

The importance of identity and empowerment to teenagers with developmental co-ordination disorder

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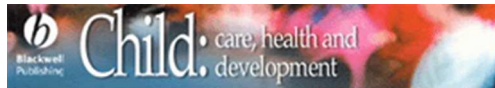
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The importance of Identity and Empowerment to Teenagers with Developmental Coordination Disorder

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Abstract

Aims: The aim of the current study was to gain an understanding of the experiences and aspirations of young people living with Developmental Coordination Disorder (DCD) in their own words.

Methods: Eleven young people aged 11 to 16 years with a prior diagnosis of DCD were identified from child health records of two participating NHS trusts. The sample included seven boys and four girls, from different socio-economic backgrounds living in different parts of one large urban area in England. In depth one-to-one semi-structured interviews and subsequent small group interviews discussions were carried out with the young people. Interviews were enhanced using participatory arts-based techniques. All interviews were recorded verbatim and transcribed. Narrative data were analyzed using Lindseth's interpretive phenomenology.

Results: The central theme of 'We're all different' described how the young person saw themselves and encompassed the formation of identity. Subthemes illustrated the attitude of the young people to their day to day lives, their difficulties and strategies used by the young people to overcome these difficulties in school and at home. The attitude of the school to difference, the presence of bullying, the accepting nature of the class, teachers and peers were vitally important. Areas of life that encouraged a positive sense of identity and worth included being part of a social network that gave the young people a sense of belonging, potentially one that valued differences as well as similarities.

Conclusion:

The current work highlights the need for services to adopt an empowered model of DCD where the young person talks about what they can do and considers strategies of overcoming their difficulties. This has implications for education and future intervention strategies that focus on fostering psychological resilience and educational coping strategies rather than simply attempting to improve motor skills.

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Introduction

Developmental Coordination Disorder (DCD) is a developmental disorder of childhood marked by a significant impairment in the development of motor coordination which has functional implication on activities of daily living such as self care skills, sporting activities and academic progress (American Psychiatric Association 2000). Previous qualitative research has emphasised the difficulties that children with DCD experience both at school and home from the perspective of their parents and the struggle that parents have engaging services (Mandich *et al.* 2003, Missiuna *et al.* 2006a, Missiuna *et al.* 2006b, Segal *et al.* 2002, Missiuna *et al.* 2007, Ahern 2000, Stephenson and Chesson 2008, Novak *et al.* 2011). Missiuna and colleagues (2007) described these difficulties as a “Trajectory of troubles” with parents reporting their children to have experienced increasing difficulties especially in participation and self esteem with age (Missiuna *et al.* 2007). The importance of self esteem from a young age was highlighted by Mandich (2003) using a sample of the parents recruited from an ongoing intervention study designed by the author (Mandich *et al.* 2003).

There is limited qualitative research recounting the experiences of living with DCD from the perspective of the young person. Fitzpatrick (2003) highlighted the difficulties experienced by a self selected group of adults (aged 30 to 60 years) who described themselves as physically awkward (Fitzpatrick and Watkinson 2003). Emphasis was placed on the humiliation caused by frequent failures in physical tasks (Fitzpatrick and Watkinson 2003). These findings are in contrast to those by Missiuna (2008) interviewing a self selected group of young adults, recruited from university and college, who emphasised the development of strategies they had developed to overcome difficulties (Missiuna *et al.* 2008).

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2
3 The aim of the current project was to gain an in-depth understanding of the
4
5 experiences and aspirations of a group of young people, living in the UK, who had been
6
7 diagnosed with Developmental Coordination Disorder (DCD).
8
9

10 11 12 **Participants and Methods**

13
14 We identified young people with DCD from the clinical records of two urban UK healthcare
15
16 providers. Participants were not known to the study team and were diagnosed after a
17
18 multidisciplinary assessment including formal testing of their motor skills by a physical
19
20 therapist and clinical examination by a paediatrician with expertise in child development. The
21
22 therapy notes of all young people aged 11 to 16 years, referred to the occupational therapy
23
24 services of participating sites were reviewed. The young people selected, in keeping with the
25
26 DSM VI-TR criteria and the Leeds consensus statement on DCD research, had documented
27
28 evidence of poor motor coordination below the 5th centile of a standardised motor
29
30 coordination test that affect daily living and was not caused by a known neurological
31
32 condition, marked learning difficulties or pervasive developmental disorder (Sugden *et al.*
33
34 2006 : American Psychiatric Association 2000). The age group 11 to 16 years was selected as
35
36 these young people could discuss both their experiences in junior, and secondary school and
37
38 the transition between schools.
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43
44 Fifty four young people were identified from the clinical notes as having DCD.
45
46 Sampling was carried out in batches using sampling framework to ensure maximum variation
47
48 on age, areas of residence, sex and associated developmental difficulties. Sampling was
49
50 stopped when data saturation of analytical themes was reached. The final sample consisted of
51
52 seven boys and four girls, aged between 11 and 16 years. Boys were oversampled in keeping
53
54 with the ratio of boys to girls seen in DCD (Lingam *et al.* 2009). The area sampled was
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1
2
3 predominantly white; only one young person was of dual heritage while the remaining
4
5 participants were of Caucasian descent. Characteristics of the study sample are presented in
6
7 Table 1.
8

9
10 *Insert Table 1*
11
12

13
14 All the young people (participants) were invited to take part in a face-to-face in-depth
15
16 semi-structured interview and a subsequent further group interview to expand on the points
17
18 made within the initial interviews. All 11 participants took part in the one to one interviews
19
20 and seven young people attended group interviews. Parents were not present in the same
21
22 room for the interviews or group discussions. The primary researcher performed all face-to-
23
24 face interviews with the young people in the family home which lasted between one and one
25
26 and a half hours.
27
28

29
30 The emphasis in the interviews was to gain a spontaneous account of the thoughts of
31
32 participants using open ended questions. Broad areas for discussion were identified from the
33
34 teams previous qualitative work with young people with physical disabilities and consultation
35
36 with a user group of two young people with DCD invited from a national DCD charity
37
38 (Metcalf *et al.* 2008). The interview guides are presented in Appendix 1. The interviews were
39
40 enhanced using arts-based materials and techniques to expand and add depth to specific
41
42 questions (Coad *et al.* 2009, Coad 2007). As young people with DCD can struggle with
43
44 drawing, the young people were presented with clip art pictures. These prompts were used in
45
46 a planned manner at the end of the interview, when the young people started to look bored or
47
48 when answers became very short. (Boyden and Ennew 1997, Coad *et al.* 2009) The clip art
49
50 was placed in front of the young person and they were asked to select a picture. The young
51
52 person was then asked to talk about the picture or what the picture meant to them. If they
53
54 were unable to talk about the picture, the intended meaning of the prompt was described and
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1
2
3 the young person was then asked to comment on how this related to them. These answers
4
5 were then explored with additional questions. The clip art prompts used are presented in
6
7 Appendix 2.
8

9
10 The group interviews lasted two hours and consisted of two mixed sex groups : the
11
12 first with young people aged 11 to 13 years, and the second aged 14 to 16 years. The group
13
14 interviews were used to expand on areas that the young people had highlighted as important
15
16 in the initial face-to-face interviews. Checking of initial findings has been described as “the
17
18 most crucial technique for establishing credibility” of research findings (Lincoln and Guba
19
20 1985). The group interviews were conducted by the primary researcher, with aid from a
21
22 secondary researcher and a note taker. After deciding what they wanted to discuss, the young
23
24 people were asked to compare the importance of these areas “before” (junior school), and
25
26 “now” (senior school) with the aid of ten rung ladders drawn on a poster sized piece of paper.
27
28

29
30 All interviews and group discussions were digitally recorded, transcribed verbatim
31
32 and checked for accuracy before analysis. Field notes were written after the individual and
33
34 group interviews. Separate written study information sheets and consent (assent) forms were
35
36 sent to the young people and their parents; these were completed by participants before study
37
38 enrolment. Ethical approval for the study was obtained from the local research ethics
39
40 committee reference 09/H0,101/6.
41
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44

45 46 *Analysis*

47
48 Data were analysed using a phenomenological hermeneutic method for researching lived
49
50 experience (Lindseth and Norberg 2004, Colaizzi 1978). This method of data development
51
52 and analysis aims to understand the meaning of phenomena in a life world perspective that is,
53
54 in the world of the individual and is in keeping with both participation research and
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1
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3 interpretative phenomenology. The analysis consisted of three parts: naive reading, structured
4
5 thematic analysis and comprehensive understanding i.e. interpretation (Lindseth and Norberg
6
7 2004). We selected this method of analysis as even though it is interpretative, it emphasises
8
9 the voice of the participant and attempts to balance the power between the adult researcher
10
11 and the younger participant (Miller 1999, Lindelof *et al.* 2010).

14 QSR Nvivo 8 software was used for data storage, retrieval, analysis, memo writing,
15
16 theme building and illustrative model formation (QSR International Pty Ltd 2008).

18 Transcripts were repeatedly read with additional memo writing to ensure familiarity with the
19
20 text. Transcripts were then coded line by line. A coding scheme was developed by the study
21
22 team based on meaning units within the interview data.
23
24

25 Initial themes were shared with the young people interviewed during the group
26
27 discussions, to ensure agreement with the analytical structure but more importantly as a
28
29 means of expanding meaning. The iterative analytical process was then repeated using one to
30
31 one, group interview and memo data. As the group interviews and memos expanded on the
32
33 data gathered from the initial face to face interviews, all the data were finally analysed
34
35 together (Lincoln and Guba 1985). Themes emerged by comparing and contrasting meanings
36
37 across and within transcripts and through the use of thematic maps (Braun and Clarke 2006).
38
39 Themes were then discussed between members of the study team and emergent themes were
40
41 compared to the broader adolescent, chronic illness and disability literature to ground the
42
43 research findings in a theoretical perspective around disability and identity. Using the coding
44
45 scheme developed by the author, three interviews were second coded by a separate member
46
47 of the team who was not party to the interviews or initial coding discussions. Text points
48
49 coded by the first coder were coded at the same coding point by the second coder at the
50
51 broader level of meaning (“tree node” QSR Nvivo 8) in 92% of cases and there was 69%
52
53 agreement at the narrower “free node” level (QSR Nvivo 8).
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Findings

The central theme of “We’re all different” described how the young person saw themselves. This concept incorporates five subthemes: “How I see my life”, “Things I find hard”, “Making my life easier”, “How others see me” and “How I see my future”. Though the themes are presented separately, the factors that influenced identity overlapped and merged. The central theme emphasised that life experiences of the young people were fundamentally important to how they saw themselves and how they viewed their impairment. The central theme was influenced by each of the subthemes will be discussed and integrated with the conceptual framework of disability and identity formation theory.

INSERT FIGURE 1 ABOUT HERE

“How I See My Life”

Although the young people all acknowledged that to a greater or lesser extent their DCD did affect them, most emphasised what they could do rather than what they could not. They enjoyed diverse activities like skiing, climbing, drama, playing video games, reading and hanging out with their friends. Many described seeing their lives as a “cup half full.” This positive outlook was not universal and some of the young people especially the younger teenagers and those with fewer friends could at times be negative about their lives, their abilities and in consequence at times themselves; “like my memory won't remember anything . . . my reading's rubbish and my spelling is also rubbish.”

Difficulties were considered using a mixture of denial that there was a problem, to acceptance that although there were difficulties, this was alright and it did not define them.

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2
3 Some of the older participants were able to talk more abstractly about how they had grown to
4
5 accept their DCD as an important part of them.
6

7
8 “I think that accepting it has really helped, knowing that I’ve got it. That I’m not just
9
10 a bit weird, if you know what I mean, not abnormally weird like, but sometimes you
11
12 just think you’re absolutely terrible at something and it’s all your fault because you’re
13
14 stupid or bad at something but it’s actually not, it’s because of the DSD [DCD] or
15
16 something, dyspraxia or something like that . . . Um, I don’t think I’d like to change
17
18 who I am, I wouldn't like to get rid of this [the DCD] because it’s all part of me like. .
19
20 . I’m not ashamed of it because it kind of makes me who I am. I think that everyone
21
22 has their problems.”
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27
28 For three of the young people, their DCD was not considered important; rather it was
29
30 something that they had moved on from. This sense of pushing the DCD to the back of their
31
32 mind was at times difficult.
33

34
35 “I don’t really struggle with anything really, um; because I’ve got dyspraxia it doesn’t
36
37 really take a toll on me. . . I just thought I’ll just keep it at the back of my mind, I
38
39 don’t let it get out.”
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43 *“Things I Find Hard”*

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45 Having DCD was important and at times difficult. The young people referred to their DCD as
46
47 dyspraxia when discussing their diagnosis. In the group interviews, the younger group of
48
49 teenagers found their dyspraxia more important now than the older teenagers. Two boys in
50
51 the younger group recounted how being told about their diagnosis had helped them
52
53 understand themselves better. For the older group, they were comfortable with their diagnosis
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3 and their DCD had become less important day to day as they had learned to cope with the
4
5 difficulties they had. This older group was more concerned that their DCD would affect them
6
7 in the future especially during exams.
8

9
10 All 11 young people mentioned areas of difficulty in school: academically, socially
11
12 and in sports; this was more prominent for seven of the young people interviewed. School
13
14 work was affected in several different ways. Young people had general difficulties with
15
16 learning, concentration, reading, memory and organisation together with specific motor
17
18 coordination difficulties such as in handwriting. From the face-to-face interviews, 10 of the
19
20 11 young people mentioned finding lessons difficult to understand. “It is not because he or
21
22 she is going fast it is just me not knowing because I don’t understand what they mean.” These
23
24 difficulties meant that the majority of the young people (8 out of 11) were in the lowest set
25
26 for all or most of their subjects. There were exceptions and one teenager described herself as
27
28 top in her class now although she had struggled in junior school.
29
30

31
32 All the young people struggled with handwriting which they equated with hard work.
33
34 For some, the difficulty was in the legibility of their writing whereas for others they suffered
35
36 pain when they wrote. Four young people received additional help with reading or
37
38 comprehension. Seven of the young people mentioned specific difficulties with organising
39
40 themselves, or remembering things at school and home.
41
42

43 All 11 young people mentioned some difficulties in sports, specifically difficulties in
44
45 throwing, catching and running. Most of the young people emphasised their enjoyment of
46
47 sports generally, especially sports they chose, but highlighted the difficulties they had with
48
49 formal school sports. This was apparent for both boys and girls.
50

51
52 For some young people, day to day activities like climbing the ladder of a bunk bed,
53
54 getting ready for school or doing up a school tie required help. This was talked about very
55
56 frankly with little embarrassment.
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3 Nine out of the 11 young people mentioned bullying. Some mentioned being different
4 from their peers, this lead to them being bullied, “um, when I walk I move my head so they
5 used to make fun of me about that.” In some schools there seemed to be a general atmosphere
6 or culture of bullying. The consequences of this bullying were in some instances extreme
7 with some young people having to move school whilst for others, school was almost
8 unbearable. “Sometimes I don’t even want to go to class . . . it was fine when people knew
9 [about the diagnosis] and just said stuff, but now they’re going on like about stabbing
10 people.” Three young people admitted to worrying about things and one admitted to
11 significant mental health problems including self harm.
12

13 *“Making My Life Easier”*

14 Being positive was an important way in which the young people helped themselves. Many
15 worked hard to improve their skills and seven young people mentioned practicing skills.
16 Computers and the use of technology also helped. Five young people used computer
17 packages to help with reading and spelling difficulties. In addition, being able to choose
18 subjects and activities that they were more likely to succeed at was important for all the
19 young people interviewed. Victories, however small, were important for a sense of identity
20 and self esteem.
21

22 “What I’ve achieved? . . . Probably my writing because it’s gone neater, well to be
23 honest, [you] couldn’t read my writing [before] and now I can read it so I’m actually
24 really chuffed because I can actually read my writing.”
25
26

27 The young people’s experiences of the help they received in school varied, especially
28 in relation to how they felt their teacher understood them and their needs. Learning support
29 assistants (LSA) were especially valued. For one young man, having an LSA in his senior
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3 school had transformed his experiences of school. In his current school he is able to ask
4 questions of his LSA, try to understand the question and work out the answer; this made
5 school less scary for him. For the more affluent families, their children often used computers
6 either at home or during extra private lessons. For young people living in more deprived area,
7 there was a promise of help, such as a computer for lessons, but these had not materialised.
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13
14 Therapists enabled the young people to understand some of their difficulties which
15 boosted their confidence. Intervention groups also gave the young people the opportunity to
16 meet other children with DCD making them feel less isolated.
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19

20
21 “When I was there [at the intervention group] I noticed other people had the same thing as
22 me, it wasn’t only me who struggled with different things; other people did as well. So it
23 made me think, ‘well if I can’t do it, there are also other people who can’t do it so I am
24 not the only one.’ It just makes me feel a bit better knowing that I am not the only one
25 who can’t do things.”
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34 Parents helped with homework, and practical day to day activities like cooking and
35 cleaning. Parents also acted as advocates, to get extra help in lessons, pay for extra tuition
36 and sometimes pay for private education. The experience of parental help differed between
37 individuals. For some, their parents allowed them to go as far as they could and would only
38 intervene if they got stuck. Tension resulted by parents at times taking over in tasks
39 especially when time was short, rather than let the young person do things for themselves.
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47 As with all teenagers, the young people wanted to be increasingly independent and
48 there was a gradual growing away from family toward friends. For some this was especially
49 difficult because of their reliance on their parents for daily tasks. Friends were important,
50 they helped the young people with school work and the transition to senior school, they also
51 “backed them up” in school. Four young people mentioned being helped in class by their
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3 friends if they did not understand work.
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6 “My best mate . . . She helps me a lot sometimes in lessons. If I get something wrong she
7
8 knows. I don’t like to ask for help, so she helps me because I just stare into thin air . . .
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10 She would know that I was struggling because she knows what happens to me when I
11
12 struggle, I just stare into thin air and wait until someone realises I’m stuck.”
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19 *“How Others See Me”*

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21 Friendship was the most commonly mentioned subtheme. Friends were one of the best things
22
23 about school and “hanging out with mates” was an important part of life outside school. How
24
25 the young people viewed themselves was influenced by many things including how they were
26
27 perceived and accepted by friends. Some young people had found a social group in which
28
29 they felt comfortable and where their talents rather than their failings were valued.. Goffman
30
31 described the ownership of difference between the individual and society as stigma (Goffman
32
33 1963). The young people interviewed, especially those that managed to maintain a positive
34
35 sense of self were able to negotiate themselves into a social group where their skills were
36
37 valued. For some, their peer groups were not sporty so their difficulties with sports were not
38
39 important to them individually or within the social group.
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43
44 “Oh, sports, is it important? No because a lot of my mates, including me, they don’t
45
46 really watch sports. . . . If we end up talking about TV, we end up talking about
47
48 something like "Mock the Week" [a TV program] or something like that instead of
49
50 like ManU [Manchester United Football Club] or Arsenal or stuff like that.”
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3 One young person said he was good at sports, specifically football. He described how
4 he had used this skill to become part of a group, make friends and be valued within it. This
5 young person struggled with academic work especially handwriting but this was not
6 considered a problem as his group of friends were not academic. There was, however, also
7 room in these groups for difference. “They’ve [his group of friends] got like all different like
8 talents, if you get my drift like. Some of them might like dancing and all that but . . . most are
9 into sport, different sports and that.”
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21 Divulging their diagnosis to friends was a dilemma which was made more difficult as
22 many classmates did not know what dyspraxia was. Some had told their friends and it was
23 accepted, for others, they found it easier to keep their diagnosis a secret as they did not want
24 their friends to think they were different. This perpetuated the concept of DCD being a
25 hidden disability.
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32 How others especially friends and family saw the young people sometimes directly
33 related to how they perceived themselves. One young person repeatedly described herself as
34 not smart which mirrored how she felt she was perceived by her peers at school and her
35 siblings at home. She described how her brother had said she was going to be a prostitute
36 when she grew older as she did not like school. This is in contrast to other young people who
37 felt confident in their own worth reflecting how they were seen by others. “A lot of my mates
38 say I am funny; I think I am quite funny and I am quite strong and um, my mates have told
39 me I am quite reliable.”
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51
52 Being understood was the most important thing a teacher could do to help. The
53 teenagers interviewed did not want special attention or for teachers to excuse bad behaviour
54 but rather just “get them.” Having an atmosphere in the class where questions were supported
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3 and the whole class was shown a particular point was appreciated as this did not single out
4
5 the young person with DCD as the one that did not understand. Accepting help if this was
6
7 needed was at times easier if there was a support teacher that was accepted and respected by
8
9 the whole class. If this was the case, having additional help was seen as an advantage and
10
11 something special.
12

13 14 15 16 *"The Future"* 17

18 How the young people saw themselves often related to how they perceived their own futures.
19
20 Four of the older young people specifically mentioned college and one mentioned university.
21
22 They recognised their difficulties but these were considered a challenge that needed to be
23
24 overcome. They had developed strategies to help with difficulties they faced and they were
25
26 clear that DCD should not be thought of personally or by others as an excuse to not let them
27
28 get on. Others were not sure if they would be able to do what they wanted because of the
29
30 difficulties they had.
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37 *"We're all different"* 38

39 The central theme of "We're all different" encompassed the formation of identity, how the
40
41 young people saw themselves. This was affected by things that were important to them, how
42
43 they saw their difficulties and how they were perceived. Although all the young people
44
45 struggled with areas of daily life such as writing, school work and sports, many had
46
47 developed strategies to help themselves and accepted help gratefully if it left them feeling
48
49 empowered. The young people's view of themselves was specifically influenced by how
50
51 others saw them in school and at home; their friendship group and their family's attitude to
52
53 them. As the majority of time was spent in school, the attitude of the school to difference, the
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3 presence of bullying, the accepting nature of the class, teachers and peers were vitally
4
5 important. Some young people described themselves generally positively as funny, reliable,
6
7 or trustworthy whereas others, specifically three of the younger teenagers, were very negative
8
9 about their abilities.
10

11
12 Only two young people mentioned the term disability. The first mentioned how one
13
14 boy with a disability, Down's syndrome, was picked on in school. He did not describe
15
16 himself as disabled but swore his friends to secrecy when he told them about his DCD.
17
18 Another young person described her DCD as a "discrete disability" then corrected herself to
19
20 say it was an "inability rather than a disability". The young people interviewed did not relate
21
22 themselves with a wider "disabled community". This is similar to previous work looking at
23
24 British, Canadian and Swedish children with different impairments (Shakespeare *et al.* 1999,
25
26 Mundhenke *et al.* 2009, Shikako-Thomas *et al.* 2009).
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32 **Discussion**

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35 To our knowledge this is the first study that has investigated the experience of young
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37 people with DCD in their own words. The central theme of "We're all different" emerged and
38
39 encompassed the formation of identity. Developing a positive sense of self was complex as
40
41 the young people wanted to be like their peers and friendship groups but at the same time
42
43 acknowledged their difference. Areas of life that encouraged a positive sense of identity and
44
45 worth included being part of a social network that gave the young people a sense of
46
47 belonging, potentially one that valued differences as well as similarities. This sense of
48
49 belonging was also supported by parents, teachers and the environment or ethos of the school.
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53 There is no one unifying definition of identity and the concept of identity has been
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55 explored from psychosocial, developmental and psychoanalytical view points. Identity has
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3 been defined as, “at least in part, an explicit theory of oneself as a person” (Moshman 2004).
4
5 This slightly rigid definition does not make allowance for the change that the young people
6
7 interviewed saw in themselves as they grew older. Potentially identity can be thought of as a
8
9 “narrative” rather than a “theory” of oneself, this narrative is a far more fluid changing entity.
10
11

12 The data presented is consistent with a socio-cultural approach to the formation of
13
14 identity which states that the young person is an active agent or participant in the formation
15
16 of identity in the context of their social setting (Baumeister and Muraven 1996). Erikson
17
18 described the formation of identity as an interplay between what the young person at the end
19
20 of childhood has come to mean to themselves through their childhood identifications,
21
22 compared to what they mean to significant others (Erikson 1968, Erikson 1977). The
23
24 development of identity in adolescence can thus be thought of as the fusion or at times
25
26 rejection of previous childhood images of oneself. The image of the young people as having
27
28 severe problems was an image that few of the young people shared. Many of the young
29
30 people recognised that they might have difficulties but emphasised that no one was perfect
31
32 and everyone had problems.
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36 The aim of qualitative research is to produce trustworthy findings that is, achieved
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38 results that are considered credible, transferable, dependable, and confirmable (Green and
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40 Thorogood 2005, Lincoln and Guba 1985). Our use of purposive sampling, detailed analysis
41
42 of “deviant cases” contrary to emerging themes, participant validation and additional
43
44 exploration of themes within the group interviews, and reflexivity in analysis by the use of
45
46 memo writing, all attempted to enhance the trustworthiness of findings.
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48

49 As we recruited participants from in a single urban area and there was a lack of ethnic
50
51 diversity within the group, our ability to generalise findings nationally could be affected.
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53 Outside the UK, these findings of resilience are similar to those of Missuina (2007)
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55 interviewing young adults with reported coordination difficulties in North America.
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3 The current work highlights the need for services to provide greater information for
4 young people, their parents and schools about DCD at the time of diagnosis, emphasising an
5 empowered model of DCD where the young person talks about what they can do and
6 considers strategies of overcoming their difficulties. The young people interviewed enjoyed
7 occupational therapy group interventions which not only increased skills but also gave a
8 sense of group belonging
9

10
11 School based interventions should aim to increase knowledge of staff and offer
12 practical help and support for pupils and teachers. They should encourage the use of
13 computer based programs, work sheets, and a decrease in the reliance on written work where
14 it is not essential. Practical ways of overcoming difficulties should include the young people
15 in decision making to empower them to create strategies to help themselves. Allowing young
16 people to have a choice in activities especially within sports could potentially increase
17 enjoyment, social networks, participation and physical activity.
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20
21 Bullying was a problem for all the young people interviewed. Work within school is
22 needed to implement a zero tolerance policy to bullying because of its potentially long term
23 affects on mental health. Other potential interventions also based in school should aim to
24 increase the social capital for young people with DCD in schools by helping to develop
25 school based friendship groups (Putnam 2000).
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32 **Conclusions**

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34 Our analysis showed that the young people with DCD interviewed struggled with day
35 to day activities but did not view themselves as disabled. They acknowledged their
36 impairments and had in many cases overcome significant difficulties at school and at home,
37 which at times were made worse by how others perceived them and how especially school
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3 life was organised. The importance of both acknowledged personal functional limitations and
4
5 societal imposed limits were highlighted in the interviews. This is in keeping with Bury's
6
7 "socio-medical model of disabling illness" (Bury 1997).
8

9
10 Factors that helped young people were inclusion in social (friendship) groups,
11
12 information so they had a greater understanding of their difficulties and being understood by
13
14 parents and teachers. Future work needs to consider ways of increasing the social capital in
15
16 the school environment for young people with DCD and ways of helping schools to empower
17
18 young people with additional needs to access the curriculum.
19

20 21 22 23 **Key Messages**

- 24
25 • There is limited qualitative research recounting the experiences of living with DCD
26
27 from the perspective of the young person.
- 28
29 • The formation of identity was central in the themes that emerged from the data.
- 30
31 • The young people interviewed emphasised what they could rather than what they
32
33 could not do.
- 34
35 • School based strategies are needed that enhance self esteem, psychological resilience
36
37 and educational coping strategies rather than simply attempting to improve motor
38
39 skills
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45 46 **Acknowledgments**

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50
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52
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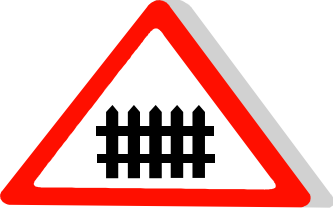
Appendix 1 Interview prompts

1. Tell me something about yourself?
2. What do you like doing?
3. Tell me three things that are good about being you?

Specific questions

1. What's school like?
 - a. Class/ school work
 - b. Sports and physical activities
 - c. Friends
 - d. What do you enjoy?
 - e. Are there things you don't like?
 - f. Is there anything you struggle with at school?
 - g. How do you cope with this?
2. After school activities?
3. What about home?
4. How do you see your future?
5. What has helped you most of all with your difficulties?
6. If you woke up in the morning and you could change something what would it be?

Appendix 2 Clip art prompts and meanings

Clip art	Intended meaning
	Angry
	Sports
	School
	Learning
	Doors opening
	Barriers

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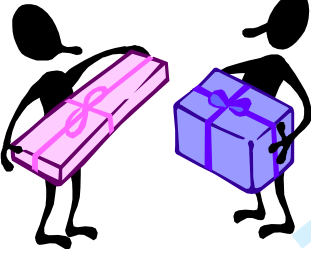




Clip art	Intended meaning
	<p>Confused</p>
	<p>Friends</p>
	<p>Home</p>
	<p>Strengths</p>
	<p>Anxious or scared</p>
	<p>Future</p>

Table 1 Characteristics of young people recruited study

Participant number	Gender	Age	Index of Multiple deprivation (IMD)	Geographical area of city	Other difficulties	School type: state/private/special needs
1	Female	12	9.10	Rural. Out of city		State (supported)
2	Male	14	4.31	North		State
3	Male	11	26.47	East		State
4	Male	15	25.28	East		State
5	Female	14	21.33	North	Attention	State
6	Female	16	4.07	West	Reading and attention	Special
7	Female	13	14.62	North		Private
8	Male	12	7.58	Central		State (previously private)
9	Male	14	38.73	West		State
10	Male	13	7.15	North	Attention and reading	Private
11	Male	12	28.68	South		State (supported)

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Figure 1: The interaction of the main theme "We're all different" to subthemes

