed guidelines compared to the evidence base on children. A pragmatic approach was taken by drawing on the experience of delegates to focus on areas where there was known to be lack of information and some confusion amongst practitioners. The focus was on supporting professionals working with young adults with DCD in further and higher education, with an emphasis on terminology, diagnosis and assessment. The issue of intervention was not considered because, unlike the work with children, intervention with adults has not been well researched. Furthermore, the context of supporting adults in the environment of higher education and in employment is very different to the context of parents, teachers and therapists planning intervention for children in the home, school and clinic.

At the workshops, delegates worked in small groups facilitated by a group leader and recorded by a note-taker. Group decisions were made through consensus and fed back to the main group for discussion and final decision making, which was recorded separately. The notes taken and decisions made were summarised at the end of the meeting, to give delegates the opportunity to correct or clarify issues.

Prior to the first workshop, representatives were sent the original EACD recommendations (the extended and ‘pocket’ version) (EACD, 2011) and asked to carefully consider which aspects were and were not relevant and applicable to the UK context and to adults. At the workshop delegates were first presented with the working definition of DCD drafted by the *Movement Matters* group. They were then divided into groups to consider the working definition and to each

work on one of the following sections of the guidelines: definition, diagnosis, assessment and intervention. There was an additional group tasked to draft guidelines for adults.

The workshop organisers ensured that the composition of each group was appropriate for the task but comprised a mix of people bringing different perspectives. For example, the group working on guidelines for adults included a medical practitioner, educational psychologists, specialist teachers, a special needs assessor, a research academic, the parent of a young adult with DCD and an adult with DCD.

After the first workshop, the detailed notes were gathered from the group work and final group discussions by the organising committee. The notes were used to compile three documents (1) A final and agreed working definition for DCD (2) a revised ‘pocket version’ of the existing EACD recommendations and (3) new draft guidelines for adults with DCD.

The three documents were circulated to all those invited to the workshop (this included delegates and those who were unable to attend in person). Corrections and comments were invited and, where appropriate, integrated into the final document. The final documents are available on the *Movement Matters* website at www.movementmattersuk.org. The main revisions made to the EACD recommendations are summarised in Table 2.

Insert Table 2 about here

4) Develop dissemination materials to explain the condition of DCD

The main focus of the second workshop was the discussion of dissemination activities and drafting of leaflets. The aim was to disseminate information to help those working or otherwise involved with individuals with DCD. Delegates divided into professional groups to draft leaflets targeting their own profession: teaching (primary and secondary), educational psychology, medicine (with separate leaflets for general practitioners and paediatricians) and allied health professionals (occupational therapy and physiotherapy). Additional groups worked on a leaflet for parents and one for those working with adults with DCD.

After the workshop the draft leaflets were checked for clarity, put into a uniform format and sent to delegates for checking and further comments. The organising committee then circulated each draft leaflet more widely within the relevant profession for feedback on the clarity and content. Feedback was responded to and final drafts of the leaflets prepared. Building on this work, further dissemination materials were drafted for additional groups (e.g. employers), using a similar format. This is now an ongoing process as *Movement Matters* attempts to reach new audiences to inform them about DCD.

Outcomes

The workshops culminated in the agreement of minor revisions to the EACD ‘pocket’ guidelines for a UK context (see Table 2) and an extension with recommendations for those working with adults with DCD (see www.movementmattersuk.org).

A series of information leaflets to disseminate this information to different professional groups was also produced. A website for *Movement Matters* was established to allow wide dissemination

of these materials. All documents can be viewed on the *Movement Matters* website at www.movementmattersuk.org.

Discussion

Many different professional groups work with individuals with DCD and have an interest in the issues of terminology, diagnosis, assessment and intervention. Thus, in order to work effectively in this field and give the best support to individuals and families, there needs to be a common understanding and guidelines shared by different professional groups. This process aligns with Knowledge Transfer principles as cited by *CanChild* in Canada (Law et al., 2004), as well as the World Health Organisation's perspective (WHO, 2006).

In this project we brought together a large and varied group of professionals, alongside parents and individuals with DCD. Our aim was to consider the new European recommendations and adapt and extend them for the UK setting. This was a challenging process as people came with different perspectives and experiences. The time dedicated to discussion and debate was fruitful in terms of understanding the perspectives of each and agreeing on minor revisions and an extension to the existing EACD document. We now share our reflections on the process and the strategies we adopted, which might be useful for those planning a similar exercise to develop other country-specific guidelines. The original guidelines, on which our work is based, were developed in accordance with recommendations from the AWMF (equivalent to NICE in the UK), obtaining consensus through a formal nominal group process. This involves taking everyone's opinion into account by using a special system of voting (Blank et al., 2012). We did not feel this was an appropriate strategy for our UK adaptation, since we did not want to divert

too far from the original guidelines, which were based on evaluation of the evidence base. Rather, the aim was to revise them for our (UK) context. For similar reasons it would not have been appropriate to use another more structured communication technique, such as the Delphi method.

As a result, one of our challenges was to manage potential discipline differences and power imbalance between individuals with DCD, parents and professionals at the workshops, to ensure that everyone could contribute to the process. We adopted four strategies to address this: (1) inviting individuals with DCD who had previous experience of acting as a representative (and therefore confidence in voicing their opinion), (2) inviting some delegates with dual roles (e.g. a medical practitioner who was also the parent of a child with DCD), (3) treating every delegate equally in terms of receiving the same information and having the opportunity to comment on drafts before, during and after the workshops and, (4) using experienced facilitators to actively encourage all group members to contribute to the discussions. We feel that these strategies went some way to address potential imbalance in the groups and to give equal opportunity for all delegates to make a contribution. In future work we would recommend that delegate perceptions of their opportunities to make individual contributions and the extent to which their views were taken into account could be evaluated through post-workshop questionnaires.

The objective for the UK revision of the child pocket version was to make minimal changes and purely to adapt the recommendations to be appropriate for, and relevant to the UK context. Compared to other European countries, the UK takes a less ‘medical’ approach to assessment and intervention for DCD (and other developmental disorders) and this was one issue that was considered in depth. It was overwhelmingly agreed that input from a medical practitioner is

crucial for excluding medical conditions that might account for the movement difficulties and indeed this is a requirement in DSM-5 (APA, 2013). Beyond this, however, it was agreed that DCD is more usefully framed in relation to education/employment and everyday living skills and that little further input would be needed from a medical practitioner.

Apart from a range of minor changes in terminology that relate to the context, only two of the original EACD recommendations were significantly altered. One (R5) was removed and the other (R16) was edited. In both cases this was because these recommendations included an ICD-10 classification (F82.0/F82.1) present in the German version but which is not included in the English version. This highlights that the substantial basis of the EACD's recommendations are appropriate in both German-Swiss and the UK contexts.

One of the original aims of the EACD working group was that the European recommendations would be developed into nation specific guidelines. This has been done in Germany, where proposals have been made for how to monitor and manage the quality of implementation of the recommendations. For example monitoring the number of individuals given a diagnosis of DCD compared to the number who have had an objective motor assessment. This type of monitoring might be possible in areas where there is only one setting in which a diagnosis can be made (e.g. a formal hospital setting). However, this type of monitoring would be impossible in the UK, where diagnoses are made in a range of health and educational settings. Furthermore, the German guidelines include a strategy for implementation of the recommendations for the German and Swiss national medical system. For example, indicating exactly when and where assessments should take place and indicating which particular institutions and services are responsible for this.

Again, this would not be appropriate with the diverse provision in the UK and any specific strategies would have resource implications. Indeed, Forsyth et al. (Forsyth, Maciver, Howden, Owen, & Shepherd, 2008), and Salmon et al. (Salmon, Cleave, & Samuel, 2006) have both described potential models of practice for the UK that have been developed to meet a particular service need in Scotland and South Wales, respectively. Such approaches may provide a more contextual, and potentially more appropriate pathway for the UK setting, although these may be country (England, Northern Ireland, Scotland, Wales), region, or district specific.

An important element of the original EACD document was its grounding in evidence from the research literature. A panel of experts on DCD undertook an extensive search of the literature available in peer-reviewed publications. The quality of the evidence and strength of recommendations based on the evidence was then graded using standard grading criteria. This resulted in the most comprehensive recommendations to date and the first to be based on a thorough review of evidence from the literature. Despite the important contribution of this work, there are some limitations that should be acknowledged. Firstly, it should be recognised that any review can be affected by the perspective and interests of the reviewers and had the original review been undertaken by others the outcome may have been different. For example, there was considerable debate and discussion in our workshops regarding perceived inconsistency in the wording of the original document. More specifically, some approaches to intervention were seen to be given different status even when levels of evidence were similar. However it was not our aim to re-evaluate the literature so this remained unchanged from the original document. Secondly, while evidence from the research literature is of great importance, other sources of evidence could also be considered. Although more difficult to evaluate formally, the extensive

experience of clinical practitioners often yields valuable information (Sugden & Dunford, 2007). Indeed when there is a lack of theory and empirical investigation we turn to experience for guidance. This was certainly the case for the new recommendations drafted for work with adults. The evidence base will continue to evolve and perhaps with further dialogue and debate theoretical, empirical and experiential evidence can become better integrated. It should also be recognised that the published recommendations will need to be updated and revised in the light of new evidence as it becomes available over time.

Overall, then, the aims of the UK consensus project were achieved in terms of bringing together representatives from a wide range of professional bodies and other stakeholders to have an input to the process. A useful working definition was agreed upon and the process of adapting the EACD recommendations to the UK context was successful. A new document relating to adults has been developed and a range of dissemination materials produced, which will be built on over time. It is hoped that this description of the adaptation process will help those in other countries consider their own adaptations.

However, if we are to continue the momentum that this European project has generated, it will be crucial to further increase awareness of DCD and these guidelines among policy makers, educators and practitioners. It will also be beneficial for all organisations and professionals involved with those with DCD to promote the guidance using the terminology and evidence identified in the project(s). Finally, it is hoped that the progress made will not only allow researchers and practitioners to work more cohesively in a bid to improve understanding of the causes and consequences of DCD, as well as validated intervention approaches, but it will also

suggest key directions for future research to strengthen the evidence base. In this way we can aspire to improve the understanding of DCD and support those who live with this condition to achieve their full potential.

Declaration of Interest

The authors report no declarations of interest.

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