

Supporting the social-emotional needs of children and young people with Developmental Coordination Disorder: occupational therapists' perceptions of practice in England

Authors

Tanya Rihtman; Nichola Gadsby; Joanne Porter

Abstract

Introduction: The social-emotional impacts of Developmental Coordination Disorder (DCD) for children and young people (CYP) are often the most disabling. Occupational Therapists (OTs) have a central role in facilitating holistic service provision for this population. There is a need to understand OTs' perceptions regarding provision of support for the social-emotional needs of CYP with DCD.

Method: A focus group (n=9) explored issues pertaining to OT support for the social-emotional needs of this population. Qualitative data were analysed through collaborative coding, organization and reorganization following the classic analysis strategy.

Results: Findings suggest that social-emotional support is not explicitly addressed in service provision for CYP with DCD. It appears that OTs know what needs to happen to improve social-emotional outcomes, and have made some progress, but more remains to be done. Holistic service provision depends upon varied factors, many of which are outside individual therapists' control.

Conclusion: In England, OTs working with CYP with DCD may be providing services in settings not geared to supporting social-emotional needs. This raises concerns as to whether practitioners are enabled to stay true to holistic principles, as well as concerns related to delivering evidence-based practice in light of growing evidence regarding this population's social-emotional risks.

Keywords

Developmental Coordination Disorder; social-emotional needs; holistic occupational therapy; integrated service provision; qualitative

Introduction

Developmental Coordination Disorder (DCD) is a neurodevelopmental condition marked by ‘long-standing non-progressive problems of specific motor skill performance, not attributable to any other known medical or psychosocial condition’ (Blank et al., 2019:245). DCD affects ~5% of the population (Lingam et al., 2009), and diagnostic criteria include evidence of impact upon occupational performance and participation (APA, 2013; Black and Grant, 2014). Research highlights risks of the secondary effects of DCD, specifically those within the social-emotional realm (Blank et al., 2019; Zwicker, et al. 2018).

Dunford and Richards (2003) note occupational therapists’ (OT) central role in the assessment, diagnosis, treatment and management of DCD in young people. Additionally, the Royal College of Occupational Therapists’ top ten research priorities (RCOT, 2020) highlights OT services that address both mental and physical health, reflecting a professional responsibility to facilitate holistic practice. As part of a broader study, this study aimed to explore the perceptions and practices of OTs working with children and young people (CYP) with DCD regarding provision of support for social-emotional needs.

Literature Review

Social-emotional wellbeing is a complex construct implying a range of concepts (including mental health, self-esteem, self-efficacy, self-belief). In this paper, the term social-emotional wellbeing is used to link between personal, social and emotional development (Dfe and DfH, 2015). ‘Mental health’ is only used in the context of direct participant quotes.

While the primary concerns of DCD relate to below-expected levels of motor performance, leading to disturbances in activities of daily living or academic performance (APA, 2013), there is increasing awareness of secondary social-emotional impacts (Hill and Brown, 2013) which have been linked to social marginalization (Wall, 2004) and poorer quality of life (Karras, et

al., 2019). Insight gleaned from the increasing body of research exploring the impacts of DCD demonstrate the range of potential social-emotional consequences. For example, van den Heuvel et al. (2016) report a four-fold increased risk of emotional and behavioural problems in children with DCD while Chung (2018) suggests that these problems are related to reduced social and emotional efficacy across home, school and community settings. Payne and Ward (2020) expand on the ubiquitous nature of self-efficacy on motivation, resilience, agency, ambition and identity of adolescents with DCD, while the psychosocial impacts of DCD have been described as the ‘most disabling’ (Karkling et al., 2017:149). DCD has also been linked to anxiety and depression in adolescence, leading to perceived lower health-related quality of life compared to peers (Draghi et al, 2019). Delays in addressing these issues, for example through educating parents and education staff, have been found to lead to persistent secondary social-emotional difficulties (Zwicker et al., 2013).

Children exist within multifaceted and multi-layered systems comprising complex reciprocal interactions which impact on their development (Bronfenbrenner and Morris, 2006). When a CYP with DCD brings motor difficulties to a complex interaction, they are likely to experience reduced competency and self-efficacy. This aligns with core OT principles, acknowledging the complex interaction between person, occupation and environment (AOTA, 2020). Recent research highlighting both primary and secondary longer-term outcomes (Tal-Saban, Ornoy and Parush, 2014) raises important questions about service provision that meets this population’s full range of needs across the lifespan.

In the UK, there appear to be specific DCD-related service characteristics. In 2003, a report from the UK National Association of Paediatric OTs (Dunford and Richards, 2003) highlighted that this population is ‘doubly disadvantaged’ due to service challenges and inconsistent pathways, with statutory healthcare services traditionally organized into physical or mental health domains. The OT profession espouses core values of holistic practice (RCOT, 2021) with therapists trained – in principle – to work across physical and mental health. However, using a school-based service example, Schultz (2003) highlights the ongoing need for OTs to ‘activate’ core values of holism and consider CYP’s psycho-social experiences. She proposes

that OTs traditionally fail to recognise that occupational dysfunction resulting from conditions like DCD affects the whole person and thus calls into question adherence to core OT values of holism.

Intervention approaches espousing function and participation have been found to offer optimal outcomes for CYP (Blank et al., 2019; Novak and Honan, 2019). For CYP with DCD, early interventions across multiple environments (Blank et al., 2019), with parent-teacher-therapist collaboration (Kennedy et al., 2020), are encouraged to reduce secondary social-emotional consequences. However, service challenges and inconsistencies described above, along with concerns over OTs' adherence to principles of holism, raise questions regarding clinical confidence and competence in meeting the full range of this population's needs. There is a need to further understand OTs' perceptions regarding the provision of services to support the social-emotional needs of CYP with DCD. The objectives of this study were to explore OTs':

- experiences of, and perspectives on, addressing social-emotional needs of CYP with DCD within their current practice
- perspectives on service-specific issues impacting upon the application of research evidence to meet social-emotional needs of CYP with DCD

Methods

Methodology

According to Sandelowski (2000), qualitative descriptive research is a relatively unacknowledged methodological approach, yet one of notable value in providing a comprehensive summary of an event in everyday terms. In comparison to highly interpretive approaches, qualitative description enables researchers to remain close to the participants' original data (Neergaard et al., 2009) and lends itself to 'obtaining...largely unadorned answers to questions of special relevance to practitioners and policy makers' (Sandelowski 2000;337). As a pragmatic approach which may be 'best-suited for providing the descriptive information that can inform professional practices' (Savin-Baden and Howell Major, 2013;170) it was deemed most suitable to support the achievement of the study objectives.

Sample and recruitment

Ethical approval was granted by XXX. A free university-based study day was offered to paediatric OTs working with CYP with DCD; final year OT students were also invited to facilitate research-informed learning. It was clarified that aspects of the event would be used to collect research data. Clinicians were recruited via opportunistic, snowball sampling; student OTs were recruited via the online student forum. Participants provided written informed consent. As noted above, the results reported here reflect one component of a broader research study which aimed to explore factors informing OT practice with CYP with DCD within the UK, whilst considering means of further development of this field.

Potential participants completed an online questionnaire which confirmed inclusion/exclusion criteria and provided an opportunity to rank six potential study day topics and their application to CYP with DCD. ‘Supporting CYP with DCD with social-emotional issues’ was the highest ranked topic selection. The other selected topics were: ‘supporting transition phases,’ ‘Health & Education Care Plans,’ and ‘theory to guide DCD practice’ (findings from these focus groups are in preparation for publication).

The study day included training sessions related to the selected topics, followed by focus groups exploring these areas. Participants collaboratively reflected upon learning and shared ideas for implementation into their practice (Appendix A). Focus groups were selected due to the exploratory nature of the study (Kreuger and Casey, 2015), as well as the nature of the study event which afforded the opportunity to generate rich discussion and sharing of participant views.

Participants were randomly allocated to the social-emotional focus group. Focus groups lasted one hour and were double video and audio-recorded. Initial transcription was undertaken by one member of the research team. Since multiple recordings could potentially lead to inaccuracies, two further members of the research team verified transcription accuracy before collaborative data analysis.

Nine people (qualified OT: n=7; student OT: n=2; all female) participated in the social-emotional focus group. Inclusion criteria for qualified OTs: HCPC-registration; >5 years

clinical experience; carry or manage a clinical caseload with CYP with DCD. Inclusion criteria for student OTs: final year; completion of all clinical placements; paediatric placement experience with CYP with DCD.

The qualified OTs had extensive experience (mean years of OT practice=13.29; mean years of DCD practice=12.71) and 5 held managerial responsibilities. No participants worked in Child and Adolescent Mental Health National Health Service (NHS) settings or held formal school-based roles. Five English counties (out of 48) were represented (Cambridgeshire, Greater London, Shropshire, Warwickshire, West Midlands).

Data collection

Demographic questionnaire: used to determine inclusion/exclusion criteria and gather descriptive information about participants' practice profiles.

Focus group interview schedule: comprising six trigger questions, based on review of relevant literature and collaborative discussion between researchers. A focus group interview guide based on expert knowledge aligned with the qualitative descriptive approach of the study (Neergaard et al., 2009). Questions were intended to allow for spontaneous, natural and nuanced discussion as opposed to being adhered to rigidly (Kreuger and Casey, 2015:41).

Data analysis

Data were analysed manually by three researchers, through collaborative data coding, organization and reorganization. While the classic analysis strategy (Kreuger and Casey, 2015) was used as a guide, analytical processes were iterative, with researchers supporting each other to maintain objectivity. Constant reference was made to the research questions, ensuring that the study purpose guided analytical direction, depth and intensity (Kreuger and Casey, 2015:138), and ensuring proximity of the results to the participants' original data (Neergaard et al., 2009).

Steps were undertaken to ensure the critical features of focus group data analysis (Kreuger and Casey, 2015). To ensure systematic analysis, all transcripts were numbered and colour-coded with consideration of frequency, specificity, emotion and extensiveness in the

identification of patterns and themes. Data analysis was verifiable (verification of transcription and collaborative data analysis), sequential (adherence to pre-defined procedures; trigger questions developed based on literature related to study aims) and continuous (semi-structured focus group discussion, with open-ended questions allowing for flexibility).

The trigger questions that had structured the focus group, as well as regular and consistent referral back to the study objectives, became that which guided the analysis and evolution of themes (Dickie, 2003). Transcription and coding processes suggested initial themes closely aligned with focus-group trigger questions, however, additional perspectives raised by participants were incorporated into the iterative process of mapping and re-mapping. This ensured that themes were identified using a data-driven analytical stance that transcended individual questions and allowed collective data integration to shed light on the overall study objectives.

Results

Three themes were identified, each with two or three sub-themes (figure 1). Theme 1: Jack of all trades... but not a master of this one. Theme 2: How do you eat an elephant? Theme 3: Structure of public sector services

Insert Figure 1 about here

Theme 1: Jack of all trades... but not a master of this one.

Despite the holistic foundation and wide scope of OT practice, social-emotional support for CYP with DCD does not appear to be explicitly embedded within the professional remit with this population group.

Subtheme 1: Jack of all trades...

While OT practice is founded on principles of holism, findings suggest that the social-emotional needs of CYP with DCD are targeted implicitly rather than explicitly. P2 stated that: “we always do questionnaires after (groups) just to get feedback from the parents and the children and we always ask about self-confidence and stuff and usually there is a positive impact on that, but it’s not something that we work on specifically”. This observation suggests

an acknowledgement that concern for social-emotional needs is an important aspect of holistic practice, yet may be neglected as a primary therapeutic target. The positive impacts of OT on social-emotional well-being were highlighted by P6 who noted *“that comes out a lot in parents’ feedback forms is they’ll often just mention the fact that their self-confidence has improved, they’re not so bothered about anything else but they’re just happier. And that actually is really important isn’t it?”* However, OTs working with CYP with DCD do not seem to explicitly articulate social-emotional goals within the observable OT process. P8 acknowledged that *“we really should be looking at this. And in a more of a sort of substantial way that we are at the moment, whereas well yes it’s at the back of our minds and we’re thinking about it, actually we maybe need to bring that to the forefront a little bit more”*.

The statement that *“there are things like the Movement-ABC checklist, you’ve got all the other lists where it has about self-esteem and you’re picking up that information...and get some of that through from the children as well”* (P5) suggests that OTs may not separate out social-emotional factors influencing function, despite their centrality to various assessments. However, as highlighted by P3, OTs draw on expertise in activity analysis to facilitate successful participation, through setting ‘just right challenges’: *“Well they live in a world of failure, don’t they? And sometimes we’re just the one person to say, ‘well have you tried rock climbing’? and they’re like ‘oh wow’ and then they try and obviously they’re really good at it”*. Additionally, the tendency of OTs to adopt strength-based approaches – implicitly supporting social-emotional wellbeing – was highlighted by P7, who noted that in direct work with children it is *“lovely to be able to say ‘you’re really good at this bit”* and in report writing *“we really try and draw out the strengths as well, so in the summary at the beginning we sort of do the strengths and challenges.”*

Subtheme 2: ...but not a master of this one

While social-emotional wellbeing improvements for CYP with DCD is often a welcome OT intervention by-product, a suggestion of an ‘*it’s not my job syndrome*’ (P4) arose, with lack of confidence or experience in targeting these needs. According to P1, *“my skill set, and my training is very different and so it wouldn’t be something I would be specifically, explicitly*

advertising that I could do.” P3 noted that further training is needed to meet wider social-emotional needs, saying, “I’m not able to do that. I can do the basics and we’re all trained to deal with that to a level but then you know you need extra training so...”. Concern was also raised about the risks of structuring explicit social-emotional interventions without appropriate skills, as highlighted by P2: “I think personally if there was a lot of anxiety and mental health stuff that came out I don’t know whether I would feel confident about where I would...you know you can sort of unleash, open a can of worms, can’t you, but then it’s what you actually do about it.”

Perceived limitations in supporting social-emotional needs appeared to be influenced by several external factors. P2 gave the example of children not being referred into OT services early enough: *“Which is obviously difficult when you get the one’s coming in where they’re 12, 13, 14 and it’s the first time it’s been picked up and you think how have you gone all of this way through school and nobody once has thought ‘ah, you could access (MH support)...”* Practicalities and risks of onward referral to CAMHS were noted by P7, *“...because, I think, giving another referral to mental health might make them feel ‘oh there’s another thing wrong with me’.”* Furthermore, P3 highlighted perceived lack of understanding about the social-emotional complexities of DCD, saying, *“I think in mental health services it’s not really thought about. And I think there is something to be said about educating schools and educating mental health services to try and make them aware because I think they underestimate the impact it [DCD] does have.”*

Theme 2: How do you eat an elephant?

Although OTs recognize their limitations in meeting the social-emotional needs of CYP with DCD, they identify **what** needs to happen to increase awareness and improve this population’s social-emotional wellbeing outcomes. The evidence suggests that OTs have successfully **made some progress**, but there is still **much more to be done**.

Subtheme 1: We know what we need to do

The challenges facing OTs in addressing the social-emotional needs of CYP with DCD do not seem to be based on a lack of knowing what is needed. There was consensus regarding the importance of educating others about early intervention relating to secondary DCD social-emotional risks, as emphasised by P3: “...*but this is... going into schools and educating them, what is DCD, the difficulties that they’re going to have and then having a whole debate with them about how much pressure they put onto the kids.*” The need to advocate for early intervention to avoid secondary social-emotional impacts was reinforced by P1, who “*always stress[es] to parents, especially with younger children, how important early support is in order to hopefully avoid those social, emotional impacts later on.*”

Subtheme 2: We’ve made some progress

Progress is being made to raise awareness about, and address the needs of CYP with DCD holistically, with increasing focus upon social-emotional needs. Therapists discussed how some intervention strategies used are appropriate to addressing social-emotional impacts of DCD, such as increasing self-efficacy by “*teaching kids to ask for help or teaching parents to...break stuff down and then give kids more time to learn*”(P1). It was also suggested that educating CYP about their diagnosis can enable better coping and adaptation through increased understanding of the source of their difficulties. P8 suggested that, “*if you explain the physical difficulties so it might be that actually then they’re not feeling sorry or frustrated because then they understand why they can’t do it and their mates can. It’s given them a reason behind it rather than just thinking ‘well why am I different to everyone else?’*”

Subtheme 3: But there is much we can still do

Participants discussed the need for greater general awareness about DCD, which may be supported by training teachers to adopt early universal approaches for all children rather than waiting for problems to become apparent for a few children. According to P5, “*Universal is a lot about schools managing and actually them learning and being educated so I think we’ve got a really good place to get in there...to go and do the training.*” P8 highlighted the importance of well-formed SMART goals that allow the child to experience success, noting that, “*It’s about setting realistic goals...once you’ve achieved those that’s going to boost self-*

confidence and self-esteem and self-worth.” According to P7, capturing this information explicitly would allow services to demonstrate clinical outcomes, acknowledging the backdrop of evidencing clinical outcomes to support a holistic service provision for this population: *“some of what you already do, if you could then prove that it’s having this positive impact you might be able to focus more on it.”* Further, the OT profession was described as having a unique, holistic skill-set that has potential to be used to greater advantage in supporting the social-emotional needs of CYP with DCD. Indeed, P3 claimed that, *“as OTs we’ve got such a great skill set...I think we need to stop shying away from just saying we can’t do that because it’s not in our service spec and instead saying to whoever ‘look what we could do’ and look at the potential outcomes...We’ve got to be savvy and promote what we can.”*

OT provision has potential for positive impact on the social-emotional needs of CYP with DCD through making intelligent use of available research evidence. One example was provided by P3, who noted that *“loads of these kids end up in mental health services, they end up in youth offending services, they end up on the unemployment list you know all those things that are actually going to cost society a fortune and there is some research that backs that up and it’s about us being really clever with that and using it and shouting about it a bit more with commissioners because I don’t think we’re very good at that part.”* In addition to using research data to demonstrate funding needs to commissioners for supporting early intervention for CYP with DCD, OTs could easily capture patient narrative as further essential evidence of the lived experience and impact of DCD. P7 gave the example of *“the lead of patients voice [who is] using digital storytelling software where you don’t even need like a camera man or anything its basically just like a PowerPoint and then you just speak over it which is a cheap way that any of us could [capture patient experience].”*

Theme 3: Structure of public sector services

Social-emotional outcomes of CYP with DCD seem to depend upon various factors, many of which are outside the control of individual therapists/teams. One such factor appears to be the structure and funding of public sector services, with private sector services having more autonomy regarding the OT scope of practice.

Subtheme 1: As compared to private services

Provision for those who can access private OT services highlighted what is missed by those who cannot in terms of meeting social-emotional needs. P4, who works in private practice, noted that, *“one of my colleagues...[is]...also qualified to...offer different programmes, loneliness, enhancement...”* Although participants working in the public sector indicated that this type of freedom to apply fundamental clinical reasoning strategies for addressing the social-emotional needs of CYP with DCD was not always available to them, P3 suggested that *“we need to stop being restrictive of what we offer cause we’re all so protective ‘we can’t do that, cause we haven’t got the money to do that, we haven’t got the time to do that’ but instead we could promote what we can do.”*

Subtheme 2: Impacts of cost efficiency and inconsistency

Despite providing statutory services across all four UK countries, DCD service availability and provision within the NHS is inconsistent across different geographical areas. Service restructuring and cost efficiency requirements have resulted in the cessation of some interventions, as highlighted by an exchange between P6: *“we used to do self-esteem groups, didn’t we?”* and P5, *“(nods) yeah, all those sorts of groups and things but we don’t have that capacity to do that now.”* OT services are required to make cost savings that lead to reduced resources, and a need to refine the OT role and scope of interventions available. P6 mused that, *“every year in the NHS you have to make a little cost savings, I don’t know how I’m going to keep making cost savings cause I’m sure we’ve all costed ourselves out.”* A comment made by P3, *“Wouldn’t it be nice if you could be holistic OTs?”* emphasised the perception that the NHS does not genuinely support holistic practice, and that services are organised in silos around physical and mental health needs. This may lead to piecemeal and disconnected services causing negative impacts for CYP; according to P5, *“Sometimes, by the time we see the children they’ve been assessed by everybody, and it’s like ‘oh, another assessment.’”*

Support for the social-emotional needs of CYP with DCD is often sought by schools via other services because NHS services are not addressing these needs. According to P6, *“now there’s this new programme called XX that schools are having, sending people on training and*

that's all about sort of like helping children with self-esteem issues.” However, participants raised questions about the quality of these offers. For example, P1 said, *“it's very hit and miss though because I find sometimes the training is delivered by teachers that might have had special interest and maybe that extra training and sometimes its reluctantly delivered by teachers that have been told that they have to do it because it's now part of what the school has to offer.”*

Subtheme 3: Schools

Perceptions specific to the school environment were noted in relation to public sector services addressing social-emotional needs of CYP with DCD. These included a sense that, although schools do recognise social and emotional needs and may seek external support, they do not necessarily focus upon these issues in terms of child achievement, but rather tend to focus upon academic results. According to P4, *“[schools] want kids to be getting C and above and really, as long they're getting C and above that's what they're monitoring isn't it?”* P3 highlighted that comparing children to peers using standardized testing approaches may prevent children from having the positive experiences of reaching their own full potential, stating that *“they compare everybody to their peers, how about that child's ability, their own potential?...I had one kid who was getting Bs in his A levels. He said I'm getting B's but I should be getting A*.”*

Standardized assessment is founded on the premise of pre-defined levels of achievement at certain ages. This may miss the identification of chronological achievement and skill mastery, leading to rigid approaches when supporting CYP with DCD, as highlighted by P1: *“education...doesn't work from a developmental approach, they work from a learning objective curriculum approach.”* Furthermore, it was felt that – rather than pursue early intervention which may ameliorate later social-emotional impacts – *“there is very much a ‘wait and see’ attitude in the world of schools...I work in private practice so I'm fortunate to [see] parents that are a bit more proactive...and the ones who sort of say ‘oh well school said ‘wait and see’ but we weren't sure’”* (P1).

Discussion and Implications

This qualitative study explored OTs' perceptions of supporting the social-emotional needs of CYP with DCD, with a range of implications for OT practice. The first theme (Jack of all trades...but not a master of this one) suggests that OTs working with this population do consider social-emotional factors, yet these achievements appear to be almost 'accidental', with lack of explicit social-emotional goal setting and outcome measurement. It is encouraging that the relationship between occupational competence, attainment of occupational potential (Wicks, 2005) and social-emotional development in childhood (Karras et al., 2019) is recognised, while simultaneously concerning that these aspects of a child's 'being' appear to be frequently separated out from more 'formal' OT goals in other areas of occupation. OTs working with this population are confident in setting functional motor-based goals, yet goals explicitly focusing on social-emotional wellbeing appear to be infrequent with gains in this realm viewed as welcome by-products.

The OT profession espouses holism as a core value (Pentland et al., 2018), and the foundation for this seemingly reductionist approach is not clear. It is possible that – despite being fully aware of what support should be offered to achieve holistic provision – OTs feel hindered in doing so by the structures in which they work, particularly for those who work within the NHS (e.g. theme 1, subtheme 2). Alternatively, this finding may be explained by therapists doubting their competency in addressing social-emotional needs of CYP with DCD due to perceived lack of knowledge and training, or issues of role definition ('this is not in my remit').

The seemingly contradictory findings of the first two themes may be explained by therapeutic confidence to prevent secondary difficulties as opposed to knowing how to treat those which have already developed. Participants seemed to express greater confidence to address broad well-being needs rather than specific, client-centred, social-emotional OT goals. This dichotomy appears to be underpinned by potentially contradictory professional requirements. Our codes of practice mandate us to work within the scope of our competency (RCOT, 2021:p24), however - when considering the professional instruction to adopt principles of holism (Pentland et al., 2018) - tension is created. Despite being supported by the

foundational literature of our profession (AOTA, 2014; Pentland et al., 2018), it is of concern that the therapeutic confidence of OTs does not seem to be high enough to confidently claim ownership of this aspect of participation and function as part of the profession's scope of practice with this client group.

The tension created between the imperative for holistic practice, with the apparent lack of ownership of the social-emotional practice dimension with this clinical population, may relate to the 'Structure of Public Sector Health Services' theme. In England, physical and mental health needs are provided for through distinct clinical services with significant implications. In 2016, a King's Fund commissioned report identified "particular fragmentation between support for physical and mental health – a finding that is perhaps unsurprising given the institutional separation of mental and physical health care in England" (Naylor et al., 2016:15-16). This creates barriers to integrated OT provision, and may prevent the development of advanced clinical skills in this area. However, there is increasing evidence highlighting that the social-emotional needs of CYP with DCD should not be ignored (e.g. Chung 2018; Draghi et al., 2019; Karras et al 2019), with core OT policies emphasising the imperative for integration of physical and mental health (RCOT, 2020) thus raising ethical concerns for OT practitioners. Additionally, the ethical concern highlighted by Dunford and Richards in 2003, that 'children with DCD are doubly disadvantaged by having to compete for OT services against other children with apparently more severe disabilities' may still be the case today.

The influence of service setting on holistic OT was further highlighted by findings that practitioners in private practice appear able to offer more integrated services. This suggests a two-tiered health system, where CYP whose families can afford to pay privately may access more holistic OT, as highlighted for example by a private practitioner participant who described their ability to undertake a broad range of assessment if deemed necessary, while those working in the NHS described commissioned service constraints. Potentially, this is also due to more opportunities for privately practicing OTs to prioritise continuing professional learning in this regard (Durocher et al., 2016).

Not only did the study findings demonstrate differences between statutory and private provision, considerations around participants' perceptions of service provision within the schools also came to the fore. This revealed participants' perceptions that stigma related to DCD, and the experiences of comparing children to other children (as opposed to comparing to themselves and their own potential [Wicks, 2005]) is particularly strong in the school environment. Lower self-efficacy has been identified in adolescents with DCD in environments where performance is measured against expected standards (Chung, 2018; Payne and Ward, 2020), and this study lends further support to these findings. Considering this, it is encouraging to note UK practice developments in recent years which have seen increasing shifts towards school-based OT practice, including the setting up of a sub-group for this within the RCOT CYP and families specialist section.

Despite the challenges identified in addressing the social-emotional needs of CYP with DCD, with a recent review of intervention effectiveness finding little evidence to guide clinical OT interventions to improve participation outcomes (compared to activity performance) (O'Dea et al., 2020), the focus group highlighted achievable changes that could be made. For example – considering the wider impacts of DCD across family members (Cleaton et al., 2019) – initiatives such as support groups for fathers/grandparents could be developed. The focus group experience led to sharing of practical ideas between participants, with the 'we've made some progress' sub-theme highlighting a broad range of good practice.

At the end of the event, participants collaboratively reflected upon their learning and shared ideas for practice (Appendix A). This exercise revealed ideas closely aligned with the study findings and suggest practical strategies that might feasibly be adopted by OTs working with CYP with DCD as well as further areas of work for future research. Examples of recommendations included facilitating networking opportunities between different NHS service strands, linking more effectively with and between parents, and working with service commissioners to facilitate joint funding and integrated pathways. Enhancing the skills, knowledge and confidence of paediatric OTs to explicitly address this population's varied needs regardless of therapeutic context is an important recommendation from this study. Furthermore,

education providers should consider how OTs learn practical skills for applying principles of holism in practice regardless of clinical population, specifically in terms of bridging between physical health and components of social-emotional wellbeing (Naylor et al., 2016).

There were several limitations to this study. The length of focus group questions may have resulted in lack of clarity, however, this was ameliorated by providing copies of the questions to be viewed by focus group members during the discussions. Lack of a sufficiently clear operational definition of social-emotional well-being may have constituted an additional limitation, with participants using varied terms interchangeably (for example, 'mental health' was repeatedly used). While an overview of current research in the field was presented to participants prior to the focus group, this interchangeability of terms suggests even greater need for professional clarity around this emerging body of knowledge. Finally, pragmatism resulted in the inclusion of study participants who were only from England and only five counties were represented. While these counties represented a geographical spread encompassing the West, East and South of England, it would have been recommended to include participants from the North of England, as well as other areas of the UK.

Conclusion

OTs working with CYP with DCD do not seem to identify explicit social-emotional therapy goals, with clear monitoring and outcome measurement, despite the ubiquitous impacts of the CYP's difficulties across more than just the functional motor domain. Health services are not sufficiently integrated, such that by the time social-emotional difficulties are identified, they have often become the primary concern. Meanwhile, OTs continue to focus on supporting functional motor concerns, in settings that are not geared to supporting social-emotional ones. This raises concerns as to whether OTs working in this field are being enabled to stay true to their core values of holism, as well as concerns related to being evidence-based practitioners in light of growing evidence regarding the social-emotional risks to this population.

Key Findings

- OTs supporting CYP with DCD understand the social-emotional risks, yet social-emotional therapy goal setting is insufficiently explicit

- Holistic service provision is impeded by institutional separation of mental and physical health

What the Study has Added

OTs working with CYP with DCD are aware of the evidence regarding the social-emotional risks to this population, however, structural service constraints may be hindering them from implementing professional values of holism and evidence-based practice.

References:

- American Occupational Therapy Association (2020) Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy* 74(Suppl. 2): 7412410010.
- American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders (DSM- 5)*. Arlington VA: American Psychiatric Publishing Inc.
- Black DW and Grant JE (2014) *DSM -V guidebook. The essential companion to the diagnostic and statistical manual of mental disorders*. Washington DC: American Psychiatric Association.
- Blank R, Barnett AL, Cairney J, Green D, Kirby A, Polatajko H, Rosenblum S, Smits-Engelsman B, Sugden D, Wilson P and Vinçon S (2019) International clinical practice recommendations on the definition, diagnosis, assessment, intervention, and psychosocial aspects of developmental coordination disorder. *Developmental Medicine and Child Neurology* 61(3): 242-285.
- Bronfenbrenner U and Morris PM (2006) The Bioecological Model of Human Development. In: Damon W and Lerner M (eds) *Handbook of Child Psychology, Volume I: Theoretical Models of Human Development 6th edn*, Hoboken: Wiley, pp. 793-828.
- Chung EY (2018) Unveiling issues limiting participation of children with developmental coordination disorder: From early identification to insights for intervention. *Journal of Developmental and Physical Disabilities* 30:373–389
- Cleaton MAM, Lorgelly PK and Kirby A (2019) Developmental coordination disorder: the impact on the family. *Quality of Life Research* 28(4): 925-934.
- Department for Education and Department of Health (2015) Special educational needs and disability code of practice: 0 to 25 years. Available at: www.gov.uk/government/publications/send-code-of-practice-0-to-25 (accessed 30 August 2020).
- Dickie VA (2003) Data analysis in qualitative research: A plea for sharing the magic and the effort. *American Journal of Occupational Therapy* 57(1): 49-56.

- Draghi TTG, Cavalcante Neto JL, and Tudella E (2019) Symptoms of anxiety and depression in schoolchildren with and without developmental coordination disorder. *Journal of Health Psychology*, p.1359105319878253.
- Dunford C and Richards S (2003) *'Doubly disadvantaged': Report of a survey on waiting lists and waiting times for occupational therapy services for children with developmental coordination disorder*. Report for the College of Occupational Therapists, UK, London.
- Durocher E, Kinsella EA, McCorquodale L and Phelan S (2016) Ethical tensions related to systemic constraints: occupational alienation in occupational therapy practice. *OTJR: Occupation Participation and Health* 36(4): 216-226.
- Hill EL and Brown D (2013) Mood impairments in adults previously diagnosed with developmental coordination disorder. *Journal of Mental Health* 22(4): 334-340.
- Karkling M, Paul A and Zwicker JG (2017) Occupational Therapists' awareness of guidelines for assessment and diagnosis of developmental co-ordination disorder. *Canadian Journal of Occupational Therapists* 84(3): 148-157.
- Karras HC, Morin DN, Gill K, Izadi-Najafabadi S and Zwicker JG (2019) Health-related quality of life of children with Developmental Co-ordination Disorder. *Research in Developmental Disabilities* 84: 85-95.
- Kennedy JN, Missiuna CA, Pollock NA, Sahagian Whalen S, Dix L and Campbell WN (2020) Making connections between school and home: Exploring therapists' perceptions of their relationships with families in partnering for change. *British Journal of Occupational Therapy* 83(2): 98-106.
- Krueger RA and Casey MA (2015) *Focus groups: A practical guide for applied research*. Los Angeles: Sage publications.
- Lingam R, Hunt L, Golding J, Jongmans M and Emond A (2009) Prevalence of developmental coordination disorder using the DSM-IV at 7 years of age: a UK population-based study. *Pediatrics* 123(4): e693-e700.
- Naylor C, Das P, Ross S, Honeyman M, Thompson J and Gilbert H (2016) *Bringing together physical and mental health*. Report for the King's Fund.

- Neergaard MA, Olesen F, Andersen RS and Sondergaard J (2009). Qualitative description—the poor cousin of health research? *BMC medical research methodology* 9(52): 1-5.
- Novak I and Honan I, (2019) Effectiveness of paediatric occupational therapy for children with disabilities: A systematic review. *Australian Occupational Therapy Journal* 66(3): 258-273.
- O’Dea Á, Robinson K and Coote S (2020) Effectiveness of interventions to improve participation outcomes for children with developmental coordination disorder: A systematic review. *British Journal of Occupational Therapy* 83(4): 256-273.
- Pentland D, Kantartzis S, Clausen MG and Witemyre K (2018) *Occupational therapy and complexity: Defining and describing practice*. London: Royal College of Occupational Therapists.
- Payne S and Ward G (2020) Conceptual framework of developmental coordination disorder in adolescence: Findings from a qualitative study. *British Journal of Occupational Therapy* 83(4): 246-255.
- Royal College of Occupational Therapists (2021) *Professional standards for occupational therapy practice, conduct and ethics*. London: Royal College of Occupational Therapists.
- Royal College of Occupational Therapists (2020) Top 10 priorities for occupational therapy research in the UK. Available at: www.rcot.co.uk/top-10 (accessed 30 August 2020).
- Sandelowski M (2000) Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4): 334-340.
- Savin-Baden M and Howell Major C (2013) *Qualitative research: The essential guide to theory and practice*. Oxford UK: Routledge.
- Schultz S (2003) Psychosocial occupational therapy in schools: identifying challenges and clarifying the role of occupational therapy in promoting adaptive functioning. *OT Practice* 8(16): CE-1.
- Tal-Saban M, Ornoy A and Parush S (2014) Young adults with developmental coordination disorder: A longitudinal study. *American Journal of Occupational Therapy*, 68(3): 307-316.

- Van den Heuvel M, Jansen DE, Reijneveld SA, Flapper BC and Smits-Engelsman BC (2016) Identification of emotional and behavioral problems by teachers in children with developmental coordination disorder in the school community. *Research in Developmental Disabilities*, 51:40-48.
- van der Linde BW, van Netten JJ, Otten B, Postema K, Geuze RH. and Schoemaker MM (2013). Development and psychometric properties of the DCDDaily: A new test for clinical assessment of capacity in activities of daily living in children with developmental coordination disorder. *Clinical Rehabilitation*, 27(9): 834-844.
- Wall AT (2004) The developmental skill-learning gap hypothesis: Implications for children with movement difficulties. *Adapted Physical Activity Quarterly* 21(3): 197-218.
- Wicks A (2005) Understanding occupational potential. *Journal of Occupational Science* 12(3): 130-139.
- Zwicker JG, Harris SR and Klassen AF (2013) Quality of life domains affected in children with developmental coordination disorder: a systematic review. *Child: Care, Health and Development*, 39(4): 562-580.
- Zwicker JG, Suto M, Harris SR, Vlasakova N and Missiuna C (2018) Developmental coordination disorder is more than a motor problem: Children describe the impact of daily struggles on their quality of life. *British Journal of Occupational Therapy* 81(2): 65-73.