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Dunford, Carolyn and Richards, Sheelagh
(2003) 'Doubly disadvantaged': report of a survey on waiting lists
and waiting times for occupational therapy services for children with
developmental coordination disorder. Project Report. College of
Occupational Therapists, London.

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The College of Occupational Therapists
and the
National Association of Paediatric Occupational Therapists

'Doubly Disadvantaged'

REPORT OF A SURVEY ON WAITING LISTS AND
WAITING TIMES FOR OCCUPATIONAL THERAPY
SERVICES FOR CHILDREN WITH DEVELOPMENTAL
COORDINATION DISORDER

July 2003



Published by the College of Occupational Therapists Ltd
106-114 Borough High Street, London SE1 1HL.

Published:
July 2003
ISBN 0-9539375-8-5

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Acknowledgments:
The College and NAPOT wish to thank Lesley Platts, past Chairman of NAPOT; Heather O'Connell, Research Administrator and Janet Kelly, Head Occupational Therapist, Gwent Healthcare NHS Trust, for their contribution to this study; and all service managers who completed the questionnaire.

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Referencing:
College of Occupational Therapists, National Association of Paediatric Occupational Therapists
(2003) *'Doubly Disadvantaged': report of a survey on waiting lists and waiting times for occupational
therapy services for children with developmental coordination disorder. London: COT.*

Children with Developmental Coordination Disorder

Report of a Survey on Waiting Lists and Waiting Times for Occupational Therapy Services

Executive summary

Introduction

Children with developmental coordination disorder (DCD) have difficulties with everyday tasks requiring motor coordination such as handwriting, dressing and learning to ride a bike. DCD can severely limit school performance, self-esteem and age appropriate activities of daily living (Hellgren et al 1993, Losse et al 1991, Soorani-Lunsing et al 1993). Long term follow up studies have shown that these children do not “grow out of it” (Hellgren et al 1993, Losse et al 1991, Soorani-Lunsing et al 1993, Schoemaker et al 1994). Eighty percent of 22 year olds with DCD had poor psychosocial outcomes compared to 13% in a comparison group without DCD. Poor outcomes included being unemployed, having broken the law, being an alcohol or drug misuser, or having mental health difficulties. The prevalence of DCD is 5% of the childhood population. These children are commonly referred to occupational therapists for assessment, treatment and advice.

The College of Occupational Therapists (COT) and its specialist section, the National Association for Paediatric Occupational Therapists (NAPOT), have been concerned for some time about reports of lengthy waiting lists and waiting times for assessment of these children due to increasing numbers of referrals to occupational therapists without a corresponding increase in staffing levels. A survey of services across the UK was therefore conducted to determine hard facts relating to referral numbers and waiting times.

Methods

A retrospective survey was conducted in February 2002 by distributing a questionnaire in the College managers' mailing. There were 134 responses covering services provided by 30% of NHS provider trusts on behalf of 47% of Health Authorities / Boards in the UK*.

Results and discussion

Only fifty-eight percent of participating services were being delivered from a child development team despite the recommendation of the Court report (Secretary of State for Social Services et al 1976) that services for children with disabilities are best coordinated by a child development team. The remainder were being delivered from a range of other teams or service settings. Waiting times vary widely across the UK. The majority of services have criteria to determine levels of priority. Children with severe physical disability are given high priority and children with DCD are usually seen as a lower priority.

* It is recognised that the Isle of Man and the Channel Islands are not part of the UK. Their data have been included so this report is inclusive of the membership of the College of Occupational Therapists.

Within the 131 responding trusts, children with DCD comprised 30.4% (11,817) of the total caseload (38,914) of children's occupational therapy services and 61.7% (6,719) of the total number of children (10,898) waiting for assessment. There were 1,493 children with DCD who had been assessed and were waiting for treatment.

For high priority children, waiting times span from an immediate response (3 services) to 16 months (1 service) with a mean waiting times of 7 weeks. In contrast, the span for children with DCD ranged from one week (1 service) to 2-4 years (8 services) with a mean waiting time of 46 weeks.

Seventy-two percent (97) of services have made a case for extra staff for seeing children with DCD. However only 40% (39) of these were given extra staff and only 10% of those have found the extra staffing to be sufficient. The majority (61%) of occupational therapists delivering services are senior I grade; there is a limited number of training posts at junior grade and few opportunities for experienced practitioners to progress to clinical specialist, research or management posts, thus services are poorly placed to recruit and / or retain staff.

On average one w.t.e. occupational therapist has a caseload of 96 children with a further 22 waiting for assessment. The Royal College of Paediatrics and Child Health document "Standards for Child Development Services" suggests a mixed caseload of 30 children per whole time equivalent therapist (for Child Development Centre as opposed to the broad spectrum of children's services; no other recommended ratio exists).

Conclusions

Occupational therapists play a key role in the assessment, diagnosis, treatment and management of children with DCD. Occupational therapists are interested in children's occupations - the things that children need to be able to do to live their lives and fulfil their occupational roles: to be part of a family, play, look after themselves, make friends and go to school. The occupational therapist's primary goal is to help children develop, restore and maintain those skills, behaviours and relationships necessary for independent living. They also play a key role in educating parents and professional colleagues to increase their awareness and knowledge of the condition, to enable them to provide appropriate teaching support and / or to identify those children who should most appropriately be referred to occupational therapy services. Occupational therapists throughout the UK are struggling to meet the needs of this group of children as they manage large caseloads and high referral rates.

Children with DCD are at significant risk of becoming socially excluded due to unemployment, unlawful activity, substance misuse or mental health difficulties. Early intervention to diagnose these children correctly and offer them, their families and the other professionals working with them support and advice is crucial in preventing the poor psychosocial outcomes. Children with DCD deserve to have the same opportunity as other children to attain their potential and successfully develop skills for adult life. At present, many children's occupational therapy services are unable to help them do so.

An acknowledgement: The College and NAPOT acknowledge that many children with developmental coordination disorder are assessed and treated by other colleagues, including

physiotherapists, within children's services. This study has sought to investigate waiting lists and waiting times for access to occupational therapy, because that is a legitimate concern of both the College and NAPOT. There is no intention to imply that occupational therapy intervention for these children is more effective than physiotherapy may be, indeed many children may need or benefit from the expertise of both professions. None the less, children are referred to occupational therapists because referring colleagues have had the experience of occupational therapy's value. Evidence of the effectiveness of outcomes is limited across the field of DCD and more study is needed on the value of all interventions.

RECOMMENDATIONS

For government and national policy makers:

- Government health and education departments to develop a national strategy, guidelines and a teaching resource on DCD to:
 - accurately inform teachers (during training and at post graduate level) about this condition
 - better enable them to provide appropriate teaching and learning support, and
 - identify those children who need referral to occupational therapy services (or other healthcare professionals)
- To provide funding for prospective and long term follow up studies, including on the effectiveness of different interventions, residual deficits and their impact, and the needs of adults who experience continuing disadvantage as a consequence of having had developmental coordination disorder

For health care commissioners and providers:

- Jointly with local education authorities, to review the level of service provided to children with DCD and their families and develop strategies to ensure they will, within a planned time frame, receive a service that is at least as good as that offered to other children with special needs and their families;
- Develop comprehensive staffing strategies for children's occupational therapy services that address:
 - the need to recruit and develop new qualifiers in this specialty
 - the need to provide career progression opportunities to retain experienced therapists (including the development of clinical specialist, consultant, research and management posts)
 - optimal ratios of support and administrative staff to ensure effective skills mix, enabling occupational therapists to delegate tasks effectively
- Ensure occupational therapists who are not based in child development teams have access to the full multi-disciplinary team, including paediatricians

For the College of Occupational Therapists:

- In the context of the review of its pre-registration Curriculum Framework, to consider the

need for improved training in children's occupational therapy

For the National Association of Paediatric Occupational Therapists:

- To develop guidelines on a protocol for assessing DCD
- To issue guidelines on the current evidence base for treatment of DCD

For the College of Occupational Therapists and the National Association of Paediatric Occupational Therapists:

- To work jointly on developing improved post qualifying training and development opportunities for members working in children's occupational therapy services
- To work collaboratively with other professional bodies, including the Chartered Society of Physiotherapy and the British Association of Community Child Health (Child Health and Disability Group) on the above objectives and the need to improve services for children with DCD and their families

For all:

- To promote the importance of a multi agency approach e.g. through an occupational therapist, paediatrician, physiotherapist, and educational psychologist being the required 'minimum team' to apply diagnostic criteria. (Additional professionals may be needed if children are also to be screened for known co-morbid conditions e.g. speech and language disorders including dyslexia, attention deficit hyperactivity disorder)
- To seek funding for prospective and long term follow up studies, including on the effectiveness of different interventions, residual deficits and their impact, and the needs of adults who experience continuing disadvantage as a consequence of having had developmental coordination disorder

The experience of one parent:

Mrs Joan Sheppard ~

'As a parent of a child (now adult) who received occupational therapy I have the following thoughts on how occupational therapy helps children with DCD.

The fact that someone takes us seriously for a start! The huge confidence boost the children get as a result of occupational therapy. The way the children can respond because they are with someone who 'understands' their predicament. The children can talk to occupational therapists without feeling embarrassed about what they can't do and are praised (without going over the top) for what they can do i.e. they are treated 'normally' - like all children should be by everyone.

Occupational therapists explain to parents why something is, or is not, happening with regards to their child's development. The child learns strategies to cope even if they cannot learn to do, as everyone else would. Most of us wish we could keep an occupational therapist in our pocket, so to speak - to act as a Guardian Angel for our children when they are having difficulties. It is often when an occupational therapist is not available that the parents feel they, and the child, need them most.

Explaining things to other professionals (especially teachers) is often our most difficult task. Parents and older children who do not understand things themselves have a greater burden to carry. Without an occupational therapist parents could do more harm than good, trying to help their child. They may try to 'flog a dead horse' or give totally inappropriate tasks to the child.

Occupational therapy is levelled at the individual child, even in a group session. Occupational therapy trains the body to carry out tasks so they appear less tiring the next time. The brain seems to learn what to do semi-automatically. It's similar to any sports person keeping fit I suppose'

Children with Developmental Coordination Disorder

Report of a Survey on Waiting Lists and Waiting Times for Occupational Therapy Services

1 INTRODUCTION:

- 1.1 Children with developmental coordination disorder have been given many labels in the past such as clumsy, dyspraxic, having minimal brain dysfunction, perceptual motor dysfunction, sensory integrative dysfunction and specific developmental disorder of motor function. In 1994 an international consensus statement concluded that developmental coordination disorder (DCD) was the diagnostic label of choice (Children and clumsiness 1994). Children with DCD have significant difficulties with motor coordination, given their age and measured intelligence, which cannot be attributed to any other medical condition. Their poor motor coordination interferes with everyday tasks such as handwriting, dressing and learning to ride a bike. DCD can severely limit school performance, self-esteem and age appropriate activities of daily living (Hellgren et al 1993, Losse et al 1991, Soorani-Lunsing et al 1993, Schoemaker et al 1994). DCD is commonly found with other conditions such as attention deficit / hyperactivity disorder, dyslexia and speech language impairments. Gillberg and colleagues have also described autistic features, conduct / oppositional-defiant problems, depressive and anxiety symptoms, personality disorders, drug and alcohol abuse, accidents, Tourettes and tics as co-morbid conditions (Hellgren et al 1993, Gillberg 1998, Rasmussen et al 2000).

The reported prevalence ranges from 4.5% to 5% depending on the criteria used (Sugden et al 1998). The British Association of Community Child Health, a specialist section of the Royal College of Paediatrics and Child Health, states the prevalence of DCD to be 5%. (British Association of Community Child Health 2000).

- 1.2 Long term follow up studies have shown that these children do not “grow out of it” (Hellgren et al 1993, Losse et al 1991, Soorani-Lunsing et al 1993, Schoemaker et al 1994). They have health problems at a rate considerably above that of children in the general population (Hellgren et al 1993). Children who had been diagnosed at seven years with DCD were followed up in a controlled, longitudinal, community based study (Rasmussen et al 2000). This study found that at 22 years of age these research participants were more likely than their matched controls to be unemployed, to have had problems with breaking the law, to be alcohol or drug misusers or to have mental health difficulties. Eighty percent of the participants with DCD had poor outcomes compared to 13% in the comparison group without DCD. Studies of the adult prison population have shown that attention deficit hyperactivity disorder common (25.5%) amongst inmates (Rasmussen et al 2001, Eyestone et al 1994). Gillberg (1988) found that 50% of children with attention deficit hyperactivity disorder also have DCD. Given that DCD appears to be an important predictor of poor psychosocial functioning in early adulthood it is imperative that early intervention aimed at reducing the impact, including social exclusion, of this condition is provided to these children.

- 1.3 Occupational therapists are interested in children's occupations - the things that children need to be able to do to live their lives and fulfil their occupational roles: to be part of a family, play, look after themselves, make friends and go to school. The occupational therapist's primary goal is to help children develop, restore and maintain those skills, behaviours and relationships necessary for independent living. Children with DCD have difficulties performing activities of daily living such as handwriting, dressing, using cutlery, wiping after the toilet, riding a bike and playing games and sports. Children with DCD are referred to occupational therapists by paediatricians, physiotherapists, school nurses, teachers, educational psychologists and many others for assessment, advice, treatment and ongoing support. Referrals to occupational therapists for children with DCD create long waiting lists and use large quantities of occupational therapy resources. Paediatric occupational therapists report that many referrers are unclear about the diagnostic criteria for DCD and therefore make inappropriate referrals. In an attempt to reduce the number of inappropriate referrals occupational therapy services invest significant amounts of time educating potential referrers about the condition.
- 1.4 The National Association of Paediatric Occupational Therapists (NAPOT) and the College of Occupational Therapists (COT) have recognised the anecdotal evidence of rising numbers of referrals for children with DCD and the impact this has on the delivery of occupational therapy services to all children with special needs. This survey set out to collect some hard data on the numbers of children referred to occupational therapy services throughout the UK. This was intended to be a "snapshot" of services in November 2001, captured before the most recent changes in health services structures.

Method of survey and data analysis:

- 1.5 This was a retrospective survey with open and closed questions. A questionnaire was distributed by the College of Occupational Therapists in February 2002 through its managers' mailing list, which is sent to over 1,200 occupational therapy managers. Recipients were asked to pass the survey request to children's services managers in their areas. Services were asked, where possible, to complete one return per (former) health authority (commissioner) area using data as at end November 2001. All returns were for services based in individual provider trusts. The questionnaire is attached as appendix 1.
- 1.6 The data was entered into an Access 97 database. Some of the data was exported into an Excel 97 database.
- 1.7 Given the way the questionnaire was distributed it is not possible to calculate a direct response rate so the returns were examined to establish how representative they were across the UK. 134 survey forms were returned covering 60 (47%) health authority / board areas, and comprising 131 (30%) provider services out of a possible 429 across the UK. This level of return is statistically acceptable but potential bias cannot be neglected; COT and NAPOT can only speculate on the extent to which services with good or poor profiles may have been more inclined to respond to this survey. None the less, we propose that the findings are valid in illustrating a snapshot of the experience of children and their families waiting for an occupational therapy service.

Table 1: Number of returns by health authority / board areas across the UK

	Returns	Number of Health Authorities / Boards	Number of Health Authorities / Boards
England	37	98	38%
Northern Ireland	6	6	100%
Wales	3	5	60%
Scotland	12	15	80%
Channel Islands	1	2	50%
Isle of Man	1	1	100%
TOTAL	60	127	47%

Table 2: Number of returns from trusts (providing children's OT services) across the UK

	Returns	Number of Trusts	Percentages
England	99	337	29%
Northern Ireland	8	19	42%
Wales	5	14	36%
Scotland	17	56	30%
Channel Islands	1	2	50%
Isle of Man	1	1	100%
TOTAL	131 (3 Trusts returned more than 1 questionnaire)	429	30%

2 FINDINGS

The Context of service provision

- 2.1 The survey collected information on the location of services catering for children with DCD and their staffing profiles in order to provide a context for subsequent information on waiting lists and waiting times.
- 2.2 Although the largest number (57%) of services are based in child development teams, occupational therapy services for children are still being delivered from a wide variety of locations and agencies. Many services operate out of more than one service setting e.g. child development team, schools and child and adolescent mental health teams.

Table 3: Organisational setting of OT services responding to the survey:

Types of services offered	Number
Child development team	76 (57%)
School based service	48
Child and adolescent service	10
Community services	28
Other: including hospital base, Sure Start team and social services	39

Profile of staff providing the service:

- 2.3 Table 4 illustrates that occupational therapy services for children are delivered by basic grade to head grade staff but the majority (61%) are of senior I grade. Only 41 basic grades were in post. This profile reflects a common perception about children's services; there are few opportunities for junior practitioners to enter the specialty and the small nature of many services means that they rely heavily upon experienced and more autonomous senior grades. Similarly, opportunities are limited at the top end of the career ladder. Amongst the 131 trusts responding to the survey, only 19 staff had achieved clinical specialist grading and only 3 trusts had established posts for clinical research specialists (Table 6). 72 services employed a manager at Head III grade but only 17 had appointments at Head II or I levels. Not atypically for the current grading structure in the NHS, if staff wish to remain in and committed to a clinical specialty such as children's services, the majority can anticipate hitting their career ceiling at senior I grade and further progress being blocked by limited opportunities to progress through the traditional entry to management grades. It is hoped that Agenda for Change (Department of Health 1999) will provide the framework that is needed to enable trust management to address these crucial factors in recruitment to, and retention within, children's services.
- 2.4 Table 5 illustrates an equally unsatisfactory skills mix. Each whole time equivalent support worker supports 9.0 w.t.e. occupational therapists. Each whole time equivalent clerical and administrative worker supports 10.62 w.t.e. occupational therapists. This cannot represent either the efficient or effective use of the scarce occupational therapist resource.

Table 4: Grade profile of Occupational Therapists for all 134 returns

	Basic grade No. (WTE*)	Senior II No. (WTE)	Senior I No. (WTE)	Head IV No. (WTE)	Head III No. (WTE)	Head II / I No. (WTE)	TOTALS No. (WTE)
England	29 (27.75)	93 (73.79)	340 (229.33)	12 (6.99)	59 (48.76)	11 (10.54)	544 (397.16)
Northern Ireland	5 (4)	11 (10)	25 (21.3)	4 (3.6)	3 (2.8)	1 (1)	49 (42.7)
Wales	0 (0)	4 (3.2)	7 (5.41)	1 (1)	2 (1)	0 (0)	14 (10.61)
Scotland	6 (6)	32 (27.15)	89 (70.41)	3 (2.6)	8 (7.6)	5 (4)	143 (117.76)
Channel Islands	0 (0)	1 (0.78)	1 (1)	0	0	0	2 (1.78)
Isle of Man	1 (1)	1 (1)	1 (1)	0	0	0	3 (3)
TOTAL Nos. As wte	41 (38.75)	142 (115.92)	463 (328.45)	20 (14.19)	72 (60.16)	17 (15.54)	755 (573.01)

*WTE= whole time equivalent

Table 5: Numbers of Support Workers and Clerical / Admin staff for all 134 returns

	Support worker No. (WTE)	Clerical & Admin No. (WTE)	Total No. (WTE)
England	91 (51.66)	72.5 (46.19)	163.5 (97.85)
Northern Ireland	2 (1.4)	2 (1.1)	4 (2.5)
Wales	2 (1.14)	3 (1.26)	5 (2.4)
Scotland	14 (9)	13 (5.42)	27 (14.42)
Channel Islands	0 (0)	0 (0)	0 (0)
Isle of Man	1 (0.3)	0 (0)	1 (0.3)
TOTAL	110 (63.5)	90.5 (53.97)	200.5 (117.47)

Table 6: Number of clinical specialists and researchers for all 134 returns

	Clinical Specialist	Researcher
England	16	2
Northern Ireland	1	0
Wales	0	0
Scotland	2	1
Channel Islands	0	0
Isle of Man	0	0
TOTAL	19	3

Service Management and Leadership:

- 2.5 The government attaches significant importance to the effective management and leadership of clinical services (Department of Health 2000). The survey therefore sought to identify the extent to which children's occupational therapy services were managed and led by members of the profession. This is not to suggest that services may not be managed effectively by other disciplines, but rather to reflect our experience that senior and experienced managers will be more informed about their own service needs; more honest about articulating their deficiencies; and more persuasive in advocating for service developments. These aspects of leadership are critical to small services that feel constantly disadvantaged against larger, acute and mainstream services. Table 7 shows forty-five (34%) services have no head posts of any grade. This finding raises questions about the extent to which leadership development is being made available to senior specialists within these services if they are the staff called upon to contribute to service planning and development.

Table 7: Numbers of services with no head occupational therapists

	No Head Posts
England (n=103)	32 (31%)
Northern Ireland (n=8)	4 (50%)
Wales (n=6)	2 (33%)
Scotland (n=16)	5 (31%)
Channel Islands (n=1)	1 (100%)
Isle of Man (n=1)	1 (100%)
TOTAL (n=134)	45 (34%)

3 WAITING LISTS, WAITING TIMES AND SYSTEMS FOR PRIORITISING CASE LOADS

- 3.1 The survey sought to identify the numbers of children with DCD and other conditions currently known to occupational therapy services, the numbers of children waiting to be assessed, and for how long they had to wait. Respondents were also asked if they had a system for prioritising referrals and how children with DCD compare with others in terms of how long they have had to wait.

Numbers of children on caseloads and numbers waiting for assessment:

- 3.2 As illustrated in Table 8, within the responding trusts, children with DCD comprise 30.4% (11,817) of the total caseload (38,914) of children's occupational therapy services and 61.7% (6,719) of the total number of children (10,898) waiting for assessment. There were 1,493 children with DCD who had been assessed and were waiting for treatment.

Table 8: Numbers on caseloads, waiting for assessment and waiting for treatment

	Total caseloads (excluding those waiting for assessment)	Total on caseloads with DCD	Total Nos. waiting for assessment	Nos. with DCD waiting for assessment	Nos. with DCD waiting for treatment
England	31,131	9,781	8,329	5,117	1,086
Northern Ireland	2,303	231	853	527	100
Wales	553	115	168	134	101
Scotland	4,579	1,587	1,509	924	187
Channel Islands	170	50	8	8	4
Isle of Man	178	53	31	9	15
TOTAL	38,914	11,817	10,898	6,719	1,493

Systems for determining priority for access to the service:

3.3 Seventy-six percent of services have a priority system. All services prioritise children with severe physical disability above children with DCD. Many services restrict entry into the service on the basis of age or diagnosis. 16 respondents reported that they do not provide a service for children with DCD. Of these, 5 were because of establishment limitations; 7 were due to numbers of staff in post; 6 did not consider children with DCD a priority within current resources; 6 said the service is provided by another service (one a physiotherapy service, 2 by hospital services and 4 another paediatric OT team e.g. if the responding service was a CAMHS team the other service may be the child development team).

Table 9: Profile of services with established priority systems

	Priority system	Priority system	% with priority system	No response
England (n=101)	81	11	80%	9
Northern Ireland (n=8)	7	1	88%	0
Wales (n=6)	2	2	50%	2
Scotland (n=16)	11	1	92%	4
Channel Islands (n=1)	0	1	0%	0
Isle of Man (n=1)	1	0	100%	0
TOTAL (n=134)	102	16	76%	15

Length of time children wait for assessment by priority:

- 3.4 High priority children (those with severe physical disability) are seen immediately in some places but in others wait for up to 16 months. The highest priority children are seen immediately in three areas; within 1 week in 5 areas; wait up to 1 year in two areas; and as long as 16 months in one area. The mean waiting time for children deemed to be a high priority is 7 weeks. Nineteen out of 134 respondents did not fill in this data. The services that see children immediately are based in acute services.
- 3.5 In contrast, children with DCD wait from one week to four years for assessment. In one area they wait for one week; from 4-8 weeks in 12 areas; and from 2-4 years in eight areas. The mean waiting time is 46 weeks for children with DCD. Fifteen out of 134 respondents did not fill in this data. Complete data are presented in Appendix 2 but are summarised in Tables 10 and 11.

Table 10: Waiting times for assessment for high priority children

	Waiting time for Assessment: High Priority children	Mean in weeks	Mode in weeks	Median in weeks
England (n=90)	Immediately to 16 months	7	4-5	5
Northern Ireland (n=8)	1-2 weeks to 2 months	4	1.5-4	4
Wales (n=4)	1-2 weeks to 1 year	15	NA	NA
Scotland (n=13)	Immediately to 3 months	4	4	3.5
Channel Islands (n=0)				
Isle of Man (n=1)	Immediately	NA	NA	NA
TOTAL (n=116)		7	4	4

Table 11: Waiting times for assessment for children with DCD

	Waiting time for Assessment: DCD children	Mean in weeks	Mode in weeks	Median in weeks
England (n=101)	1 week to 2-4 years	46	72	36
Northern Ireland (n=8)	3-4 weeks to 2-3 years	52	72	48-60
Wales (n=4)	4 months to 4 years	75	NA	18-72
Scotland (n=14)	3-4 weeks to 1 year	12	32	32-36
Channel Islands (n=1)	3 months		NA	NA
Isle of Man (n=1)	2 months	8	NA	NA
TOTAL (n=129)	3-4 weeks to 4 years	46	72	36

4 SERVICES THAT HAVE MADE A CASE FOR EXTRA STAFF TO RESPOND TO THE NEEDS OF CHILDREN WITH DCD:

4.1 Many children's occupational therapy services have never been the subject of strategic review or planning and, as a consequence, many consider that they have never been adequately staffed to fulfil, inter alia, obligations first placed upon them by the Education Act of 1981 (Great Britain, Parliament 1981). We therefore sought to establish how many services had made a case for more resources to cope with the increased demand from children with DCD and, if they had done so, how many of them had been successful.

4.2 In 97 health authority / board areas, services had made a case for additional resources. Of the 39 who were successful (in full or in part), 4 found their extra staff to be sufficient but 35 did not. 56 made a case for extra staff and were not given them. 35 have never made a case for extra staff; however, two of these were given extra staff for children with DCD.

Table 12: Numbers of services making a case of additional resources and outcomes

	No case made	Case made	Staff given	Sufficient?
England (n=101)	29	72	27	4
Northern Ireland (n=8)	1	7	3	0
Wales (n=6)	1	5	2	0
Scotland (n=16)	4	12	7	0
Channel Islands (n=1)	0	1	0	
Isle of Man (n=1)	0	0	0	
TOTAL (n=133)	35	97	39	4

4.3 The survey asked respondents to provide the number of children in their service area population. Unfortunately, a high percentage excluded this data so analysis of staffing per 1,000 child population cannot be provided as intended. However, in the areas of those services that stated they catered for children with DCD and that provided total population figures (n=97), there are 459.49 w.t.e. occupational therapists for a total population of 31,893,818, giving one w.t.e. per 69,411 of the population. Table 13 is provided simply to illustrate a very distinct geographic variation.

Table 13: Numbers of children's occupational therapists by population

	Total population	Total WTE	1 : WTE population
England (n=73)	27,102,271	308.25	87,923
Northern Ireland (n=7)	1,623,000	50.3	32,266
Wales (n=3)	375,703	4.2	89,453
Scotland (n=12)	2,628,529	91.96	28,583
Channel Islands (n=1)	88,000	1.78	49,438
Isle of Man (n=1)	76,315	3	25,438
TOTAL (n=97)	31,893,818	459.49	69,411

4.4 Where information is available for both w.t.e. occupational therapists and totals of registered and waiting children being dealt with by the service (n=108), there are 495 w.t.e. occupational therapists for 47,545 children, which gives one w.t.e. occupational therapist per 96 children.

4.5 The British Association of Community Child Health document *Standards for Child Development Services (2000)* suggests a mixed caseload of 30 children per w.t.e. is appropriate. A mixed caseload would comprise of equal numbers of review children (seen half-termly, termly or yearly) maintenance children (seen monthly or fortnightly) and intervention children (seen once a week or more). In addition to their caseload, each w.t.e. occupational therapist has an average of 22 children waiting for assessment.

Table 14: Case loads and numbers of children per 1 w.t.e. occupational therapist

	Total registered (excl WASS*)	Total WASS	Total Children	Total WTE OTs	Number of children per 1 wte OT
England (n=84)	29,917	7,743	37,660	356.55	105.6
Northern Ireland (n=7)	2,303	733	3,036	38.3	79.3
Wales (n=3)	351	136	487	9.61	50.7
Scotland (n=12)	4,579	1,396	5,975	85.96	69.5
Channel Islands (n=1)	170	8	178	1.78	100
Isle of Man (n=1)	178	31	209	3	69.7
TOTAL (n=108)	37,498	10,047	47,545	495	96

*WASS = waiting for assessment

5 OCCUPATIONAL THERAPISTS' VIEWS ON THE SERVICE THEY ARE PROVIDING

Table 15:

(n=134)	Agree/ Str.agree	Disagree/ Str.disagree	Blank/ undecided
Give all high quality	32 (24%)	85 (63%)	17 (13%)
Have to prioritise	76 (57%)	38 (28%)	20 (15%)
Unable to provide good service for most	39 (29%)	73 (54%)	22 (16%)
Children with DCD treated equitably with others	63 (47%)	54 (40%)	17 (13%)
Children with DCD compare less favourably	43 (32%)	66 (49%)	22 (16%)
Do not assess unless we can treat	56 (42%)	63 (47%)	15 (11%)
Assess many but unable to provide level of treatment they require	68 (51%)	51 (38%)	14 (10%)
Assess children but those with DCD frequently have to wait for treatment	50 (37%)	61 (46%)	23 (17%)

- 5.1 It is accepted national policy that health care services have to prioritise those in greatest need and the above table illustrates that 63% of occupational therapy services feel they are unable to provide all children with a high quality service. 47% of services do not assess children unless they can provide the follow up treatment they require, while 51% carry out assessments but are not then able to provide the level of treatment the children require. Which of these is the preferable referral management policy is a matter for debate. Many services did, however, comment that if they were unable to offer treatment, they did at least have a policy of providing parents and teachers with written information and guidance.
- 5.2 The survey invited service providers to make additional comments on meeting the needs of children with DCD and to describe any innovative practice in their areas. Many services described making appeals year after year for adequate staffing but always losing out in the priority stakes. It is startling that services, perhaps with one or two occupational therapists, can describe one added post as a 'success'.
- 5.3 Descriptions of service innovations illustrated many services writing information and guidance material for teachers and parents, often as a substitute as well as a complement to occupational therapy intervention. The justification for services all writing their own, and different, material must raise concerns not only about the efficient use of time but also about the consistency and validity of the material provided. Group treatment sessions, often organised during school holiday periods and in collaboration with other professions and / or agencies (such as sports centres), appear to be a popular and time efficient approach. Some therapists consider this model has added merit in reducing the perceived stigma of children receiving individual intervention in the school setting, and in promoting peer support between parents and their children.

6. DISCUSSION

- 6.1 The results of this survey should be considered in the context in which the data was collected. It is a snapshot of services covering 47% of health authorities / boards and provided by 30% of provider trusts across the UK.

Context of service provision

- 6.2 The Court Report (Secretary of State for Social Services et al 1976) in 1976 recommended that services for children with disabilities are best coordinated by a child development team and in this study, 57% of respondents are based in child development teams. However, the remaining 42% of occupational therapist services are based in a wide range of other service settings. Where services are not part of a child development team liaising and networking with other team members will be much more difficult, especially as the nature of the work means professionals are not easy to contact by phone. Informal relationships are not easily made between team members when they do not share a base and it is these relationships which promote good inter professional communication. A significant number of services are based in schools. Whilst this allows occupational therapists to see the child in the everyday context of their school life, and to communicate easily with school based staff, it may make communication with non educational staff and parents / carers more difficult. It is evident that there are organisational blocks to effective service delivery. Implementation of the forthcoming

Children's National Service Framework (Department of Health 2003a) and / or development of proposed Children's Trusts (Department of Health 2003b) would provide ideal opportunities to review best service models. Good service structures should facilitate easy access to and between the range of professions needed to achieve optimum outcomes for the child and his / her family.

- 6.3 Sixty-one percent of occupational therapists are senior I grade. Anecdotally occupational therapists have said it is hard to "get into" working with children. Relatively little time is allocated to children's occupational therapy in the undergraduate programme so training must be provided "on the job". Training junior staff creates pressures for the senior staff providing the service. Working with children is considered a specialist area and even occupational therapists with experience in other areas will usually start at basic grade or senior II level. It can be seen that there are a relatively small number of these posts. There are known difficulties with recruitment and retention of staff and if a senior I member of staff leaves, the service often does not have the capacity to train a less experienced, new staff member. There would appear to be limited opportunities for career progression as there are low numbers of head grade staff with a bottleneck at the senior I level. There are very few clinical specialists or researchers which means adopting new ideas and implementing evidence-based practice is difficult, and reliant upon staff who are already under pressure. It is evident that incentives to join or remain in the specialty are far from ideal.
- 6.4 Statistically, each w.t.e. support worker supports 9.0 w.t.e occupational therapists. Each w.t.e. clerical and administrative worker supports 10.62 w.t.e occupational therapists. Clearly ratios differ between services. Nevertheless, this profile illustrates an overall skills mix which is unlikely to ensure that the scarce resource of qualified staff is used to best effect.

Waiting lists and their management

- 6.5 Children with DCD wait longer to be assessed and are seen as a low priority compared to children with physical disabilities. Occupational therapy services have developed a range of strategies to try and manage large waiting lists. Many services described education and training packages devised for colleagues in education and other referrers aimed at empowering teachers to distinguish between those they should be able to manage and those who need and justify referral to the occupational therapy service.
- 6.6 Seventy-two percent of services have made a case for extra staff to provide a service to children with DCD. However only 40% of these were given extra staff and only 10% of those found the staff to be sufficient.
- 6.7 Children with DCD comprise 30.4% of children registered to caseloads and 61.7% of those waiting for assessment and treatment. This may represent a rise in referrals and / or that not all children referred with possible DCD are taken on for treatment. It may be that children are not treated because services only offer assessment and advice to these children, or that the referrals are inappropriate. In a survey (Gillberg et al 1993) of 67 children referred to an occupational therapy team with a presumptive diagnosis of DCD, only 21 (31%) children met the DSM- III (American Psychiatric Association 1987) criteria (see appendix 3) for DCD.

Caseloads

- 6.8 As table 14 illustrates, occupational therapists throughout the UK are theoretically dealing with caseloads three times the recommended level. In addition to their large caseloads each w.t.e occupational therapist has an average of 22 children waiting for assessment. The initial assessment period often requires a high level of direct and indirect intervention. The assessment may need to be done over more than one session. The other professionals involved with the child need to be consulted and this may include a school visit. Writing up the report may take one or more hours even for an experienced therapist. Writing home and school programmes is also time consuming. Occupational therapists have to chose between carrying a large caseload or allowing waiting lists to grow longer; to give a good service to a few or a minimum service to a lot of children and their families. If they increase the number of assessments they conduct, both children and their parents will be disappointed if time cannot subsequently be given to providing the level of treatment or interventions they require. But if they do not carry out assessments, needs are not identified and will remain unmet.
- 6.9 Establishing a diagnosis and informing the child, parents and teachers has a positive effect (Gillberg et al 1993). Occupational therapists are the key professionals in establishing whether the motor coordination difficulties are impacting on academic achievement or activities of daily living, which is one of the diagnostic criteria. The literature on occupational therapy and DCD calls for larger trials incorporating long-term follow up and using outcome measures that provide a holistic assessment of the effects of the intervention on children (Logan 1997). Approaches which focus on remediating the functional deficits (top down) rather than the underlying motor impairment (bottom up) is emerging as the way forward in the light of current motor learning theories (Mandich et al 2001). Outcome measures for occupational therapy should be based on the actual tasks that the child and carers identify as the presenting problems of living with DCD. Needs and wishes will be unique to each child and require therapy skills beyond the use of standardised tests alone. A task specific, functional approach has been shown to be more effective (Mandich et al 2001). Further UK based research is required.

Conclusions

- 6.10 Children, young people and adults with DCD are at significant risk of becoming socially excluded through unemployment, unlawful activity, substance misuse or mental health difficulties. Occupational therapists play a key role in the assessment, diagnosis, treatment and management of children with DCD. They also play a key role in educating parents and professional colleagues to increase awareness and knowledge about the condition. Occupational therapists throughout the UK are struggling to meet the needs of this group of children as they manage large caseloads and high referral rates. Early intervention to diagnose these children correctly and offer them, their families and the other professionals working with them, support and advice is crucial in preventing the known poor psychosocial outcomes. Children with DCD are doubly disadvantaged by having to compete for occupational therapy services against other children with apparently more severe disabilities.
- 6.11 Occupational therapy is likely to reduce the risk of educational under achievement and low self-esteem common in many children with DCD. Children with DCD are placed in

mainstream schools and have the same expectations as their peers placed upon them as DCD is often termed a “hidden handicap”. In these settings, children have to adapt to, and master skills in, many different environments and with different equipment. Therefore, effective service provision requires that the occupational therapist devotes a considerable amount of time to educating individual teachers about aspects of the individual child’s needs in relation to their subject and classroom setting.

- 6.12 This survey has provided only a snapshot of waiting lists and waiting times in around 30% of provider trusts across the country. It has revealed 10,898 children waiting for occupational therapy assessment, of whom 6,719 are purported to have DCD. If extrapolated nationally, these data must represent untold distress for disabled children and their parents.
- 6.13 It is the view of the College and NAPOT that children with DCD deserve to have the same opportunity as other children to attain their potential and develop occupational skills necessary for the successful performance of roles and responsibilities in their adult life. At present, many children’s occupational therapy services are unable to help them do so.

RECOMMENDATIONS

For government and national policy makers:

- Government health and education departments to develop a national strategy, guidelines and a teaching resource on DCD to:
 - accurately inform teachers (during training and at post graduate level) about this condition
 - better enable them to provide appropriate teaching and learning support, and
 - identify those children who need referral to occupational therapy services (or other healthcare professionals)
- To provide funding for prospective and long term follow up studies, including on the effectiveness of different interventions, residual deficits and their impact, and the needs of adults who experience continuing disadvantage as a consequence of having had developmental coordination disorder

For health care commissioners and providers:

- Jointly with local education authorities, to review the level of service provided to children with DCD and their families and develop strategies to ensure they will, within a planned time frame, receive a service that is at least as good as that offered to other children with special needs and their families;
- Develop comprehensive staffing strategies for children’s occupational therapy services that address:
 - the need to recruit and develop new qualifiers in this specialty
 - the need to provide career progression opportunities to retain experienced therapists (including the development of clinical specialist, consultant, research and management posts)

- optimal ratios of support and administrative staff to ensure effective skills mix, enabling occupational therapists to delegate tasks effectively
- Ensure occupational therapists who are not based in child development teams have access to the full multi-disciplinary team, including paediatricians

For the College of Occupational Therapists:

- In the context of the review of its pre-registration Curriculum Framework, to consider the need for improved training in children's occupational therapy

For the National Association of Occupational Therapists:

- To develop guidelines on a protocol for assessing DCD
- To issue guidelines on the current evidence base for treatment of DCD

For the College of Occupational Therapists and the National Association of Paediatric Occupational Therapists:

- To work jointly on developing improved post qualifying training and development opportunities for members working in children's occupational therapy services
- To work collaboratively with professional bodies, including the Chartered Society of Physiotherapy and the British Association of Community Child Health (Child Health and Disability Group) on the above objectives and the need to improve services for children with DCD and their families

For all:

- To promote the importance of a multi agency approach e.g. through an occupational therapist, paediatrician, physiotherapist, and educational psychologist being the required 'minimum team' to apply diagnostic criteria. (Additional professionals may be needed if children are also to be screened for known co-morbid conditions e.g. speech and language disorders including dyslexia, attention deficit hyperactivity disorder)
- To seek funding for prospective and long term follow up studies, including on the effectiveness of different interventions, residual deficits and their impact, and the needs of adults who experience continuing disadvantage as a consequence of having had developmental coordination disorder

SURVEY OF WAITING LISTS FOR CHILDREN WITH
SUSPECTED DEVELOPMENTAL COORDINATION DISORDER

How to complete this survey:

- Ideally, we wish this questionnaire to be completed by one manager responsible for children’s occupational therapy services in a Health Authority / Health Board’s catchment area
- However, where services are managed by more than one occupational therapist, and you are sending separate responses, please indicate in Q7 that another (or more) responses will be coming from your area
- We are aware that there is much debate regarding terminology for this group of children, e.g. dyspraxia, DCD. For the purposes of this survey, we have used DCD as a generic term to include children with motor co-ordination difficulties without significant generalised learning disabilities. We are not concerned about the ultimate diagnosis or term you use, what we want to identify are the numbers of children referred to you and on your waiting list because the referrer believes they have a motor coordination difficulty that is the basis of their functional deficits. Please complete the survey on that basis.

A. Background Information – please answer all questions:

1. Name of Occupational Therapy service manager completing this survey:

_____ Date _____

2. Job Title and Grade: _____

3. Address: _____

Postcode: _____

Phone No: _____ Fax: _____ E Mail: _____

4. Name of Employing Authority (e.g. Blankshire NHS Trust)

5. Name of Commissioning Body (e.g. Health Authority or PCG): _____

6. Total Population served (if unaware, this should be readily available from your Chief Executive’s office): _____

7. This response covers the whole service in our area

OR - a further return(s) will be forwarded from our area

8. Type of service (please tick):

- Child Development Team
School based service
Child & Adolescent Mental Health Team
Other (please describe): _____

9. Do you provide a service to children with developmental coordination disorder (DCD)?

- Yes if yes, Go to Q 11
No if no, please answer Q10 then Go to Q19

10. Could you please let us know why a service for children with DCD is not provided
Please tick as many as appropriate:

- Establishment limitations
- Staffing limitations
- Not considered a priority within current resources
- Service is carried out by another service
- Please specify _____

- Other (please specify) _____

B. Information about the children in your area

11. Total number of children registered to the service on 31.11.01:
Include all children who have been assessed by an OT but exclude
those waiting for assessment.

12. Number of above children registered to caseloads with DCD at the
same date:

13. Total number of children waiting for assessment at 31.11.01:

14. Number of this total referred with possible DCD (and
therefore not yet diagnosed / confirmed):

15. Number of children who have been assessed as having DCD and
are waiting for treatment (at the time you are filling this in):

16. Do you have a system for prioritising children on the waiting list?

Yes No

17. Average time all children with the highest priority (e.g. severe physical disability) wait for assessment (in weeks or months):

18. Average time children with DCD wait for assessment (in weeks or months)

C. Information about your staffing for children's services

19.

	Total Number	Wte
Head I / II		
Head III		
Head IV		
Senior I		
Senior II		
Basic Grade		
Support Workers		
Admin & Clerical		
TOTAL		

20. Are any of the above OT team designated as:

Clinical Specialists - Yes No

If yes, Number / wte:

Researchers - Yes No

If yes, Number / wte:

21. Now tell us a little about the context of your services.

Please tick Yes or No - but there is space at the end to add comments that you think would be helpful to this survey.

	YES	NO
• Have you ever made a case for extra staffing to deal with children with DCD?	<input type="checkbox"/>	<input type="checkbox"/>
• Have you been given extra staffing to deal with children with DCD?	<input type="checkbox"/>	<input type="checkbox"/>
• Has this staffing been sufficient?	<input type="checkbox"/>	<input type="checkbox"/>

22. Overall, which of the following statements describe the service you are able to provide for children referred to you:

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
We are able to give all children a high quality service					
We have to prioritise, some children receive a good service, but others receive a poor service					
We are unable to provide a good service for most of our children					
Children with DCD are treated equitably (whether the service is good or poor) with children with other disorders					
Children with DCD compare less favourably with children with other disorders					
We do not assess children if we are unable to provide treatment					
We assess many children but are then unable to provide the level of treatment they require					
We assess children but those with DCD frequently have to wait for treatment					

Please add any comments that would enable us better to understand your response and anything you wish to say about meeting the needs of children with DCD. If you have developed any innovative practice in this area, we would appreciate hearing about it. Innovations might include information booklets for parents, groups or holiday scheme initiatives, organising training for teachers on DCD and when to refer to occupational therapy services etc.

Thank you for taking the time to complete this survey. Please return it to:

Sheelagh Richards
Chief Executive
College of Occupational Therapists
106 – 114 Borough High Street
LONDON, SE1 1LB

BY FRIDAY 19th APRIL 2002 AT THE LATEST PLEASE

SERVICE SETTINGS DATA:

Number of services	Child Development Team	School based service	Child & Adolescent Mental Health Team	Other service
1				
1				Community covering all 3 (CDT etc)
2				Community Paediatric OT Service
2	0	0	0	
1	0	0	0	Acute in-patients paed
1	0	0	0	All Paed refs-School, community, hosp
1	0	0	0	Ch/Mod-severe disability & families
4	0	0	0	Community Paediatric Services
1	0	0	0	Community - to integrated services
1	0	0	0	Community OT service in Acute Trust
5	0	0	0	Community Paed Team
1	0	0	0	Community Paed Therapy Team
3	0	0	0	Community Paediatric OT Service
4	0	0	0	Community Therapy Service
2	0	0	0	Disabled Children's Team
1	0	0	0	Hospital, Community
1	0	0	0	In/day patients/community/paeds
5	0	0	0	Paediatric OT Services
2	0	0	0	Paediatric Therapy Dept
1	0	0	0	Physical/learning needs/spec schools
1	0	0	0	PICU, ward, OP - Heart & Lung
4	0	0	0	Social Services
2	0	0	1	
7	0	1	0	
1	0	1	0	Child & Family Services
1	0	1	0	Clinic based
1	0	1	0	Com paed/Learn Dis & Phys/Sens Dis
1	0	1	0	Pre-school service
2	1			
27	1	0	0	
1	1	0	0	0-5yrs acute ax + advice
1	1	0	0	Acute in + out-patients
1	1	0	0	Acute service, inpatients, community /school
1	1	0	0	Ch/Mod-severe disability& families
1	1	0	0	Community Paediatric Services
1	1	0	0	Hospital, Community
1	1	0	0	Surestart
2	1	0	1	
1	1	0	1	Hospital based in & out-patients

22	1	1	0	
1	1	1	0	Acute in + out-patients
1	1	1	0	Acute service, inpatients, community /school
1	1	1	0	Community/home/clinic/outpatients
1	1	1	0	Community covering above
1	1	1	0	Community Nursing Team
1	1	1	0	Community Paediatric OT Service
1	1	1	0	Hospital Based in & out-patients
1	1	1	0	In/day patients/community/paeds
1	1	1	0	Paed assessment clinic
1	1	1	0	Social Services
2	1	1	1	
1	1	1	1	Acute in-patients paeds
1	1	1	1	Outpatients
1	1	1	1	Primary care in HC

DATA SHOWING HIGH PRIORITY WAITING TIMES:
(Where no times are given the form was left blank)

Number	Area	Average Wait	Wait in weeks
1	Channel Islands		
12	England		
5	England	< 1 week	<1
13	England	1 month	4
5	England	1 week	1
1	England	1 year	48
2	England	1-2 months	6
12	England	1-2 wks	1.5
1	England	1-6 months	12
1	England	1-6 months	14
3	England	2 months	8
5	England	2wks-3months	7
11	England	3 months	12
7	England	3-4 wks	3.5
3	England	3-6 months	18
1	England	4 months	1
3	England	4 months	16
2	England	4-5 months	18
13	England	4-6 wks	5
1	England	6 months	24
1	England	Immediately	0
3	Northern Ireland	1 month	4
3	Northern Ireland	1-2 wks	1.5
1	Northern Ireland	2 months	8
1	Northern Ireland	4-6 wks	5
1	Isle of Man	Immediately	0
3	Scotland		
4	Scotland	1 month	4
3	Scotland	1-2 wks	1.5
1	Scotland	2wks-3months	7
1	Scotland	3 months	12
2	Scotland	3-4 wks	3.5
1	Scotland	Immediately	0
1	Scotland	n/a	n/a
2	Wales		
1	Wales	1 month	4
1	Wales	1 year	48
1	Wales	1-2 wks	1.5
1	Wales	4-6 wks	5

DATA SHOWING DCD WAITING TIMES:

Number	Area	Average wait	Wait in weeks
1	Channel Islands	3 months	12
11	England		
1	England	< 2.5 years	<120
2	England	1 month	4
1	England	1 week	1
4	England	1 year	48
2	England	1-2 months	6
4	England	1-2 years	72
1	England	1-6 months	14
2	England	10 months	40
1	England	10 weeks	10
1	England	10-20 months	60
2	England	11 months	44
1	England	14 months	56
4	England	15 months	60
5	England	18 months	72
1	England	19-21 months	80
3	England	2 months	8
6	England	2 years	96
3	England	2-3 years	120
1	England	2-4 yrs	144
3	England	20 months	80
1	England	22 months	88
1	England	26 months	104
8	England	3 months	12
1	England	3-4 years	168
2	England	3-6 months	18
1	England	4-5 months	18
4	England	4-6 wks	5
2	England	5 months	20
11	England	6 months	24
2	England	7 months	28
5	England	8 months	32
2	England	8-10 months	36
3	England	9 months	36
1	Northern Ireland	1 month	4
1	Northern Ireland	1 year	48
1	Northern Ireland	1-2 years	72
1	Northern Ireland	15 months	60
1	Northern Ireland	18 months	72
1	Northern Ireland	2-3 years	120
1	Northern Ireland	3-4 wks	3.5
1	Northern Ireland	8-10 months	36
1	Isle of Man	2 months	8
2	Scotland		
2	Scotland	1 year	48
1	Scotland	10 months	40
1	Scotland	14 months	56

1	Scotland	2 months	8
1	Scotland	2 years	96
1	Scotland	2-3 years	120
1	Scotland	3 months	12
1	Scotland	3-4 wks	3.5
3	Scotland	4 months	8
1	Scotland	8 months	32
2	Scotland	9 months	36
1	Wales		
1	Wales	1-2 years	72
1	Wales	4 months	16
1	Wales	4 years	192
1	Wales	4-5 months	18

**Diagnostic and Statistical Manual of Mental Disorders : Fourth Edition
DSM-IV International Version with ICD-10 Codes**

Diagnostic criteria for F82 Developmental Coordination Disorder

- A. Performance in daily activities that require motor coordination is substantially below that expected, given the person's chronological age and measured intelligence. This may be manifested by marked delays in achieving motor milestones (e.g. walking, crawling, sitting), dropping things, "clumsiness", poor performance in sports, or poor handwriting.
- B. The disturbance in Criterion A significantly interferes with academic achievement or activities of daily living.
- C. The disturbance is not due to a general medical condition (e.g. cerebral palsy, hemiplegia, or muscular dystrophy) and does not meet criteria for a Pervasive Developmental Disorder.
- D. If Mental Retardation is present, the motor difficulties are in excess of those usually associated with it.

Coding note: If a general medical (e.g. neurological) condition or sensory deficit is present code the condition on Axis III.

(American Psychiatric Association 1995)

Editorial Note:

Although Gillberg's study referred to in paragraph 6.7 used the DSM III criteria, DSM IV is reproduced above to provide the unfamiliar reader with the contemporary diagnostic criteria.

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'Doubly Disadvantaged'
**Report of a survey on Waiting Lists and Waiting Times for Children with
Developmental Coordination Disorder (DCD)**

Survey carried out by The College of Occupational Therapists
and its specialist section
The National Association for Paediatric Occupational Therapists (NAPOT)

FACT SHEET

Key findings:

- In 30% of NHS trusts providing children's services across the UK, nearly 11,000 children were waiting for assessment by an occupational therapist. Of these, 6,719 were children purported to have DCD. A further 1,493 had been assessed but were waiting for treatment.
- Services give children with severe physical disability high priority. For high priority children, waiting times for occupational therapy services span from an immediate response to 16 months, with a mean waiting time of 7 weeks. In contrast, the span for children with DCD ranges from one week to 2-4 years, with a mean waiting time of 46 weeks.
- If extrapolated nationally, these waiting times must represent untold distress for disabled children and their parents.
- Occupational therapists throughout the UK are struggling to meet the needs of this group of children as they manage large caseloads and high referral rates. 42% of occupational therapy services do not assess children unless they can provide the follow up treatment they require, while 51% carry out assessments but are not then able to provide the level of treatment the children require.
- Children with DCD often have the same expectations as their peers placed upon them as DCD is often 'a hidden handicap'.
- Children with DCD are 'Doubly Disadvantaged'. In addition to being given low priority, children and young people with DCD are at significant risk of becoming socially excluded in adult life. A long term study (Rasmussen et al 2000) has shown that 80% of the children diagnosed with DCD at age seven were, by age 22, unemployed, had broken the law, were alcohol or drug misusers or had mental health difficulties (in comparison to 13% of the comparison group without DCD).
- Occupational therapists play a key role in the assessment, diagnosis, treatment and management of children with DCD. "Without an occupational therapist, parents could do more harm than good, trying to help their child": Mrs Joan Sheppard, parent of a child with DCD.

- Occupational therapists also play a key role in educating parents and professional colleagues to increase awareness and knowledge about the conditions. Paediatric occupational therapists report that many referrers are unclear about the diagnostic criteria for DCD and therefore make inappropriate referrals. Occupational therapy services invest significant amounts of time educating potential referrers about the condition to try to reduce the number of inappropriate referrals that exacerbate the problem of waiting times for children with DCD and indeed impact on the delivery of occupational therapy services to all children with special needs.
- Children with DCD deserve to have the same opportunity as other children to attain their potential and develop the occupational skills necessary for the successful performance of roles and responsibilities in their adult life.
- Early intervention to diagnose these children correctly and offer them, their families and the other professionals working with them, support and advice is crucial in preventing the known poor psychosocial outcomes.

**A snapshot of services covering 47% of health authorities / boards
and provided by 30% of trusts across the UK**

Waiting times for assessment for children with DCD

	Wait time for Assessment: DCD children	Mean in weeks	Mode in weeks	Median in weeks
England (n=101)	1 week to 2-4 years	46	72	36
Northern Ireland (n=8)	3-4 weeks to 2-3 years	52	72	48-60
Wales (n=4)	4 months to 4 years	75	NA	18-72
Scotland (n=14)	3-4 weeks to 1 year	12	32	32-36
Channel Islands (n=1)	3 months		NA	NA
Isle of Man (n=1)	2 months	8	NA	NA
TOTAL (n=129)	3-4 weeks to 4 years	46	72	36

Note: 15 out of 134 respondents did not fill in this data