Emerging Adulthood and Developmental Co-ordination Disorder

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to work of others.

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Abstract.

The aim of this thesis was to investigate key themes of emerging adulthood in young adults with motor co-ordination difficulties from both a parental and personal perspective using a mixed method approach. A number of studies over the past twenty years have considered longer term outcomes in children with Developmental Co-ordination Disorder (DCD) (Losse *et al.*,1991, Cantell *et al.*,1994, Cousins and Smyth,2003) but few have considered the social experiences of these young people and the views of their parents as they move into further and higher education. This study has focused particularly on the 16-25 year age group, a time of emerging adulthood and continuing developmental change (Arnett, 2000), which differs from the key previous study in adults by Cousins (2003), which centred around an older age group.

Emerging adults in further and higher education with motor difficulties completed questionnaires alongside a cohort of parents of these individuals. A subset from each group were also interviewed. A retrospective analysis of case notes of those seen in childhood from a clinical setting was also undertaken, in order to consider changes from childhood. Students were matched with a cohort of students without any reported difficulties. Social behaviour including driving, drinking, and leisure pursuits were compared with typically developing students. An additional comparison was made with students who considered themselves to be 'clumsy' but had a diagnosis of Dyslexia, in order to compare current support in Further and Higher Education.

This study has highlighted the persistent, pervasive and variable nature of DCD with over 50% of students reporting some level of impairment in an area of their life. These difficulties included learning to drive a car, difficulties with planning and organising themselves and their property, and continuing motor difficulties especially with handwriting and everyday tasks. Differences in social behaviour were also noted compared with control students. This study provides evidence that even in this resilient group who had reached further and higher education, DCD does not disappear for all once they reach adulthood.

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INTRODUCTION TO THESIS

A personal and professional journey.

I have both a personal and professional interest in children who have motor difficulties. My interest was first sparked over 20 years ago when my son was diagnosed at three years of age with Dyspraxia and has continued through school, further education and university. At the time of his diagnosis I was working in paediatrics and undertaking General Practice training. I was taught very little about Dyspraxia at that time or about any other developmental disorders. A neurologist diagnosed my son and this started a journey of exploration seeking out information, advice and guidance. Nineteen years ago there were few journal articles or books to read apart from Jean Ayres book (1965) about one intervention approach- sensory integration therapy which evolved in California. Most of my knowledge about motor difficulties came from talking to the Occupational Therapist that treated my son and from other parents who talked of their own experiences. I listened carefully to what practically had helped them. Most of the advice I sought for my son was about how to manage difficulties in school and how to encourage and enable him to become independent. I was also keen to try to find out what were the outcomes of some of the children whose parents I talked to, in order to reflect on my son's future.

Eleven years ago I opened a centre for children and adults with developmental disorders. Today the Centre has an interdisciplinary team of health and educational professionals who provide a clinical service to children and adults with developmental disorders. When the centre was first opened it focussed on children with Developmental Co-ordination Disorder (DCD) but expanded to see children with a range of developmental disorders and then expanded further to encompass adults, because many of the clients were growing up but their difficulties were persisting and as awareness grew adults were emerging recognising their difficulties and wanting help.

My work at The Dyscovery Centre has allowed me to have the privilege of being able to follow a number of young men and women over the past ten years who were seen in childhood as I have been able to stay in contact with their parents and learn from them of the changes that have occurred both positive and negative. This is a unique position in the UK, as the centre is one of the few specialist centres in the world that sees children, adolescents and adults with motor difficulties of this nature. The clinical work at the Centre has allowed me to observe some of the continuing difficulties that young people have, their strengths and positive qualities as individuals, and what has arisen as a secondary consequence of having difficulties in childhood. I have also witnessed the wide variability in how different children with DCD present. Some have differences in their patterns of motor difficulties and others have a picture of overlapping difficulties with other developmental disorders. This makes it difficult to predict the outcome for the young people and their families. I have also seen and experienced personally the impact and challenges of living with a young person with difficulties and how this can have an effect on the rest of the family. For this reason listening to parents as well as the young people is important in order to understand the context of their families and this is explored in this work.

I have also undertaken a personal longitudinal study of an individual with DCD as I have continued to be my son's parent, carer, careers counsellor as well as being a parent of two other children, one older brother and a younger sister, who have always found learning and living easy to do. More recently I have witnessed my son entering, participating, and studying at university and have had direct experiences of finding the pathway to access specialist and additional support at university and to see that at times this is tortuous and has some 'kinks' in it. For example, I have observed my son trying to handwrite a Disability Student Allowance (DSA) form three times (I then had to handwrite it for him) and only then to have it lost by the Local Education Authority. The application forms had boxes to fill in that were small and difficult for someone with poor handwriting to complete He had to travel to an appointment to be assessed 30 miles away when organisation, time management, and accessing new places may all be the skills he could have had difficulties with. It has also took him a term and two weeks before he had a note taker and student support assigned to him and already had three tests and two assignments. When he turned up for his first exam, they had forgotten to tell him he needed to go to a different campus for the exam. He was given a laptop on loan but it did not have additional software that may be of help. Sixteen weeks into his year he got a laptop. Finally he received two full boxes of software to help him that he did not have any training to use it, and they still remain on his shelf in his room [from case notes, 2005].

Thus from this very personal perspective I have witnessed emerging adulthood. As most of the research in DCD in the past has centred on 6-11 year olds this life long journey has prompted me to consider the stage of emerging adulthood. This is a sensitive time between adolescence and adulthood (16- 25 years) and has not previously been explored in detail. Looking at issues and experiences of emerging adults with motor difficulties along with the changing parental concerns may provide greater insight into both the persistent areas of difficulties but also will allow a greater view of the patterns of difficulties that also resolve.

Background to the study.

Children with co-ordination difficulties have been described in a number of ways since the 1930s (Orton, 1937). The names have changed over the years but few studies have examined the lives of children moving from adolescence through emerging adulthood (Arnett, 2000) and into independence. Most studies have looked at young people under eleven years of age. Four studies have looked at individuals around the age of 15 to 17 years, and only one has looked specifically at adults but the cohort had a mean age of 38 years. The stage of emerging adulthood presents the individual with a number of significant changes. The young person moves through puberty and also has the opportunity to become independent and self sufficient. This is the beginning of the individual being able to make choices in the way they live, study and socialise.

Understanding what are persisting difficulties in DCD, what resolves and what arises is not only important for the young person and their parents but also for the colleges, universities and workplaces that they may go to in order for appropriate support to be provided. There are also implications of the findings of this work on services for children, as if there is an understanding of what persists as a difficulty, either this can be addressed first at a young age or avoided and adaptations put in place.

This study firstly focuses on students who are in college and university who consider themselves as having motor co-ordination difficulties and examines their level of difficulties in childhood, and the diagnosis assigned to them. It looks at what they perceive to be their strengths and remaining difficulties. In order to gain a view of the characteristics of emerging adults with motor difficulties their daily functioning is explored compared with "Typically Developing" (TD) students without a known diagnosis of specific learning difficulties and also compares their social habits including smoking, drinking, sporting and hobby choices to a group of students without these difficulties. Additionally, the thesis examines in some detail their approach to learning to drive a car as this represents an important "rite of passage" for many young people as a marker of arriving at adulthood.

Gathering information from a cohort of parents whose children were diagnosed in childhood and then interviewing some of these parents allows a rich insight into their perceived concerns for their children and what had changed (or not) for them over that time. For some, this had been a painful journey with some of their children having additional mental health difficulties. For others, emerging adulthood heralded a time of hope and an opportunity for new horizons.

Much of the focus of the few previous studies in this age group (described in Chapter 3) has been on the *motor* functioning of young people with motor difficulties and has been in small numbers. None have focussed specifically on the lived experiences of students and their social habits and characteristics. Cousins and Smyth's (2003) study describe some aspects of functioning, including driving. It has been one of the few studies where this has been undertaken.

Research questions.

This thesis represents an attempt to broaden the understanding of DCD in a stage called emerging adulthood and covers the age of 16- 25 years. It attempts, by taking a mixed method approach, to answer the following questions.

1. Are there differences between students in further and higher education with motor difficulties to students without reported or recognised learning difficulties in terms of their experiences and behaviours? (The TD group).
   a. How can these be distinguished?

   b. How do students report their strengths and difficulties?

2. What are the social characteristics and behaviours of the motor difficulties group compared to the TD group including specifically:
   a. Leisure and hobbies.
   b. Smoking, alcohol consumption and drug usage.
   c. Driving behaviours.
3. How does the reported support given in further and higher education differ between those with motor difficulties given a diagnosis of DCD/Dyspraxia and other students with other diagnoses such as Dyslexia.
4. What are the lived experiences of emerging adults with motor difficulties as seen from the individual and parental perspectives?

Outline of the thesis

In order to answer the questions stated above it is necessary first to understand the historical perspective of motor difficulties. In Chapter 1 the literature review describes the changing terminology and descriptions attributed to children with motor difficulties and the challenge this presents at considering which group of individuals are being considered at any one time. It also describes the overlapping nature of DCD with other developmental disorders. This is an important feature in the study when considering the outcomes in individuals as compared to the group as this may influence their behaviour and pattern of responses. Chapter 2 describes what is understood about emerging adulthood in general and frames the basis of the study. Chapter 3 then describes the studies that have been undertaken specifically in adolescents and adults with movement difficulties and also presents the comparative literature from other developmental disorders. As previously stated, an overlapping pattern is common in DCD with other developmental disorders and it would be remiss not to understand the work that has been undertaken especially in the area of further and higher education in Dyslexia, Asperger Syndrome (AS) and Attention Deficit Hyperactivity Disorder (ADHD). Chapter four describes the current journey of assessment and support that a student with DCD takes in higher education at present and describes some of the pitfalls. Chapter five describes a rationale for the methodology chosen. The mixed method approach provides an opportunity to answer both the 'what' questions as well as the 'how'. By gathering information from a large number of students from across the UK with both motor difficulties and without this allows an understanding of the differences between students and some generalisations are able to be made. By then gathering additional information from students that were specifically assessed in childhood and diagnosed, a comparison can be made about their changing difficulties and behaviours over that time. This has been taken from a parental perspective as histories were originally obtained from them at that time. In interviewing a cohort of students along with a cohort of parents, this provides a rich insight into the lived experiences of the individuals and allows specific examples to be generated and further elucidated from the group data to give a richness and depth to the understanding of this group of individuals.

CHAPTER 1 DEVELOPMENTAL MOTOR DISORDERS

1.1.Introduction.

In order to gain an understanding of DCD in adulthood it is important to also understand the historical and changing views of what are motor disorders in childhood and how DCD is now defined at the present time. It is then necessary to consider the variability within the disorder and what is known about the overlap with other developmental disorders. Finally, in order to understand the social and emotional characteristics of the adult with motor difficulties, it is important to consider the literature in childhood. Understanding childhood behaviours in DCD allows one to predict potential social outcomes in emerging adults. It grounds the hypothesis that emerging adults with motor co-ordination difficulties are likely to continue to display some social behaviours different from the TD group and remain more socially isolated with fewer friends. This study also considers whether this impacts on their leisure choices.

1.2. Terminology and definitions.

In order to set the context of this study it is useful to consider the changing terminology and how individuals with motor difficulties have been identified and then grouped together in research, clinical and social settings and how this has changed over time.

Over centuries different terms have been used to describe children with a predominant picture of motor difficulties. Clumsy has been one of the most consistent terms used, derived from "clomsen" thought to be a Scandinavian term *"to be numb with cold"*, a term used since the Middle Ages. Collier in the 1900s'was thought to describe "congential maladroitness" (Ford, 1966). In 1925, Dupre and others referred to the debilite motrice (motorically deficient) and others described "motor awkwardness". First used by Orton in 1937, clumsiness has in recent times been seen to be a more pejorative term, to describe children with motor difficulties.

Articles referring to children with co-ordination difficulties were noted as early as the 1940s. In 1962 the first article on clumsy children appeared in the British Medical Journal (BMJ) (no author cited). The article referred to an earlier paper by Annell (1949) who had described the clumsy child as being:

> "awkward in movements, poor at games, hopeless in dancing and gymnastics, a bad writer and defective in concentration. He is inattentive, cannot sit still, leaves his shoelaces untied, does buttons wrongly, bumps into furniture, breaks glassware, slips off his chair, kicks his legs against the desk, and perhaps reads badly"
>
> *(pages not available)*

Other terms such as *"Awkward"* have been used to describe the movements. This stems from a middle English term *"awkeward"* meaning *"in the wrong way"* and was derived from “awke” or *wrong* -from an Old Norse term “öfugr” meaning backward. The last comment in this editorial highlights how children who were termed clumsy were viewed: “there is a real need for a concerted study of our *backward* children so that we can determine whether we can help them”. *(pages not available)*

The following terms used over the years to describe an individual with motor difficulties have been terms such as “minimal cerebral palsy”; “minimal cerebral dysfunction” (Bax & MacKeith ,1963) although this was used to describe children with wider deficits than just motor difficulties ;“perceptual-motor dysfunction” (Ayres,1965), and then Brenner and colleagues (1967) in the BMJ described “ visuo-motor disability in school children” . The descriptors have tried to highlight the potential underlying deficits such as perceptual-motor difficulties (Domrath, 1968), suggesting problems in perceptual-motor integration. However the more descriptive term “motor impaired” was used by Whiting, Clarke and Morris (1969). Ayres (1965) referred to clumsiness as developmental dyspraxia. Illingworth, (1968), Dare and Gordon (1970) at around the same time was using the term the ‘clumsy child’. Developmental agnosia and apraxia were used by Gubbay (1975) and described the children as displaying impaired motor performance despite normal intelligence.

Denckla (1984) used the term developmental dyspraxia. The term dyspraxia, one commonly used in the UK today, was derived primarily from adult brain injury literature and was linked to acquired difficulties more relating to gestural performance. It was described as: "a disorder of skilled movement which is not caused by weakness, ataxia, akinesia, deafferentation, inattention to commands, or poor comprehension" (Roy, 1996).

Canadian workers (Dewey & Kaplan, 1992) have defined dyspraxia in children as a difficulty in "performing gestures and use of tools" .Dewey later goes onto to state an exclusion criteria:

> "The term dyspraxic has been used to children demonstrating motor problems not due to documented basic motor impairment such as cerebral palsy"
>
> Dewey, 1995, p 256.

The term Dyspraxia is derived from the words "dys" and "praxis" meaning difficulty with planning. However the self help literature uses the term synonymously with children with co-ordination difficulties and would use DCD interchangeably.
The difficulties in getting a consistent terminology to describe these children drove the need to gain some consensus among researcher and led to an agreement to use the term Developmental Co-ordination Disorder, and was first started to be adopted in the 1990s especially after the International Consensus Statement in London, Ontario (1994) and to define it as:

> "DCD is a chronic and usually permanent condition characterised by impairment of both functional performance and quality of movement that is not explicable in terms of age or intellect, or by any other diagnosable neurological or psychiatric features. Individuals with DCD display a qualitative difference in movement which differentiate them from those of the same age without the disability. The nature of these qualitative differences, whilst considered to change over time, tends to persist through the life span".
>
> p 3.

Developmental Coordination Disorder (DCD) appears in both the Diagnostic and Statistical Manual for Mental Disorders ,The American Psychiatric Association; (APA) (DSM-III-R, 1987; DSM-IV, 1994; DSM-IV-TR, 2000) and the International Classification of Diseases and Related Health Problems ,World Health Organisation (WHO) (ICD-10, 1992a; 1992b; 1993). APA (DSM -IV-TR, 2000) and the WHO (ICD-10, 1992a; 1993) both have inclusive and exclusive criteria in the definition.

For APA the inclusive criteria see table 1 below. The definition most commonly used by both researchers and clinicians in the UK is the DSM-1V criteria (APA, 1994).

Table 1A: Diagnostic criteria for 315.4 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.

The WHO (ICD-10, 1992a; 1993) have both inclusive and exclusive criteria in the definition. The WHO (1992a) definition overlaps with the APA definition by noting that on a standardised test of motor impairment a child would score two standard deviations below the mean accompanied by interference with academic performance and/or activities of daily living. It notes that there should be no diagnosable neurological disorder and excludes those with an IQ below 70.

Table 1B: ICD-10 definition of SDD-MF (WHO, 1993).

F82 Specific developmental disorder of motor function

A. The score on standardized test of fine or gross motor co-ordination is at least 2 standard deviations below the level expected for the child's chronological age.
B. The disturbance in criterion A significantly interferes with academic achievement or with activities of daily living.
C. There is no diagnosable neurological disorder.
D. IQ is below 70 on an individually administered standardised test.

In 2006 (Sugden) a series of meetings were held in Leeds with international researchers and clinicians who critiqued the definitions and issues around this. A document and website with the consensus from the meeting was produced. Many of the issues that are highlighted in later chapters, such as the presence of overlapping patterns with other developmental disorders, the heterogeneity within the diagnosis, and the relevance of DCD in adulthood were all discussed.

These definitions were primarily constructed for use for childhood developmental disorders and were not coined to include adults and to consider how they may present once reaching adulthood and if these terms would remain suitable or relevant.It is questionable whether DSM-IV criteria for DCD can be fully applied to adults or would require additional questions about current functioning with amendments such as using work instead of school as an additional setting where impairment takes place. A second difficulty is at the present time there has been also a lack of standardised tests of motor functioning for this age group.

Despite the presence of consensus statements the confusion over terminology and the usage between professionals remain. Peters, Barnett and Henderson (2001) found in 234 adults (57% from the health professions and 43% from education) 'DCD' and 'Dyspraxia' were less familiar than the term 'clumsy' which was, however, least acceptable.

1.3. DCD in adults.

Regardless of the debate over terminology, there is evidence that some individuals continue to exhibit poor co-ordination into adolescence and adulthood. (Hellgren *et al*, 1994; Losse *et al*, 1991; Cousins & Smyth, 2003) (see Chapter 3 for further information on these studies). There remains no clear criteria for diagnosing adults and despite the evidence for persistence, and young people emerging requiring an assessment, there also remains poor service provision in the UK for those with DCD who are 16 years of age and over. In many areas services are limited, even for secondary school age children. Few paediatricians and adult physicians have experience of assessing and diagnosing DCD in adolescents and adults. This problem has stemmed partly from a lack of standardised tools and protocols to do so, and also little awareness of the continuing nature of the disorder. This can be mirrored in lack of services for adults with Asperger Syndrome (AS) and Attention Deficit Hyperactivity Disorder (ADHD) (Coghill, 2004; Berney, 2004).

1.3.1. Prevalence rates in child and adulthood.

Wright and Sugden (1996) advocated a two-step approach to assessment using the Movement ABC Battery (Henderson & Sugden, 1992) as the standardized measure for motor impairment and the Movement ABC checklist as a guide to examining the effects on daily living. Using this methodology, they found that the prevalence figure was 4-5% in mainstream primary schools. Clearly, prevalence is directly related to the manner in which assessment is employed and the establishment of cut-off points, and APA suggests a figure of around 6% for the age range 5-11 years.

It has been difficult to predict prevalence rates of DCD in adults as there have been different measurements used in the research, and as previously stated, there are no standardised tests for motor function in adulthood that cover a range of tasks. However, poor long-term outcome has been reported. This has ranged from 30-87% of participants with DCD having continuing difficulties into their late teens (Hellgren *et al.*, 1994; Losse *et al.*, 1991). There may be a number of contributory factors that explain why this figure varies so greatly, such as selection criteria, severity of symptoms and/or if the individual has overlapping difficulties with other developmental disorders such as ADHD, Dyslexia and AS. This will be discussed in greater detail in Chapter 3.

1.4 .Co-occurrence with other developmental disorders.

The term comorbid is used often in referring to conditions which overlap such as Dyslexia, ADHD and speech and language impairment. However the term comorbidity is misused in this context.

> "Co-morbidity-the presence of co-existing or additional diseases with reference to an initial diagnosis or with reference to the index condition that is the subject of study. This is 2 or more "diseases" with separate and different aetiologies which can present simultaneously or sequentially"
>
> Perrin & Last ,1995, p 412.

The above states that there must be *differing* aetiologies. However recent genetic work has considered that in some individuals with ADHD there may be a similar or shared aetiological base as DCD (Martin, Piek & Hay, 2006) and this causes increasing confusion over even using the term comorbidity at all. Clinically the lines of demarcation are not so clear either:

> "Taking a symptom approach (where criteria for a full co-morbid diagnosis are not necessarily met), hyperactivity, inattentiveness, labile mood, anxiety, aggression, sleep problems, eating problems, and elimination disorders are all much more common in children with developmental disorders"
>
> Baird & Santosh, 2003, p17.

At the Leeds consensus meetings there was extensive debate whether DCD is indeed part of a developmental spectrum rather than a discrete disorder (Sugden, 2006). Evidence for overlap with other disorders is extensive. Green *et al.* (2002) discusses the widespread prevalence of motor impairment in developmental disorders and discusses the difficulties of seeing this as being discrete and distinct syndromes. Some researchers have looked for overlap or co-occurrence (Kaplan *et al.*, 1998) as a way of gaining a greater understanding into the aetiology and mechanisms in DCD and the pattern of particular overlap may be important. Kaplan *et al.* (1997) in the Canadian population study showed overlap with ADHD, and dyslexia. In this study nearly 25% of the affected children were found to have all three disorders, while 10% had both ADHD and DCD, and 22% had dyslexia and DCD.

A number of studies over the last 15 years have demonstrated an overlap of DCD with other conditions and these include:

- Reading, attention and motor deficits (O'Hare & Khalid (2002), Kaplan *et al.* (1997), Powell & Bishop (1992), Tervo *et al.* (2002), Kooistra *et al.* (2005)).
- Social and emotional and behaviour, anxiety, and depression (Geuze & Borger,(1993), Hellgren *et al.* (1994), Sigurdsson *et al.* (2002), Francis & Piek, (2003); Piek *et al.*(2007)).
- Specific Language Impairment (Hill (1998); Powell & Bishop (1992); Elbert (1993), Powell & Bishop (1992)).

AS and motor difficulties have also been associated (Green *et al.*, 2002; Ghazuiddin & Butler, 1998). For example, in the latter small study all 12 of their subjects with AS demonstrated motor coordination problems on the BOTMP (Bruininks, 1978). Green *et al.* (2002) found that 81% of the children with AS who were tested, scored in the definitely impaired range and all scored in at least the borderline impaired range, on Movement Assessment Battery for Children (MABC)(Henderson & Sugden, 1992). A recent study by Hilton *et al.* (2007) compared 41 six to 12 year olds with AS with 56 controls of a similar age using the M-ABC and showed that 65% of children with AS were in the category of definite impairment with another 25% with borderline impairment, showing very high levels of associated motor impairment.

Particular interest has focused on the overlap between ADHD and DCD for over 30 years (Denckla & Rudel ,1978; Gillberg, 1998; Piek, Pitcher & Hay, 1999; Pitcher *et al* ., 2003; Rasta & Eliot ,1999). One of the first studies to highlight a potential shared genetic basis between ADHD and DCD, is the twin study by Martin, Piek and Hay (2006) which showed a particular linkage between the ADHD –inattentive and DCD-fine motor grouping. 1285 twin pairs aged 5 and 16 years were analysed using the criteria from DSM-1V for ADHD and alternative SWAN (Strengths and Weaknesses of ADHD Symptoms and Normal Behaviour scale)(Swanson *et al.*, 2001) and the Developmental Coordination Disorder Questionnaire (DCDQ) (Wilson *et al.*, 2001). Statistical analyses showed a strong shared additive genetic component between most subtypes of ADHD and DCD to the subtypes of the other disorder. The DCD (fine motor) and ADHD (inattentive) were most strongly linked using the DSM-IV based scale. On the SWAN scale results were similar, but also on the general coordination scale were strong linkages.

The evidence for high overlap of ADHD with DCD led Gillberg and Gillberg (1989) to describe this combination as DAMP (deficits in attention, motor control and perception). DAMP is diagnosed when ADHD and DCD co-occur in children who do not have severe learning disability or cerebral palsy. Gillberg (1995) criticised studies on ADHD not focussing on the motor elements of the disorder i.e. the "concomitant neuropsychological and motor coordination problems" (p. 139). He later stated that:

> "DCD is probably the most consistently associated conditions encountered in children diagnosed with ADHD"
>
> Gillberg *et al.*, 2004 , p 83.

Sergeant (2000) in proposing the three-tiered cognitive-energetic model to try and conceptually understand ADHD firmly links executive functioning (EF) *and* motor functioning. (EF is defined "as the ability to maintain an appropriate problem-solving set for the attainment of a future goal", p1). The implications of having this overlap are discussed in some of the studies described in Chapter 3. One study from Piek *et al.* (2007) demonstrated that children and adolescents with ADHD and DCD demonstrated higher levels of depressive symptomatology than those with one or other conditions separately implying a summative role.

A further discussion about the literature relating to this overlap in later life is discussed in Chapter 3.

Kaplan *et al.* (1998) believe that there are underlying causes for all the specific learning difficulties and uses the term Atypical Brain Disorder to describe the spectrum (ABD) rather than specifying conditions. This suggests that syndromes described actually represent semi-random cluster of symptoms. She proposes that by using a single term for all learning difficulties and then focusing on the individual's symptom patterns, the pressure to pigeonhole children would be removed. This may be considered to be turning the clock back to the term minimal brain dysfunction (MBD) and may lose the focus on the primary deficit.

Pennington (2006) in a detailed analysis challenges the current thinking and describes the current issues:

> "a probabilistic, multifactorial model of the etiologies of these disorders is widely accepted, our cognitive analyses of them often relies on a deterministic, single deficit model. So, there is a potential contradiction between our etiological and cognitive models for understanding such disorders"
>
> p 386.

The overlapping patterns may not be just of academic interest but may have implications for predicting outcome and also selecting the type of support and intervention approaches to choose. Caron and Rutter (1991) discussed the need to attend to co-morbid patterns. They concluded that if co-morbid patterns are not recognised then this may result in misleading conclusions by researchers and subsequent negative intervention or inappropriate results from practitioners. Similarly, Blondis (1999) recommends that in order for the needs of patients with ADHD to be addressed, paediatricians must be able to recognise motor co-ordination deficits and give appropriate advice to caregivers. In reality taking two children with similar motor disorders but differing associated characteristics they are likely to show different profiles and will require a differently focussed intervention schedule.

1.5. DCD- social and emotional characteristics in childhood.

It is important also to describe what is understood from the childhood literature with regard to the social and emotional characteristics that are associated with DCD. The childhood perspective is important when considering adult outcomes, as childhood experiences and behaviours are likely to be linked. There have been a number of studies in DCD examining the impact of DCD on social behaviours such as leisure pursuits and friendships. Motor competence has been repeatedly emphasised as a crucial element in the psychosocial lives of children (Rose, Larkin & Berger, 1997). Children with DCD have also been shown to experience social isolation, low self-esteem and increased levels of depression (Henderson & Hall, 1982; Maeland, 1992).

The emotional impact of having DCD in childhood has been demonstrated in a number studies (Bouffard *et al.,* 1996; Gubbay, 1975; Schoemaker & Kalverboer, 1994). Children with motor difficulties have been shown to be more introverted and anxious and see themselves as less physically and socially competent than their peers (Cummins, Piek & Dyck, 2005; Schoemaker & Kalverboer, 1994; Skinner & Piek , 2001). Skinner and Piek (2001) also found that children with DCD aged between eight and ten years had significantly higher levels of state and trait anxiety. Socio-emotional problems have been noted in children with motor difficulties starting from the age of six years old (Schoemaker & Kalverboer, 1994).

Some researchers have measured the effects of poor motor co-ordination focusing on self esteem (Rose, Larkin & Berger, 1997). These studies have shown children with DCD to perceive themselves as less competent than their peers not only in the domain of physical play (athletic competence), but also in several other domains including physical appearance and social acceptance (Demetre *et al.*, 1996; Rose, Larkin & Berger, 1997; Skinner & Piek, 2001). Skinner and Piek (2001) also showed that children with DCD reported lower perceptions of social support than their co-ordinated counterparts. Of particular interest is that as the children in their study became older, these feelings increased, as did their levels of anxiety. Schoemaker and Kalveboer (1994), in their study using Harter's (1985) Pictorial Scale for Perceived Competence for Children, also concluded that children with DCD perceive themselves to be less athletically and socially competent than control children. A number of researchers (Cantell, Smyth, & Ahonen, 1994; 2003; Maeland, 1992; Piek *et al.*, 2000;Van Rossum & Vermeer, 1990) have all described significant differences in perceived competence in the athletic domain between DCD children and control children. Both Piek *et al.* (2000) and Skinner and Piek (2001) work have also shown the importance of physical appearance as a significant contributor to global self-worth.

Appearance in DCD may be an additional factor in the choices of leisure pursuits. Faught *et al.* (2005) showed an increased rate of obesity in boys (but not in girls) with DCD and also an associated lowered cardio-respiratory fitness in these children. The link between self efficacy and physical activity has been studied by Cairney *et al.* (2005). If children are less active because of their motor difficulties this has a limiting effect on the leisure choices they then make. This may be mediated by the fact that other children don't want to play with them, or they themselves choose to interact less (George & Feltz, 1995; Mandich, Polatajko & Rodger, 2003).

Boys with DCD show lower participation in team sports and informal social and physical activities (Poulsen, Ziviani & Cuskelly, 2006) .This study demonstrated that "only team sports participation was identified as a significant mediator of the relationship between physical ability and life satisfaction" (p 855). This study also described that the boys that participated less in structured team activities were also then less likely to participate in non adult led activities such as playing out with other kids.

1.6.Conclusions.

This chapter describes the changing terminology in the field of motor difficulties. The changes in terminology make comparisons from studies over the years harder to achieve. Secondly, the overlapping nature of DCD with other developmental disorders makes it even harder to present a uniform understanding of outcome in adults as the additional factors such as presence of other conditions such as ADHD may have a distinct influence on this. The challenge has been to consider a model that can be used to represent the individuals who are live with more than one diagnosis. Terms such as atypical brain disorder and minimal brain dysfunction have come and gone in popularity. The continuing representation of disorders in separate boxes for the purpose of diagnosis, research and support makes moving to an over arching descriptor to present a group of difficulties a continuing challenge but one that needs to be considered in the light of the emerging genetic and behavioural literature.

CHAPTER 2 EMERGING ADULTHOOD -DEVELOPMENTAL TRAJECTORIES

2.1. Introduction.

In order to gain an understanding of emerging adulthood in those with motor difficulties it is important to consider what is known in general. This chapter describes the literature around this area and what factors may increase the success rates of emerging as a resilient adult. Finally, the role parents play in this process is discussed in the context of the balance between the need for continuing support with the need to develop increasing peer – peer interaction and ultimate independence.

This chapter is especially relevant for the young person with childhood motor difficulties, who may be postulated from the childhood research to have lowered self worth, less risk taking behaviour, and an increased need for maintaining parental support. All of these factors may lead to greater delay in reaching the stage of individuation. Past behaviours may result in the young person with motor difficulties arriving at college or university having not undertaken any risk taking behaviour, been at home more with his or her parents than peers, and have less self confidence and fewer independent living skills. The individual may also have fewer skills in grading their behaviour, because of lack of experience and being presented with 'all the candies in the shop' all at once could be postulated to make poor choices such as drinking excessively or experimenting with drugs (Baumrind, 1991; Dworkin, 2005). The research presented in later chapters will highlight key aspects of behaviours seen in the adults with motor co-ordination disorders in FE and HE.

However this chapter is centered around what is known about the "typically developing" emerging adult and what influences both positive and negative outcomes.

2.2 Emerging adulthood.

Emerging adulthood is the name given to the important stage bridging adolescence and adulthood, where the individual is clearly still dependent on their parents. Arnett (1994) describes this time as a distinct period in terms of identity exploration. It is seen more in industrialised countries, where economically and so practically the adolescents may have time for social and workplace experimentation before settling into adulthood. This period of time may also ultimately have a consequence on the future course of the psychopathology and mental health of individuals (Schulenburg *et al.*, 2004). It is a unique time for identity exploration in order to establish a basis for values and attitudes, establish rules of social behaviour and create a value system for the individual themselves in the context of their society (Hauser & Greene, 1991).

The arrival at adulthood can be marked by a number of factors. First of these is the ability to establish a relationship with parents as an equal adult i.e. having independent views and seeing them as a separate entity (Arnett, 1994; 1997). Secondly, the individual needs to learn what social norms are and be able to comply with them. These include refraining from behaviour such as drinking to excess or experimentation with illegal drugs (Arnett, 1994). There have been different definitions of the emergence from child to adulthood.

Arnett (2000) states that:

> "Having left the dependency of childhood and adolescence, and having not yet entered the enduring responsibilities that are normative in adulthood, emerging adults often explore a variety of possible life directions in love, work, and worldviews"
>
> p 469.

2.3. The process.

One of the key elements of arrival at adulthood is the formation of a stable identity (Marcia , 1980). There is some evidence that the process of identity formation can continue into the twenties and thirties (Waterman, 1999). The individual is forming their identity in the context of the society they are living in and the family structure they are belonging to. The individual's sense of self is important to consider in terms of their ability to emerge as a strong and independent adult. The construct of the self is influenced by both past events as well as the individual's present status. Negative events at school for the individual may affect the ability to goal set and gain hope for a positive future. The hopes of the individual are based on the ability to set goals and be motivated to decide on how to reach their goals and follow a path towards them.

Different researchers have used different models to explain this process. Reifman *et al.* (2003) talk about the five main features of emerging adulthood:

1. The age of identity explorations- in relationships, studying and work
2. Age of instability
3. The most self – focused age of life
4. Age of feeling in between - in transition
5. Age of possibilities

The adolescent in the process of becoming an adult has to undertake two processes one of separation and one of individuation. The individual needs to leave behind the parents' view of him or her as a child. The process of separation and individuation (Meeus, Maassen & Engels, 2005) has been seen as essential developmental stages to go through in order to reach adulthood. However the two processes have not been seen to be directly linked to one another. In individuals with DCD, there may be a delayed process in terms of separation as they continue to spend more time with their parents, and need for continuing social support. Identity develops progressively, and is undertaken through exploration. This is born out of a strong sense of self, and confidence. However the young adult who is uncertain of himself may explore too much and also demonstrate high levels of risk taking behaviour. The transition to high school has been associated with increased importance of peer social support (Harter, 1987). As young people go into their teen years, approval from classmates and peers becomes more central in determining the perceived popularity and general social acceptance of young people both with and without motor difficulties. Harter (1987) showed a high correlation between physical competence and social acceptance or popularity.This is intrinsically linked to the individual's self perception. Self-perception refers to the ways in an individual sees him or herself as separate from everything and everyone else (Harter, 1999). Views on self perception differ. Rosenburg and Kaplan (1982) describe self-perception as the totality of the individual's thoughts and feelings with reference to himself as an object. Dworkin's study (2005) showed that college and university students attributed their rates of experimentation to two transitions:

> "The transition out of high school and into college and the transition to greater independence"
> p 234.

In order to develop independence there needs to be a level of autonomy over decisions that are made. The definition of autonomy as it is defined within the self-determination theory is that:

> ''Autonomy involves being volitional, acting from one's integral sense of self and endorsing one's action. It does not entail being separate from, not relying upon, or being independent from others"
>
> Deci & Ryan, 2000, p 242.

The emerging adult needs to experiment and this is seen to have a key developmental role (Baumrind, 1991). Dworkin (2005) describes examples of this as:

> “as facilitating peer interactions, teaching youth to negotiate behaviours that become legal post-adolescence, and facilitating identity achievement.”
> p 219-220.

Once in further and higher education there is far greater opportunity to party, drink and experiment. The ability to successfully traverse these choices may require a set of behaviours. These may be related to readiness and a maturity of the emerging adult to make these choices and to control the level of impulse control. In many individuals some experimentation will have started to happen in teen years before arrival at college or university but for the individual with motor difficulties this may have been to a far more limited level.

2.4. Factors affecting successful emergence into adulthood.

2.4.1. The Process of Individuation and Separation.

Terms to describe the process of emerging adolescence into adulthood have included: individuation, independence, autonomy and detachment. Research has focused on the importance of separation of the individual from parents and the effect this has on adjustment to college (Byers & Goossens, 2003). Impaired separation from parents has been linked to symptoms of distress in college populations and poor adjustment (Lapsley & Edgerton, 2002; Rice *et al.* 1995).

The need for separation from parents, the process of individuation and the parallel needs for compensation and support may be at odds with becoming truly independent. The individual although not completely independent may leave home to go to further or higher education but may not be at the stage where they can cope with being fully independent or able to make autonomous decisions. Work by Baumrind (1991) and Barber (2002) have shown that the style of parenting can influence this process. Over intrusiveness can be as damaging as letting go too soon. Emotional autonomy is the perception the adolescent holds about his or her parents' rather than the adolescent's actual behaviour, and one measure that considers this is the 'emotional autonomy scale' (Steinberg & Silverberg, 1986). It is thought to measure the

> "degree to which adolescents have relinquished childish dependencies on and infantile perceptions of their parents"
>
> Byers & Goossens, 2003, p 367.

However other factors in the parent-adolescent relationship also need to be considered in order to gain a full picture. Changes in parents can impact also on the emerging adult. As the child becomes an adult, the parents are of course ageing, and ill health in a parent may become an additional issue. One example of this was a referral to the Dyscovery Centre from a family where the father had a severe cardiac condition and the mother had poorly controlled Diabetes. This resulted in the adolescent no longer being able to be taken to extracurricular activities which had helped him socially and with his motor difficulties.

2.4.2. Positive Parental Relationships.

In order to reach adulthood the individual has to separate from their parents. First, before this takes place, according to Bowlby and Parkes (1970), creating good foundations of early attachment to parents are important in creating good self esteem and development of identity. Secure attachment has also been linked with greater safety in exploring new activities (Felsman & Blustein, 1999). Parental monitoring, knowledge, support for autonomy, closeness, and warmth have been found to be critical to the healthy development of adolescents (Bugental & Goodnow, 1998). There may be gender differences in these influences, where females are more greatly influenced than males by family socializing resulting in reduced risk factors for behaviour (Roche, Ahmed & Blum, 2008).

Parental separation today may not mean leaving the parental home, as increasing numbers of students are remaining in their home town, many for financial reasons. In order for a successful transition it would still be necessary to encourage the five key criteria to occur: identity exploration, instability, self focus, feeling in between and widening of possibilities (Riefman *et al.*,2003).

2.4.3. Peer relationships.

As the emerging adult matures, there is a tendency to begin to look more to their peers as sources of support (Shucksmith & Hendry, 1998). Learning how to make close and personal relationships tends to come from the relationship from parents and from early attachment bonds with parents (Allen & Land, 1999). Increasing freedom from the family normally provides the opportunity to experience relationships and situations away from the familiar, protective shelter (Hass, 1979). Baumrind (1991) has shown the individual usually moves closer to their peers in order to practise new skills and as a consequence of this are more able to cope with changes in their life. Young adults with DCD may have fewer opportunities to gain friendships and so less opportunity to rehearse these skills before arriving at adulthood.

Internalisation of values is also an important stage, moving from being controlled by others to having views of one's own and making own decisions. Kiesling *et al.* (2006) have also shown in US studies that religiosity is another positive factor at the stage of emerging adulthood, but it may be the positive relationship with family and the stable family influences that are the true factor here.

Loneliness has correlated as a factor during adolescence and college with alienation and social anxiety, and lowered self esteem (Sandstrom & Zakriski, 2004). A key time for students may be when they first arrive in their new setting. Wiseman, Mayseless and Sharabany (2006) examined several factors that may be attributed to loneliness in 146 undergraduate students in the middle of their first-year at university. They state that:

> "A particularly high risk of loneliness was found during the transition to college when emerging adults are faced with the stress of living away from their family and of lacking their previous social support system."
>
> p238.

This may be related to self perception and then as a secondary consequence of how others perceive the individual. Students who remained lonely have been shown to be critical of the quality of the relationships they had formed (Shaver, Furman & Buhrmester, 1985). Wiseman *et al.* (2006) go on to say that:

> "The negative self-view might induce others to stay away leading to greater social isolation."
>
> p245.

Immature social interaction patterns may also be a risk factor for chronic loneliness in adolescents (Carr & Schellenbach, 1993). Children with DCD may have less opportunity for social interaction and so may arrive at FE and HE with less practice and therefore less confidence and be at increased risk of social isolation and consequent loneliness. Jobe and Williams White (2007) alternatively posited that abnormal social communication may be a factor in resulting loneliness and examined autistic traits in a general population of college students (average age 19 years) to test this hypothesis. They found that those individuals with a stronger autism phenotype were significantly more likely to be lonely and have fewer and shorter duration of friendships.

2.5. Risk taking behaviours.

It has been well documented that adolescents participate in risk taking behaviour more than adults such as reckless driving and alcohol and drug experimentation (Arnett, 2002). By late teens there is a greater understanding and ability to reason about these situations but it is thought more recently that this stage may be related to psychosocial maturity (Cauffman & Steinberg, 2000). An alternative view has been posited that the influence of peers may be a particular factor at this stage. This has been seen from the criminology literature, which has shown that crimes undertaken at this stage are generally undertaken with their peers (Zimring, 1998). However this may in fact be dependent on the group one is associating with i.e. risk taking depends on the risk-taking tendencies of the group members (Hogg, Turner, & Davidson, 1990). Young people with DCD may or may not be in risk taking groups. This may be related to the presence or absence of having other developmental disorders such as ADHD and Conduct Disorder, which may increase the risk of the presence of impulsivity and negative behaviours.

2.6. Sibling relationships.

Sibling relationships at all times can have a balance between warmth and friendship and conflict and rivalry. It could be conjectured that the sibling of a young adult with DCD may become increasingly vocal about the time parents spend with the emerging adult with DCD rather than with them and this may provoke increased family tension. The need in the teen years to provide increasing mentorship and guidance may result in the sibling having to take a back seat. Alternatively the sibling may act as protector and supporter, allowing the individual with DCD for example to "share" in social occasions with his or her own friends. Some research (Scharf, Shulman & Avigad-Spitz, 2005) has shown at this time:

> "that emotional attachment between siblings remains moderately strong throughout adolescence."
> p64.

Little is known of the relationship between siblings in emerging adulthood. However the younger sibling may achieve independence before the individual with difficulties and this may accentuate the differences in. Particular markers, for example, may be passing a driving test, or stage of leaving home.

2.7. Prosocial behaviour

The literature has predominantly documented the assorted negative risk behaviours of emerging adults such as binge drinking, unprotected sex, and illegal drug use (Schulenberg, Sameroff & Cicchetti, 2004). Less focus has been placed on the emerging adults' positive orientations. Nelson and Barry (2005) showed that good self perception has a better outcome for adulthood and is linked with less risk taking behaviour. The emerging adult who can display prosocial behaviours appears to serve as an indicator of a positive developmental trajectory for the transition to adulthood (Padilla-Walker *et al.*, 2008). Mayseless and Scharf (2003) have even described emerging adults as gaining the ability to develop greater consideration for others as a necessary step for one to be considered an adult. However there may be specific aspects of prosocial behaviour that are indicators for a positive outcome. These may be important to recognize as they may be a potential resilience factor in some individuals with motor difficulties.

2.8. Conclusions.

A successful outcome in emerging adulthood has been described as the ability of the young adult to be able to select appropriate goals, optimization of ability and compensation for their difficulties (SOC). This model was first described by Baltes and colleagues (1999). This takes an ontogenetic approach, in that optimal development is achieved by increasing efficacy and driving for higher levels of functioning. A successful individual will select and optimise their strengths and then learn to compensate for their weaknesses. The fundamental basis of this model is the selection of appropriate goals where the individual is functional, in order to focus resources appropriately, and to compensates for difficulties provides an ideal model for development.

There has been some interest in the ability of children with DCD to set their own (Missiuna & Pollock, 2000). They may also have difficulties being able to make changes of the goal set fails. It could be that poor past experiences of goal setting and a lack of knowing how to adapt or compensate may have a longer term impact for the emerging adult when they are going though emerging adulthood. Reifman *et al.* (2003) describe this stage as the "age of instability". In my clinical experience working with adults with motor difficulties, some individuals have been noted to have made poor career decisions and have had difficulties optimizing their strengths, seeing the need to concentrate on their weaknesses rather than learn to compensate. This may be of particular consequence in FE and HE with students applying for courses without a clear idea of skills or eventual goals and resulting in the individual starting one course and then moving several times or giving up the course all together.

> "In both love and work, most people make a transition by their late twenties from the explorations of emerging adulthood to the more settled choices of young adulthood"
>
> Arnett, 2004, p124.

There are several reasons why students "fall out" of FE and HE. Some individuals may not be ready to start in FE or HE but are encouraged by parents to do so because they have reached the correct age and stage. Some students may lack the organizational skills required to be successful and still require high levels of parental support and so cannot cope when they get to their college or university. Some students start the academic year but may have a lack of self control and so get into trouble physically, psychologically or emotionally. Finally, some students have to stop attending for financial reasons.

The interplay between the number and type of choices or goals the individual makes and the ability to adapt or compensate and choose alternative pathways is of interest not only in terms of general understanding of the emerging adult but in particular in the context of DCD.

An alternative emotional theory could be considered for differences in being able to set appropriate goals. This is one of "hope theory" described by Snyder (2002) who considers two major types of goals: positive goals with a clear outcome or a negative goal, deterring something, so that it never occurs. This view of hope defines the way an individual may decide which pathway or goal to choose. The emerging adult with DCD from experience of not achieving educational and social goals may become a low hope individual and emerging into adulthood being less able to goal set appropriately because of these emotional responses.

If the period of adolescence is a time of re-organisation and movement towards independence it is likely that certain changes may go along a number of different trajectories. A mismatch in pace and coupling between some areas of skills acquisition and others may be seen in the emerging adult with DCD, where attaining some skills may be at the same speed as others but where other skills may still show some time delay. It may be only when the emerging adult has *all* the skills in place that independence and adulthood are ultimately reached. Alternatively, it may in fact be there are an optimum *number* of skills one must have to operate adequately.

CHAPTER 3 OUTCOMES FOR ADOLESCENTS AND ADULTS WITH MOTOR AND RELATED DEVELOPMENTAL DISORDERS.

3.1. Introduction.

This chapter describes the current understanding and knowledge of DCD in adults and describes some of the studies from key authors that have been undertaken in this area.

Secondly, it describes the literature on comparative developmental disorders including ADHD, Dyslexia and AS in view of the high levels of co-occurrence that have been evidenced and described in Chapter 1. Cousins and Smyth (2005) in their detailed review of the literature in their chapter "Progression and development in Developmental Co-ordination Disorder" (p119) described many of the studies below. They also emphasise the host of intrinsic and extrinsic factors that may change the outcome for an individual including drive and motivation, external parental or professional support.

3.2. Persistence of DCD.

Views have changed about the nature of developmental disorders over the last 60 years and have gone from a standpoint of inevitable resolution to one of understanding the potential for persistent and more pervasive nature of all developmental disorders including DCD. Historical beliefs were linked to the current understanding at the time of the nature of the conditions. Annell (1949) regarded motor difficulties as "one of delayed maturation" and because of this it is presumed, then concluded that "recovery is usually spontaneous", thus implying that children grew out of their difficulties or their difficulties disappeared with maturation. The unnamed author of the editorial in the British Medical Journal (BMJ) in 1962 described a series of cases of children who had been reported as clumsy and thought at that time the causes were diverse but postulated that "In some it is due to delayed maturation of part of the nervous system " (p 1666). A differing view from a BMJ leader article from 1988 by Hall discussed the need to look at the cause for clumsiness as related to "motivation and good teaching" and refers to extrinsic factors affecting the young person. He described how he thought that motor performance was influenced by emotional state. This demonstrated a change in understanding of the impact of having a motor difficulty as being an isolated difficulty and the link between emotion and motor functioning. However he seemed to have conflicting ideas that motor difficulties resolved in the teen years, but he also thought that they could re-emerge when a new or novel skill needed to be learnt. An additional interesting viewpoint by Hall showed that he may have believed that DCD was not a medical condition at all, but one of a lack of talent and should be dealt with educationally rather than medically.

> “we do our patients no service by treating clumsiness as if it was a disease. With only rare exceptions clumsiness is a talent deficit and like other learning disabilities is primarily an educational problem”
>
> p 376.

From the 90s onwards there was an increasing interest in the outcome of children with DCD. At that time little specific work had been undertaken following young people into adulthood in order to see who continued to have difficulties and also what effect intervention had might have on the outcome. There has been difficulty in comparing the outcome of different studies, because until DSM-1V (APA, 1994) appeared and criteria were set, different researchers used different criteria and terminology.

Increasingly today more children have been diagnosed with DCD and greater emphasis has been placed on supporting students in college and university with specific learning difficulties. As a consequence of greater awareness other individuals are either presenting asking for advice or wanting to know whether they have DCD. This has led to a need to consider how young people present, what criteria should be used to diagnose adults with DCD, and the tests to be used.

Current criteria describing childhood developmental disorders may not adequately describe the subtle cognitive or motor symptoms that may change and present differently in emerging adults with DCD. The present guidelines and consensus on the identification and management of DCD is for childhood alone and may need to be extended or indeed separate criteria set down to include adolescents and adults. The current DSM-1V criteria are written for children and make no mention of employment or adult life. In the field of ADHD there has been greater debate and research in the past few years about the adult with ADHD compared to the field of DCD, and indeed the latest book by Barkley, Murphy, & Fischer (2008) describes current understanding and research in this field.

When considering persistence and resolution in DCD it is likely that some symptoms of DCD may diminish in adulthood. This may be because of several reasons. Firstly, the individual may have received intervention in childhood, and so improvement could be attributed to this. Secondly, symptoms appear to be reduced, because the young adult has learnt coping mechanisms and finally, the individual may have acquired the skills through prolonged practice. Adults are also able to choose an optimal environment and avoid situations that emphasise their difficulties e.g. being able to avoid playing team games, or using a keyboard to record information rather than hand write. Difficulties may only be apparent when trying out new skills or when they are more complex tasks such as learning to drive a car.

Two potential rationales for improvement may be firstly at puberty hormonal changes that may have a positive effect on motor function. Hadders -Algra (2002) postulated that the onset of puberty, mediated by hormonal changes (such as thyroxine and oestrogen) can affect myelination which could possibly result in an improvement of the underlying neurological condition (Sporns & Edelman,1993). Another potential rationale for improvement in adolescence may be linked to continuing brain maturation, especially of the pre-frontal cortex, and this may be associated with a consequent improvement in executive functioning (EF) skills in the individual's 20s as has been discussed in the field of ADHD (Diamond, 2000 ; Giedd, 2004).

It is important to consider which children are likely to continue to have difficulties during the stage of emerging adulthood so support can be provided for them. In attempting to predict different children's outcomes Sugden and Chambers (1998) have shown the difficulty in doing this, as they have shown the wide variability in children's responses to intervention from a relatively permanent state of improvement to no improvement at all. Wilson and McKenzie (1998) also postulated the different patterns that may improve and concluded that motor aspects were likely to improve but visual perceptual skills may be more resistant to change.

It is likely that the presence of other developmental disorders may also be a predictor for continuation. The overlap particularly with ADHD may be an important area to consider in emerging adults with DCD. The presence of overlap has been discussed in chapter 1 describing a number of studies on children (e.g. Gillberg, 1998, Kaplan *et al.*, 1998). The combination has been shown by a number of researchers to predict a worse outcome. For example, Tervo *et al.* (2002) showed that children with a combined picture of ADHD and DCD were more likely to have other neurodevelopmental and behavioural problems than children with ADHD alone. Crawford and Dewey (2008) have also shown that the combination of difficulties may change the presentation seen in children, " the presence of visual perceptual difficulties in children with DCD appears to be associated with co-occurring ADHD or RD" (p166) and not distinctly to do with DCD alone. This may be an important factor when considering outcome in adults as the *pattern* of heterogeneity may be a predictor i.e. which difficulties are combined together. It could be conjectured that a worse outcome would occur for the individual who has poor social and organisational skills as well as poor motor skills than poor motor and literacy skills as this combination may be more pervasive and harder to compensate for. Hellgren *et al.* (1993) in their long term follow up study also showed a poorer outcome for the ADHD and DCD combination, and these individuals had a greater risk of long term psychiatric morbidity than those with DCD alone. This was also echoed by Rasmussen and Gillberg's (2000) longitudinal community-based study followed up children who had been diagnosed at seven years of age with ADHD. This study found that at 22 years of age, 58% of the participants with either ADHD and/or DCD had a poor outcome compared to 13% in the comparison group with neither diagnosis. The DCD group alone and the ADHD/DCD combined group had the worst prognosis of 80% and 69% respectively. Those with the combination of DCD and ADHD showed that they were more likely than their matched controls to be unemployed, have had problems with breaking the law, to be alcohol or drug misusers and to have mental health difficulties. Depression was noted in all groups but the only ones with current depression came from the combination DCD and ADHD group. Caution should be applied with this study as the numbers at follow up were small.

If adding in ADHD to the diagnosis is a potential key factor in the outcome, it may be useful to consider the literature in adults with attention and concentration difficulties in order to consider if there are specific factors that may need to be considered in the context of DCD. Far greater focus and research has been undertaken considering the ADHD-like symptoms at this age than in the field of motor difficulties. In some studies the motor aspect even when described has been given little attention. One example of this was in one study carried out on young adults by Shelley and Reister (1972). They described 16 individuals (18-23 years) with difficulties coping with military training in the Air Force. These individuals were described as having "behaviour consistent with hyperkinetic behaviour syndrome" even though poor co-ordination and perceptual motor difficulties were also described as problematic The motor difficulties were explicitly mentioned but they were ascribed to the hyperkinetic disorder:

> "All patients showed "soft" signs of "neurointegrative disturbances" such as motor clumsiness, poor balance, confused laterality, and poor co-ordination. Psychological testing also revealed evidence of perceptual-motor problems and motor inco-ordination and timing."
>
> Barkley, Murphy & Fischer, 2008, p 12.

This emphasises the difficulties when researchers are working in one field and may demonstrate the potential for a biased viewpoint, concentrating on some aspects but not recognising the importance of others.

3.3. Studies on DCD in adolescence and adulthood.

In comparing studies on outcomes of young people with DCD there are a number of methodological issues that arise. These include the definition and cut off points for including or excluding children into the groups being studied and the method of testing used in each study. Some studies have used a neurological screening process (Shafer *et al.*, 1986) and others have used teacher or parent reporting of symptoms for inclusion into their studies (Losse *et al.*, 1991).

Tests used within the studies vary from study to study. Knuckey and Gubbay (1983) in one study reassessed 16-20 year olds who were previously tested at six to12 years of age (Gubbay,1975). They modified the tests and did not use the complete battery again. The Test of Motor Impairment (TOMI) (Stott, Moyes & Henderson, 1984) was used by Geuze and Borger (1993) who modified this when they tested children between 11 to 17 years of age, despite it not being normed for this age group.

Testing of adults for DCD is a relatively new phenomenon and choices of assessment tools remain limited. There are not "recognised checklists", as discussed by the Department for Education and Skills (DfES) Specific Learning Difficulties (SPLD) working group for colleges and universities, that have been formally validated in order to be able to determine who requires additional help or support. Three of the normed tests that are available that cover a range of motor skills are the Movement ABC- 2 (Henderson & Sugden, 2007) often used in the UK, and the Bruininks Oseretsky Test-2 (Bruininks & Bruininks, 2005) more often used in the United States but also used in the UK. The first test now has norms to 16 years of age, and the latter up to 21 years. A third test, the McCarron Assessment of Neuromuscular Development (MAND) (McCarron, 1982) has been normed to 18 years of age.

It is questionable whether using these tests which examine skills such as ball skills are appropriate in a clinical setting for adults in order to decide how to intervene, as games requiring ball skills can be avoided all together once the student has left school. Alternatively some of the subtests may be useful. However not all children display a similar pattern of weaknesses. The benefit of these tests is that they do cover a range of motor skills and can be used as a marker of motor impairment; the downside is they are not focussed on specific skills relating to adulthood, such as measuring the ability to prepare a meal, handwrite or self care. These tests may be more useful in a research domain in longitudinal studies, for example to follow up change over time.

In order to gain a view of current understanding it is useful to examine some of the previous studies. There have been both some follow up and epidemiological studies in recent years considering the outcomes of children with motor difficulties and some have considered the social and educational outcomes (Knuckey & Gubbay, 1983; Losse *et al.*,1991; Cantell, Smyth & Ahonen,1994).

3.3.1. Follow up studies.

As has been described comparison of studies is difficult. The longitudinal studies that have examined individuals with motor difficulties have considered different groups. This has been because of changing terminology and differing definitions of groupings. A number of early studies considered individuals with Minimal Brain Damage (MBD) and only later studies have considered children defined as having DCD. However the majority of these studies focussed on the motorical changes and did not always include the social impact these difficulties may have on the individuals.

3.3.1.1. Minimal Brain Damage or dysfunction and long term prognosis.

Both epidemiological and follow up studies have viewed motor difficulties from a wider perspective and have used terms such as Minimal Brain Damage (MBD) and ‘minor neurological dysfunction’ (MND) to describe children with some neurological impairment. Some other studies have considered aetiological factors in determining outcome such as the link between prematurity and poorer motor outcomes (Jongmans *et al.*, 1998).

MBD was first described by Strauss and Lehtinen (1947, p 4.) who defined their use of this term more in the context of a “brain-injured child” as:

> ...“ a child who before, during, or after birth has received an injury to or suffered an infection of the brain. As a result of such organic impairment, defects of the neuromotor system may be present or absent; however, such a child may show disturbances in perception, thinking, and emotional behaviour, either separately or in combination. These disturbances can be demonstrated by specific tests. These disturbances prevent or impede a normal learning process. Special educational methods have been devised to remedy these specific handicaps.”

MBD was also associated with the presence of “soft” neurological signs (Kessler, 1980; Tupper, 1987). These descriptions may seem more closely aligned to a diagnosis of cerebral palsy. To add to confusion MBD was also used to describe a population study in Sweden. In the 90s it fell into disrepute because of the inconsistent way it was used and it did not have clear operational definition. This changing use can be seen from the Swedish population study where children were followed up from the 1980s. The project was set up to examine the incidence of MBD in the population. A number of papers arose from this work (Gillberg, 1985;Gillberg & Gillberg,C.1988;Gillberg & Gillberg,C.1989; Gillberg,1995). However during the follow up of the study terminology describing the same cohort of children changed several times. MBD was used here to mean the child having attentional and perceptual and motor problems. Then the term Deficit in Attention, Motor and Perceptual difficulties (DAMP) was used.

The results of this study again showed some evidence for the ADHD/DCD overlap. At seven years of age, two thirds of children were noted to have language difficulties who had a diagnosis of DAMP (also known as MPD-ADD) (Landgren, Kjellman & Gillberg, 1998). Behavioural and emotional problems were also more common in the MPD-ADD group at ten and 13 years of age. (80 % and 64% respectively). Interestingly, almost half of the motor difficulties were no longer present on testing in the MPD-ADD group by age ten and two thirds by 13 years. At 16 years of age, the MPD-ADD group was more likely to have speech and language problems. Eight out of the thirteen in the MPD-ADD group still "appeared clumsy" (Hellgren *et al.*, 1993, p 886). Substance abuse was more common in boys in the MPD-ADD group than controls. However, numbers overall were very small - four boys compared to one boy. At 22 years of age, 55 subjects with ADHD (+/-) DCD were followed up from the original study (Rasmussen & Gillberg, 2000). At this stage the terminology had changed yet again and the groups were then referred to as individuals with DCD and ADHD. Thirteen of them were considered to be severe ADHD and DCD and 26 moderate ADHD and DCD. Five of the study group had DCD only. The severe DCD and ADHD, and the DCD only groups had the worst prognosis. The worse groups had greater difficulties over a number of areas compared to the control group. Major depression was common in all groups. Six of the ADHD and DCD group also had a diagnosis of AS. Thirty three percent of the ADHD –DCD group also had personality disorders diagnosed. Only one individual had attended university. Fifty eight percent of the DCD-ADHD group also had a diagnosis of a reading /writing disorder. Persistent inattention was present in almost half of the DCD-ADHD group, but hyperactivity was now at a much lower level. The reduction of the overt presentation of hyperactivity has been described in more recent adult literature.

Another major study of children with MND was from Holland and was the Groningen Perinatal Project. This project followed up children born between 1975 and 1978, and measured their neurological status. They were reviewed at six, nine and 12 years (Hadders-Algra *et al.*,1985; Hadders-Algra, Huisjses & Touwen,1988). This study is hard to compare with other studies. 21.5% were determined as 'suspect/mildly abnormal' and five percent were described as 'neurologically abnormal' were assessed at different times. However there were more males than females with difficulties, and the link between early neonatal difficulties and longer term problems is made in this study. This has also been noted in studies such as from Jongmans *et al.* (1998) who demonstrated increased motor difficulties in premature babies.

While of interest the lack of focus around the motor difficulties in particular makes it difficult to draw conclusions about outcomes from these studies.

There have also been very few follow up studies in the teen age group considering specifically the DCD group. Many of these studies have again described the children by a range of different terms including Minimal Brain Dysfunction and 'clumsy' as well as using terms such as Dyspraxia.

3.3.1.2. Follow up studies focusing on motor difficulties in adolescents.

One of the first of the follow up studies was by Menkes, Rowe and Menkes in 1967 in a 25 year follow up of patients diagnosed with MBD. Eight out of the 11 individuals still were shown to have definite abnormalities on neurological examination. Hyperactivity was still present in three patients. Eight individuals had in the past or currently had psychiatric disturbance.

Knuckey and Gubbay (1983) undertook a follow up study from an original 52 children who were classified as clumsy selected from a population study, compared with 51 controls. These were originally assessed at between ages five to 12 years and then samples of these were reassessed eight years later. Thirteen 'clumsy' children were matched with 13 controls. The mean age of the clumsy children was 18.9 years, and the controls were 18.8 years, with a range of between 16 to 20 years. They were tested on five out of the original eight tests. Originally, the children were significantly different on all tests compared to controls. However eight years later they were the same on all three tasks apart from a clap and catch task, and a piercing 20 pinholes task which distinguished the two groups. The children's social and educational outcomes were also examined and showed that the 'clumsy' group had less skilled jobs than controls, but this was not shown to relate to intelligence. Current engagement in sporting activities showed no difference between groups.

Losse *et al.* (1991) followed up children who had been assessed at six years of age and were now 16 years old, using a revised TOMI (Stott *et al.*, 1984). The test items used were from the 11 year age band as this was the maximum age the test was normed for. In addition, a short form WISC (Wechsler, 1974) was obtained and a scale of self perception. School reports were also obtained. The authors developed their own five point scale of academic achievement and coded the reports. They also asked the children about their hobbies and social participation.

The researchers showed that the 11 out of the 17 original children described as "clumsy" remained "poor" or "very poor" compared to age matched controls on the TOMI. Ten reported poor self concept. Ten out of the seventeen performed poorly or very poorly on the neurocognitive battery. From the school reports nine out of the fifteen were reported as having "poor concentration, easily distracted, forgetful", seven reported to have " personality and social problems/no friends"; seven, " shy /timid"; six were reported to "lack confidence". It was commented that the children studied were:

> "highly selected, frequently coming from very supportive middle-class homes and may have had intensive therapy"
>
> p 63.

This makes these results even more concerning as it is likely from this study that a significant number of children with motor difficulties are likely to have a poor outcome unless intervention is given and in some case continued.

Geuze and Borger (1993) re-examined 12 'clumsy' children and 14 controls from a group of 62 children that had been assessed in 1989. These subjects were aged between 11 to 17 years. They were reassessed using the TOMI (Stott, Moyes & Henderson, 1984). Information was gathered from parents and teachers as well as the children undertaking the motor assessment. They attempted to make the 11 year old band tests harder than the original ones. Half of the original children from the 'clumsy' group were now no different from the control group on the original test. Two children still had serious motor difficulties. However when the tests were made more difficult only three of the 12 children scored in the 'normal' range. The tests that most discriminated were the clap/catch task (also noted by Knuckey & Gubbay, 1983), the catching a ball and the flower trail tasks. Most parents of children in the 'clumsy' group reported that their children still had some difficulties. Two parents reported that their children did not have any difficulties any more. The 'clumsy' children were more likely to have repeated a year in school. The teachers reported that the 'clumsy children' had significantly more problems in:

> " social contacts, concentration or distractibility and classroom behaviour" p17.

The Cantell, Smyth and Ahonen study (2003) followed up a similar age group of 17 year olds who had previously been tested at 15 years of age (Cantell, Smyth & Ahonen, 1994). There were three groups in the study: a DCD group, an intermediate group with lesser motor difficulties and a control group. This study included completion of two questionnaires (25 min), a structured interview (30 min), eight movement tasks (20 min) and an IQ test (15 min.). All the tasks used were from established batteries and had norms up to early adolescence, or else were also normed for adults. For the perceptuo-motor tasks it was shown differences between all groups except on the hitting wall target and the visual motor integration tests where there was no difference between the intermediate and the DCD groups.This study showed 65% remained classified as "clumsy". Cantell described subgroups that were noted from the study. There was one subgroup of young people who had difficulties across all tasks, and a second group who had difficulties with pegboard tasks, visual matching and spatial relation tasks only. This suggests that either some young people continue to improve at different rates, or that some areas of motor deficit may be more difficult to improve at all in some individuals, or that they had started out as different groups in the first place such as having visual perceptual deficits, alongside motor difficulties.

Educational outcomes were also described in this paper. High school was chosen by 90% of the adolescents in the control group, 50% of the intermediate group and 29% of the DCD group. Vocational training was chosen by 10% of the control group, 29% of the intermediate group and 51% of DCD group. However these results may have been influenced by the difference in IQ between groups, with individuals with DCD having significantly lower IQ scores than in the control group. This may have also influenced the results of lower self-perception seen in the DCD group compared to the control group on the scholastic competence. Of particular interest in this study was the level of self understanding and identity development with the DCD group. They were reported to be at a younger developmental level compared to the other two groups being at middle /late childhood, the intermediate group being in early adolescence and the control group in late adolescence.

The follow up studies show variable outcomes and are again difficult to directly compare. However, they do demonstrate that in all studies more than 50% of the children had persistent motor difficulties, and in some cases there was evidence of social and poorer educational outcomes. Poor outcomes were also associated with poor attentional difficulties. It could be conjectured that overlap with other symptoms predicts a poorer outcome.There has been a paucity of studies specifically focusing on adults with motor difficulties in order to understand presentation at this stage.

3.3.1.3. Adult studies.

One of the early studies noted, as described in an earlier chapter was one by Shelley and Riester (1972). Sixteen trainees had been identified as not coping with basic training. Difficulties included tasks such as such as learning to march properly, and folding clothing properly. They also were reported to have:

> "marked irritability, anxiety, self depreciation and emotional lability" p335.

It was reported that their families had considered them as "sloppy". Interestingly, their difficulties only emerged once they were "thrust into military training … demands a high degree of visual – motor competency".

It was noted that:

> " all of the patients had a tendency to think in concrete rather than abstract terms….they would frequently appear " infantile" to the casual observer" p336.

All exhibited some 'soft signs' on neurological testing. They all showed some fine motor and perceptual motor difficulties. Fourteen out of the 16 were reported by their parents to have had temper tantrums. Twelve fitted 'hyperkinetic syndrome.' Ten out of 16 had speech problems in childhood. A point made in this paper in 1972 is as pertinent today:

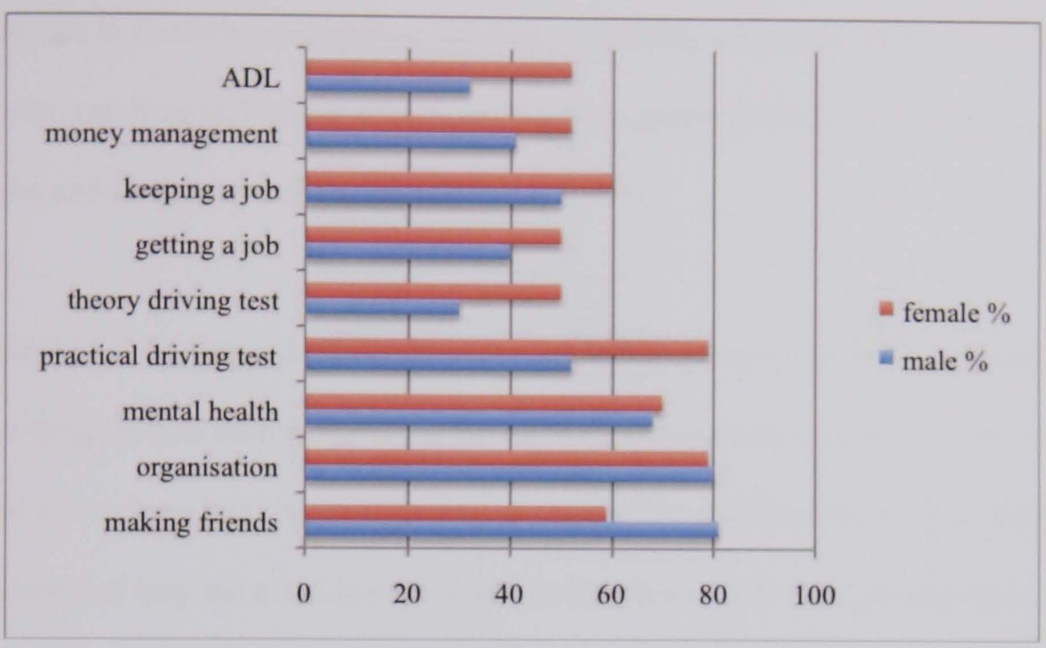
> "It would appear to be less important to try to make a diagnosis than to carefully categorize each patient as to the abilities and disabilities he actually has and the way in which he learns and functions. On the basis of such an evaluation, a physician or educator could make appropriate plans for dealing with each individual over a period of time".
>
> p338.

The focus of this study was not specifically on the motor functioning. However, it again exhibits the overlapping difficulties that may present at this stage with poor motor functioning in some adults sitting alongside some difficulties with executive functioning skills, visual perceptual difficulties and language skills.

An interesting study by Porter and Corlett (1989) explored the concept of 'accident proneness' in undergraduate and postgraduate students. A questionnaire included questions on involvement in sport, driving skills, accidents, bumping into objects, and knocking things over, for example. The answers the students gave separated them into two distinct groups. The two groups were then tested on a 'visual motor' and 'blind reach' task. The accident prone group performed significantly worse on the visual motor tasks than the controls.

A retrospective study by Kirby and Drew (1999) was undertaken where 22 adults were interviewed who had received a diagnosis of DCD or Dyspraxia in childhood. Semi-structured interviews were undertaken in order to ask about what areas of daily living were causing the most problems. Figure 3A. shows the high levels of difficulties reported for males and females. Males reported greater difficulties making friends and then organisational and mental health issues were reported to be second and third most problematic. Sixty six percent of males and 70% of females reported having been bullied in childhood.

Figure 3A: Percentage response of continuing difficulties reported.



Kirby and Drew, (1999).

A more recent study of adults undertaken by Cousins and Smyth (2003) describe the motor deficits in 17 adults, 12 females and 5 males, aged between 19 and 63 years with a mean age of 39.3 years. The adults recruited were self reported to have motor difficulties. They tested adults by undertaking a number of tasks including adapting the Movement Assessment Battery for Children (Movement ABC; Henderson & Sugden, 1992) using dual tasks to increase the difficulty of performing the tasks and also assessed handwriting (asking them to write a copy sample in their best writing and another copy task as fast as they could) and constructional ability. In addition, reaction and movement time were measured. None of the tests had been normed with an adult population. However, their performance was compared with a matched group, and the movement difficulties group were three standard deviations (SD) below the control group in their performance. The participants were asked to self report their functioning by completing a questionnaire. This showed significant differences to controls on questions relating to avoiding obstacles, balance, manual dexterity, catching and hitting things, handwriting, putting things together from patterns and diagrams, and for reading.

Overall this study showed that in the index adults the gross motor abilities remained poorer than the fine motor. However the cohort's educational status was commented on and it may have had an effect on this, as most of the participants were in higher education and may have had greater practice with fine motor tasks or could have been a subgroup where this was less of a problem for them to begin with or had less overlap with other developmental disorders.

Variable performance between participants was reported, with some participants not being able to undertake dual tasks for example at all, whereas others could complete them. Some participants showed marked difficulties on all tests, whereas one male participant only scored significantly below 2.5 SD in the dual task.

The aiming, clap-and-catch, balance sway and rating of the speeded handwriting explained 80% of the variance in group performance and were able to distinguish 36 out of the 38 participants successfully. On the handwriting test the group of adults reporting motor difficulties showed worsening performance when having to write fast. On obstacle avoidance those with reported motor difficulties were slower but did not make more errors. Interestingly, the study was able to discriminate the drivers from those reporting difficulties with driving when using "the catch, clap-and-catch, variability of MT (go/no-go condition), dual task time and error, and handwriting error" (p 453). Performance in dynamic balance and ball skills most correlated to self report. The authors remarked that participants with motor difficulties either chose a fast and inaccurate or slow and careful approach. Again there was a comment about the variability in approach. A final comment exemplifies the rationale for following through and supporting young people with motor difficulties:

> "Although the effects of coordination difficulties may seem less important in adults, the difficulties reported here indicate that for some adults these difficulties may continue profoundly to affect their lives"
> p 456.

The Cousins and Smyth study (2003) is one of the first to specifically measure motor functioning in an adult population. However this was not a follow up study but a self referred group and it would be of interest to compare clinical and adult self referred populations to consider whether there are differences. The earlier study by Kirby and Drew (1999) was from a clinical population and considered some areas of daily functioning but did not measure motor performance. The latter also did not also have a control group to compare what were typical levels of functioning.

3.4. The impact of the deficits on individuals with DCD and associated influences.

In order to understand the continuing difficulties that present for the adult with DCD and the impact these have on their lives it is valuable to consider how these may present. This may be based on either evidence from childhood research or in the few studies in adolescence. It is also useful to consider the research from comparative developmental disorders.

The study by Losse *et al.* (1991) showed less favourable outcomes academically for the individuals with co-ordination difficulties than their controls. Seven out of 17 individuals also showed social difficulties. However, in contrast Cantell, Smyth and Ahonen (1994) did not show a similar pattern. The underlying intellectual functioning may also affect outcome for the individual with DCD - as motor function deteriorates with lowering IQ. Is there a correlation with poor outcome and IQ? Certainly Cantell's group had a lower IQ than the controls and may have been a factor in poorer educational outcome. Cousins' (2003) cohort with motor difficulties mainly came from a HE background and demonstrated better fine motor than gross motor skills. Level of co-occurrence with other developmental disorders may be an additional factor especially if conduct or behavioural disorders are comorbid.

3.4.1. Persistent and new deficits in emerging adulthood in DCD.

Some difficulties in acquiring new skills in adulthood may be predicted. Individuals with DCD are noted to find skills such as learning to competently ride a bike difficult to achieve (Sugden, 2007). Riding a bike requires a number of co-ordinating skills including pedalling, controlling, planning where to go, and steering, for example. A comparative motor skill in emerging adulthood could be learning to drive a car. Driving represents an important rite of passage and a visible demonstration to others of a move towards independence. From a parental perspective this may be one of the last times that they will be involved teaching their child a new skill. Once the driving test has been passed it will then allow the individual greater ability to become independent and a potential means of "freeing the nest".

Driving may be difficult because of several reasons. These may include the need for good motor control and ability to dual task; attention and concentration required and also the importance of having good visual perception to be able to judge distances and for parking. Cousins and Smyth (2003) demonstrated that adults (average age 38 years) who had co-ordination difficulties also had corresponding difficulties with learning to drive a car. In particular when dual tasking was required difficulties were observed. They concluded that the adults with DCD:

> " may not show differences from controls if activities are self paced and carried out singly, but may be more affected when carrying out dual tasks under time pressure"
>
> p 436.

Wilson and McKenzie (1998) described different patterns that may improve for young people with DCD as they get older and concluded that motor aspects were likely to improve but visual perceptual skills may be more resistant to change. If this is so, then this may make it harder to become competent in tasks such as parking and perceiving distances accurately. Porter and Corlett (1989) study of students who were more "accident-prone" also demonstrated poorer ability with more complex visuo-motor tracking and dual tasking compared to controls.

Driving may be especially difficult for young people in the UK where most drivers learn on a manual car with gears and not in an automatic car,unlike for example the US and Australia.

The result of delay, difficulty or avoidance in gaining these skills may not only have a practical impact of restricting the ability of the individual to mix socially but at a psychological level may also continue to highlight the real differences between the individual and his or her peers that have been noted in earlier years.

3.4.2. Psychological effects of DCD.

One of the few studies examining anxiety in individuals with motor difficulties in one by Sigurdsson, van Os and Fombonne (2002) showed that child motor impairment was strongly associated with persistent anxiety in males but not among females. However there are some caveats in this study as individuals were selected by teacher reporting and not by any motor measures and the gender differences may not be so discrepant if levels of motor dysfunction had been measured. In addition anxiety was measured by maternal reporting. However the information was blind as it was a prospectively collected birth cohort .The Swedish study (Hellgren *et al.*, 1993; Hellgren *et al.*, 1994) also showed a higher rate of psychiatric morbidity and personality disorders among the MPD-ADD and MPD groups. This included affective, anxiety disorders, borderline personality disorders, social negativism and withdrawal, and higher rates of depression and suicidal risk. This was again re-iterated in when some of the cohort were followed up (Rasmussen & Gillberg, 2000) and showed a worse prognosis in the motor disordered group. Skinner and Piek (2001) did show children with DCD had greater anxiety than controls in 8-10 year olds.

The psychiatric interviews used with adolescents with DCD have shown many psychiatric symptoms ranging from mood and anxiety disorders to social negativism and withdrawal (Hellgren *et al.*, 1993; 1994; Shafer *et al.*, 1986). Few studies have looked qualitatively at the outcomes for emerging adults (Cantell & Kooistra, 2002).

The anxiety and depression could have stemmed from greater social isolation and worsening self esteem. An alternative hypothesis could be that there could possibly have a similar biological regulatory difficulties mediated by the dopamine system such as seen in ADHD increasing the risk of associated mental health difficulties.

> "Insufficient dopaminergic activity in this pathway will result in excessive motor output. Thus, the motor hyperactivity seen in ADHD may reflect a 'reverse Parkinsonism' characterized by either excessive dopaminergic activity in the internal segment, or insufficient inhibitory tone in the external segment"
>
> Solanto, 2002, p 66.

Long term poor self concept may also be a risk factor for mental illness. Self concept has been seen as a multi-dimensional construct (Harter, 1996) and ratings can be made across different domains. Four studies have used Harter's self perception questionnaires with a multidimensional perspective to study self-perception (Cantell, Smyth & Ahonen, 1994; Larkin & Parker, 1997; Losse *et al.*, 1991; Skinner & Piek, 2001). Adolescents with DCD were found to perceive themselves as less competent in several domains, most often in physical, academic and social competence. It is interesting this persistent pattern affecting certain domains does not seem to affect the global self esteem measures. This is contrary to the belief that sustained difficulties may drive a lowered self esteem. However, there are difficulties in measuring self concept in a heterogenous population as has been emphasized by Zeleke (2004) in a review of self concepts of students with learning disabilities. The author voiced the need to subtype students in order to understand which young people may have persisting difficulties. These difficulties can be mirrored in emerging adults with DCD and make it harder to make generalizations.

Emotional immaturity is likely to be greater in emerging adults with DCD. Cantell, Smyth and Ahonen (1994) noted in adolescents with DCD that:

> "these adolescents were functioning at a developmentally younger age level than their age peers. In an earlier phase of this study the parents had reported that the children with DCD were immature in their behaviour. This tendency might protect the adolescents from comparing themselves with their age group, and to take less responsibility for their own actions, but also to make them vulnerable when it comes to societal expectations related to young adults"
>
> p 427.

One way of examining this is to ask parents what level of parental support they are continuing to give their children. This support, while being potentially important, may also be a marker of persistence of difficulties. Alternatively, some parental support and family closeness may act as a key protective factor against certain high-risk behaviours such as smoking, alcohol and drug use, and early initiation of sexual intercourse (Resnick, Bearman & Blum, 1997). This may in fact have a negative effect. Too much support may reduce the opportunities for the young person to leave home and experiment with others, away from parents, and effectively move through this stage to adulthood.

It can be postulated that the young person with DCD may show delay in what Arnett (2000) describes as three important aspects towards moving to adulthood: work and work opportunities, love and relationships with others and thirdly, life opportunities. He or she is likely to have had poor past experiences in school, having fewer friends and being more socially isolated (Mandich, Polatajko & Rodger, 2003). Lowered self esteem, may also result in lowered confidence and ability to experiment socially (Rose, Larkin, & Berger, 1997; Skinner & Piek, 2001).

3.4.3. Executive Functioning and DCD.

In order for a young person to become an adult and move through the stage of emerging adulthood it is necessary for the individual to learn the skills of organisation, planning , time management, goal setting and prioritisation. As there is evidence of high levels of co-occurrence with ADHD and DCD, as has been cited by a number of researchers as described earlier in this chapter and in chapter 1, it is likely that there will be executive functioning (EF) skills difficulties. A number of researchers have recently posited the importance of considering a common underlying neurocognitive mechanism between some subtypes of ADHD and DCD. One study (Piek *et al.*, 2007) tested children with DCD, ADHD – combined and

ADHD, predominantly inattentive type, on executive functioning tasks and showed that the DCD group were slower on all tasks supporting a timing deficit. This would fit in with some of the longitudinal study outcomes.

Barkley, Murphy and Fischer (2008) discuss extensively the concept of EF deficits. They describe four EFs': non verbal working memory; internalisation of speech; self regulation of affect and planning and generativity. They even go on to emphasise specifically the motor element:

> "EFs' are dependent on inhibition for their effective execution and for their regulation over the motor programming and execution component of the model (motor control)"
>
> p172.

In studying emerging adults with DCD, evidence of persistence of symptoms relating to EF may give greater weight to this hypothesis or, at a minimum, may direct future research more towards this specific area. While attention and concentration is mentioned, the impact of this remains vague.

3.5. Views from adults with motor difficulties.

There is a paucity of studies hearing the voices of adults themselves. This is not only in the field of DCD but in comparative areas such as in Dyslexia (Davie, 1996).

Some work has been done in the field of self perception but there remain few in depth qualitative studies considering attitudes, thoughts and feelings from individuals with regard to their educational and health, and social experiences as individuals with DCD once they have grown up.

> *"I have a difficult time being organised on every level, even in thought. My wife thinks that if I plan out every single level of my actions before I do them, whether I am driving or walking, that this will compensate for my problems. I genuinely try but often have trouble accomplishing my goal. Establishing a habit of organising everything I do is a daunting task. I have difficulties even remembering to plan everything"*
>
> (E-mail personal correspondence from a male, 32 years with DCD)

Dyspraxic Voices (Werenowska, 2003), a collection of personal commentaries from adults mainly aged over 30 with Dyspraxia or DCD, gives some insight into thoughts, feelings and experiences. One 38 year old student described:

> "From beginning to end my life has been one long struggle... I decided to laugh. For some reason dyspraxics don't seem to understand the signposts and then suddenly lots of obstacles appear"
>
> p 28.

Cousins (2003) also described a number of discourses that emerged from the interviews undertaken, especially about the terminology and language used to describe motor and related difficulties.

It is helpful when understanding emerging adulthood in DCD to turn to comparative literature from other developmental disorders where there has been some research undertaken.

3.6. Literature about other developmental disorders in emerging adulthood.

The stage of emerging adulthood has been better understood in other developmental disorders such as ADHD, Dyslexia and AS (Attwood, 2000; Barkley, 2004; Wilson & Lesaux, 2001).The outcomes for individuals with ADHD are especially interesting as DCD overlaps with ADHD in about 35% of cases (Kaplan *et al.*, 1998). Adolescents with ADHD have been shown to have higher rates of social skills difficulties compared to peers and are more likely to engage in high-risk activities e.g. cigarette smoking, unprotected sex and drug usage (Weiss & Murray, 2003). More traffic offences, particularly for speeding, vehicular crashes, and license suspensions have been noted than in controls (Barkley *et al.*, 2002; Jerome, Habinski & Segal, 2006). However, there is some indication that these behaviours may be more linked to other co-morbidities such as Conduct Disorder rather than the ADHD characteristics themselves (Barkley, 2004).

As DCD is seen as a part of a neurodevelopmental spectrum, it is of value to consider what knowledge has been gained from research in the three conditions commonly co-occurring with DCD.

3.6.1. Asperger Syndrome (AS)

Hans Asperger first described this developmental disorder in 1944.There have been several different hypotheses for the aetiology of AS. One of these, the concept of an extreme male brain (Baron-Cohen, 2002) has been used as a hypothesis to explain AS behaviours, but may be also seen as a potential strength in individuals with AS. Systemizing is defined as a drive and ability to analyse the rules underlying a system, in order to predict its behaviour. This is seen more in individuals with AS, along with other symptoms including having less ability to empathise. A lack of ' theory of mind' in those with AS, may potentially differentiate some individuals with those with a diagnosis of DCD. However, clarification of these potential differences has not yet been undertaken. Overlap with DCD and AS has been noted as previously discussed but it could be postulated that some individuals with DCD may have less social opportunity and some of their difficulties may be attributed to social naiveté rather than social disorder.

Billington, Baron-Cohen and Wheelwright (2007) have shown that these specific traits influence the entry into specific courses in university and colleges. A study of students attending humanities and physical science courses to see whether they had high systemising or empathising quotients on the questionnaire, devised by this research group, showed that:

> "regardless of sex, stronger systemizing and weaker empathizing was associated with students in the physical sciences compared to students reading humanities."
> p 265.

3.6.1.1. AS and Social characteristics.

It has been reported that students with AS do want to seek friendships and are more lonely (Attwood, 2000; Beardon & Edmonds, 2007; Harpur, Lawlor & Fitzgerald, 2004). Jobe and Williams White (2007) also showed fewer and shorter duration of friendships and this was related to lack of social skills rather than avoidance. However, having narrower ranges of interests (part of the diagnosis), may limit choices of friends also. Research also suggests that children and adolescents with AS experience significantly higher levels of anxiety than community-based populations (e.g. Farrugia & Hudson, 2006; MacNeil, Lopes & Minnes, 2008)

3.6.1.2. AS and Parental support.

By virtue of the diagnosis, it is not surprising that students with AS have social and communication difficulties that will therefore also impact on their ability to be independent. A study by Barnard *et al.*, (2001) demonstrated that only 3% of adults with AS are living fully independent lives. Engstrom, Ekstrom and Emilsson (2003) considered the psychosocial outcomes in Swedish adults with AS or high-functioning autism (HFA) and showed that the majority were unemployed but living independently and that none were married or had children. A study by Howlin *et al.* (2004) of 58 adults with autism demonstrated that most individuals remained very dependent on their families or other support services. Few individuals lived alone, had close friends, or permanent employment.

> "Some groups in our society, such as those with ASD, can experience enormous difficulties in both getting a job and keeping it. But this should not be the case. Researchers have shown that people with high-functioning ASD with the right support can be competitively employed and thereby better integrate with the rest of society"
>
> Jarbrink *et al.*, 2007, p 95.

However, they may require different levels of support at home and in the community that has wide reaching economic cost. The first group of costs relates to the value of patient time spent receiving care. The second cost relates to time that parents, friends and relatives spend in caring and supporting the person with AS as a result of their disability. Jarbrink *et al.* (2007) in Sweden cited an average annual cost for community support of €7154 and Knapp, Romeo and Beecham (2007) using a different formulae in the UK, showed an annual cost for an individual living at home with AS of £32,861. This is contrast to costs if the individual needs to be in supported accommodation which are at least twice the cost. This has implications for college and university support systems.

Berney (2004) describes the stress of growing up with AS that arises from limited achievement and a feeling of a sense of failure. He also highlights the contrast with other, more successful siblings and peers. The difficulty for the individual and the family is the imbalance in the degree of dependency which is disproportionate to the level of intellect. The emerging adult moves into the "open", without the boundaries of school around him or her and has to move towards independence.

There remains an issue of how to help emerging adults who have difficulties socially integrating. Attwood (2000) however makes the point that:

> "We must remember that some adults with AS never had opportunities available... yet they succeeded in acquiring the ability to be socially integrated to a level where other people would not easily perceive the difficulties they encounter in everyday social interactions".
>
> p 98.

He goes onto say:

> "We need to establish what strategies they found that aided or hindered their successful social integration"
>
> p 98.

This latter point is important in the context of this work, as it is the factors that allow success, integration, education and employment that will be as important as the factors that influence failure that will need to be identified. Both have implications in the context of the emerging adult with DCD.However, there are limitations on research on this group, as Green *et al.* (2000) expressed the difficulties of defining the phenotype in adults with AS. This study compared individuals selected from a clinically referred population and showed that the "AS group showed severe impairments in practical social functioning despite good cognitive ability" and in addition "depression, suicidal ideation, tempers, and defiance" was found.

The blurring of the edges with other psychiatric symptoms seen in some adults with DCD, make it harder to at times see which are the primary and secondary features of the condition.

3.6.1.3. AS and Motor skills.

Sahlander, Mattsson and Bejerot (2008) compared the motor skills of adults (21-35 years) with AS with controls using the Bruininks-Oseretsky Test of Motor Proficiency (BOTMP) (Bruininks & Bruininks, 2005) and showed that those with AS performed significantly worse. There were gender differences in terms of physical activity with males with AS worse but not females.

3.6.1.4. AS in Higher Education.

Issues of disclosure of difficulties to others have been reported in the field of AS also. The Disabled Student's Allowance (DSA) is operating under a framework of a medical model. The individual requires a diagnosis to get help. However, some individuals are resistant about accessing assistance in this way and the impact of this in AS is then greater (Beardon & Edmonds, 2007).

3.6.2. ADHD.

ADHD has been recognised as continuing into adulthood since George Still (1902) discussed the chronicity of the disorder. In the 1960s and 70s there were a number of follow up studies demonstrating persistence (Mendelson, Johnson & Stewart, 1971; Menkes, Rowe & Menkes, 1967). This was followed by some studies demonstrating the linkage between parents and children having symptoms (Alberts-Corush, Firestone & Goodman, 1986; Cantwell, 1975). Murphy and Gordon (1998) remarked that:

> "The idea that... ADHD might persist into adulthood is relatively new on the clinical scene. We now have clear evidence that ADHD symptoms do not usually diminish with the onset of puberty"
>
> p345.

Wender (1995) was first to recognise that the DSM- II(American Psychiatric Association, 1968) and the later DSM-III (American Psychiatric Association, 1980) were not appropriate diagnostic descriptions for adults with ADHD. Barkley, Murphy and Fischer (2008) have recently proposed adult DSM-V criteria, specifically for adults following two major studies following up children with ADHD and state in their proposed criteria that to be diagnosed there needs to be:

> "significant impairment in social, educational, domestic (dating, marriage or cohabiting, financial, driving, childrearing, etc), occupational or community functioning"
>
> p192.

As in follow up studies of DCD, persistence is variable depending on the studies cited and has been shown anywhere from 8% to 70% (Mannuzza *et al.*, 1993;

Rasmussen & Gillberg, 2001; Weiss & Hechtman, 1993). Huge variability reported relates to different selection criteria used, including whether the children had conduct problems or not. It was also dependent on who was the informant. When parent's and adolescent's views were compared there was marked discrepancy (Manuzza & Gittelman, 1986).Wender (1995) was one of the first to recognise the need for a third party informant to describe childhood behaviours. This has been most recently reinforced by Barkley, Murphy & Fischer (2008):

> "The source of information being used to judge persistence of disorder into adulthood is exceptionally important".
>
> p 20.

Faraone *et al.* (2000) make the point that the presenting symptoms in adulthood may differ to those of childhood because:

> "The administrative and multitasking demands faced by adults are qualitatively different from those faced by children, who function in more structured family and school settings. As opposed to tasks in early childhood that predominately require simple responses to focused demands, the demands of adulthood require juggling of competing tasks, independence, organization, and planning."
>
> p 17.

Manuzza, Klein & Moulton (2003) reviewed the four published prospective follow up studies of children with ADHD. Three of these were clinically referred children (Barkley, 2002; Manuzza *et al.*, 1993; Weiss & Hechtman, 1993) and one was a community based study (Rasmussen & Gillberg, 2000). In the Weiss and Hechtman study, 36% of probands reported their symptoms were still moderately to severely disabling and 64% on asking responded that they were "restless".

Unlike DCD, there is a symptom threshold for diagnosis, i.e. the individual has to have in childhood more than a certain number of symptoms to be diagnosed. Barkley, Murphy & Fischer (2008) describe a method of diagnosing ADHD in adulthood using some of the symptoms recognised in childhood, additionally with those now present in adulthood.

Defining outcomes in adults with ADHD, may be dependent on who is rating, persistence since childhood, current status (such as life events at the time), observational ratings used, and, also interestingly, whether the assessor is blind to the childhood status and this can be similarly applied to DCD. Harpin (2005) showed in individuals with ADHD as they get older the executive functioning difficulties, if core, become one of the main difficulties "depending on the demands made on the individual by their environment". Barkley, Murphy and Kwasknik (1996) highlight the difficulties in individuals with ADHD in "doing what you know" rather than the "knowing what to do".

The gender differential seen in childhood has been noted to be less pronounced in adult ADHD samples (Gualtieri, 1985;Wender *et al.*, 1985). This may be related to sensitivity of the tools used or the route to clinical diagnosis may be related to the associated conduct disorders seen (Biederman *et al.*, 2004).

3.6.2.1. ADHD and social behaviour and characteristics in adults.

The social impact of having hyperkinesis has been shown in adolescence, where there is twice the rate of "severe lack of friendship" (Meltzer *et al.*, 2000). Friedman *et al.* (2003) found, when asking adults with ADHD to rate their own social and emotional competence , they viewed themselves as less socially competent but more sensitive toward violations of social norms than controls.

Many studies have shown a higher rate of smoking among individuals with ADHD compared with the normal population (Milberger *et al.*, 1997). Pomerleau *et al.* (1995) in their work showed that smokers had higher rates of ADHD symptoms than those who had never smoked.This could be the reverse in DCD as dopamine is one of the pathways driving the motor difficulties. This could result, if true, with low levels of smoking or addictive behaviour. It is of interest to note that adults with Parkinson's disease (where there are low levels of dopamine) also have a lower rate of nicotine dependency than the general population (Grandinetti & Morens, 1994).

3.6.2.2. ADHD and lifestyle.

ADHD has been linked to a higher risk of drug usage and abuse and an increased risk of antisocial acts (e.g. shoplifting) and being a smoker, as seen both in the Milwaukee study and UMASS study among those at aged 27 years with childhood ADHD described by Barkley, Murphy and Fischer (2008). The ADHD group also showed greater problems with sleep, social relationships, and emotional health. One study of adults with ADHD study reported that the individuals at 21 years of age exercised less than controls (Fischer & Barkley, 2006).

3.6.2.3. ADHD and Driving.

There have been a number of studies in ADHD focussing on driving behaviour in this group. Research has shown that individuals with ADHD are more likely than controls to violate traffic rules and to be involved in motor vehicle accidents (Barkley *et al.*, 2002; Barkley *et al.*, 2004). They are also more likely to be involved as a driver in a crash that resulted in injuries. An extensive study from New Zealand (NadaRaja *et al.*, 1997) examined 916 adolescents and showed that ADHD symptomatology and associated conduct disorder were strongly associated with driving offences. Barkley *et al.* (2002) in a study compared individuals with ADHD and controls on cognitive abilities, multiple levels of driving ability, and number of traffic citations/accidents. Unlike their previous studies (Barkley *et al.*, 1996), no differences were found between the ADHD group and the control group on driving abilities, and co-morbid ODD, depression, and anxiety did not affect any of the outcome or performance measures. They also found that IQ did not affect driving knowledge or performance differentially for the ADHD group. Alcohol and drug usage did not relate to performance. Executive functioning was also only modestly related to accident frequency and traffic violations. Some researchers are now suggesting that driving simulators are a better potential way of measuring difficulties. However, they may still remain different to seeing driving in a real life setting. Fischer *et al.* (2007) used a dual approach to capture information; first, gained reports from driving instructors who reported significantly more impulsive errors. Secondly, a driving simulator was used and showed marked differences compared to controls on reaction time, greater errors of impulsiveness (false alarms, poor rule following), more steering variability, and more scrapes and crashes.

3.6.2.4. ADHD in further and higher education and employment.

Having ADHD in adulthood has a pervasive impact and the difficulties involve both academic and social domains. The economic impact has been shown by Biederman (2004) from a large survey in the US, after controlling for other factors such as personal and family characteristics, and estimated that having ADHD results in yearly losses in the US of 77 billion dollars. He highlighted that ADHD affects every area of life from school to the workplace. His study showed that adults were less likely to have finished school or to go onto further education. Other studies have also demonstrated continuing problems with academic achievement in college (Gittelman, 1987; Heiligenstein & Keeling ,1995; Heiligenstein *et al.,* 1999).

However, positive outcomes have been reported as achievable (Adelman *et al.*, 1995).

3.6.3. Dyslexia.

It has been shown that adults with a history of dyslexia, continue to have spelling problems which persist through their life span (Bruck, 1993), especially in males (Lefly & Pennington, 1991). Work with college students showed continuing problems with spelling compared to controls (Connelly *et al.*, 2006). However, when considering students with dyslexia the aspect of writing difficulties is sometimes overlooked and difficulties may be as great as those with spelling and reading (Berninger, 2001). Individuals with dyslexia have also been noted to have difficulties with executive functions (Berninger *et al.*, 2006) but this may be a factor of a high rate of co-occurrence with ADHD.

The experiences of one university student with dyslexia:

> "It is anybody's guess how many dyslexics there are nationally, probably millions. In any case there are a vast number of people being systematically discriminated against by the very institutions that set themselves up to cater for learning opportunity."

(http://www.futurenet.co.uk/charity/ado/adomenu/adomenu.htm,2005)

3.6.3.1. Dyslexia in further and higher education

Much of the focus on supporting students with specific learning difficulties has been related to dyslexia .For example, a national working party on dyslexia (1999) made 101 recommendations for supporting students but a similar process, in contrast to this, has not been undertaken for individuals with DCD. Prevalence rates in higher education are measured by those students disclosing once reaching higher education. Singleton (1999) reported 43% of the dyslexic student population was diagnosed only after admission to their chosen programme. These give an estimate of numbers of students with Dyslexia and show a substantial increase entering HE in the United Kingdom (UK) which almost doubled between 1995/6 (18%) to 1999/00 (33%). The Government's White Paper "The Future of Higher Education" (DfES, 2003) implies this increase in numbers may be related to the incentives given if disclosure is made (HESA, 2001).

In order for the UK government to reach an objective of having 50% of 18-30 year olds experiencing H. E. by 2010 and reaching those who may have previously been marginalised or underrepresented, they are now focussing on those from "disadvantaged localities and people with disabilities" (DfES, 1998). This move has also been stated in other documents including " The Committee of Vice-Chancellors and Principals of the Universities in the UK published "From elitism to inclusion. Good practice in widening access to higher education" (CVCP, 1998).

However, not all students with specific learning difficulties want to be viewed or view themselves as disabled. Riddell, Tinkin and Wilson (2005) found that students with dyslexia or mental health difficulties wanted to reject the term disabled as they felt this was associated strongly with a physical or sensory impairment. However, some were pragmatic and would adopt the label if it attracted support and funding. This may result in even more students with dyslexia not coming forward and disclosing their difficulties because of the potential stigma of being labelled as *disabled.* An alternative view is that:

> "dyslexia should not be characterized only by deficit, but also by talent. Global visual-spatial processing (what we refer to as "holistic inspection") may underlie important real-world activities such as mechanical skill, carpentry, invention, visual artistry, surgery, and interpreting X-rays or magnetic resonance images (MRI)."
>
> Von Karolyi *et al.*, 2003, p 430.

3.6.3.2. Dyslexia and employment.

With regard to employment in individuals with dyslexia, Reid and Kirk (2000) carried out a research project commissioned by The U.K. Secretary of State for Education and Employment acting through the Employment Service. The aim of the project was to identify affordable, up-to-date, good practice in relation to assessment and remedial help for adults whose employment prospects are impaired by dyslexia. The findings of this report highlighted shortcomings in services for adults with Dyslexia, and in particular a) unclear routes to referral for diagnosis; b) lack of uniformity in screening methods c) a need for appropriate tests to be used by Occupational Psychologists to be able advise on workplace supports and d) the nature and length of this post-assessment support.

Shaywitz *et al.* (1999) make a point that adults do not always need remediation but for appropriate accommodations to be made. This is particularly true when students move in to higher, further education and employment where there is no opportunity for remediation.

3.6.3.3. Dyslexia and driving.

Brachacki, Nicolson and Fawcett (1995) examined the ability of adults to recognise road signs and concluded that those with dyslexia recognised traffic signs significantly less well than controls and this result in those with Dyslexia did not correlate with experience (i.e. length of time driving).

3.6.3.4. Dyslexia and self esteem

Low self esteem has been reported by researchers also in the field of Dyslexia (Riddick *et al.*, 1999) and resulting also in feeling less competent both in their written work and in their academic achievements. Ingesson (2007) has also shown from interviews with 75 teenagers and young adults with dyslexia, the emotional impact related to having literacy based difficulties. Many of the participants in this study described their first six years in school as causing them distress and had experienced bullying. Many had not chosen to go to college as their academic self esteem was low. Some further information regarding students with Dyslexia is described in Chapter 4, specifically about further and higher education.

3.7. Conclusions.

In order to understand the emerging adult with motor difficulties it is useful to compare and contrast previous studies that have been undertaken in adolescents and to recognise the paucity of detailed information about the social behaviours and characteristics of this group. It is also difficult to compare specific motor impairments as different measures have been used in the different studies. However, there are some general themes emerging. One fact that is consistent is that a significant number of individuals (in all studies cited this was more than 50%) continue to have motor difficulties when tested.

Cousins (2003) in her PhD, is one of the few studies to ask about sports participation and other related quality of life issues. No studies so far have specifically explored the types of support received in the educational setting such as further and higher education and their perception of this.

In comparison, studies especially in the field of Dyslexia and ADHD have explored many areas of emerging adulthood in greater depth but only in the US. Harpin (2005) in a review paper was one of the first authors in the UK to mention adults in her article on ADHD, but again she was quoting US and not UK specific work. Barkley (2004) has undertaken extensive work examining the association with driving in ADHD. In the field of Dyslexia, there has been specific work about experiences in further and higher education by Pollak (2003), Riddick (1999) and Ridell *et al.* (2005) to name a few. This is encouraging as it allows a comparison to be made between these defined groups and the category that are called motor difficulties.

CHAPTER 4 EMERGING ADULTS WITH DCD IN FURTHER AND HIGHER EDUCATION

4.1. Introduction.

This chapter begins by describing how individuals with motor difficulties gain support in FE and HE and compares this to processes and support for other developmental disorders including Dyslexia, ADHD and AS. Secondly, it discusses the implications in labelling individuals in order for support to be given. Finally, there is a discussion how the present system fits in terms of different models of disability and then considers these models in the context of DCD. This relates to Chapter 8 in the thesis where results from the study about students' experiences of support are presented, as well as their perceptions of having a diagnosis, and reflections made on how this is interpreted by others.

4.2. Assessment and support in further and higher education.

Adults with co-ordination difficulties are presenting to colleges and universities with either a diagnosis of DCD or Dyspraxia , in increasing numbers. There are no figures available for the number of students in Further and Higher education specifically with DCD but, as there is evidence that DCD overlaps with Dyslexia (Kaplan *et al.*, 1998), looking at a comparative rise in students with Dyslexia may be a proxy for increase. Recorded figures from the Higher Education Statistics Analysis (HESA) for students arriving at university at undergraduate level with Dyslexia have increased in the UK. From 2000 - 2004 the number of undergraduate students reported with Dyslexia went from 9025 to 17560 students. Thus, it is likely that greater numbers of students with DCD are also arriving at university and colleges.

Students may go to university with a diagnosis of DCD/Dyspraxia. Alternatively they may arrive with no diagnosis but recognise that they have been "clumsy" since childhood or, alternatively they may have been given another diagnosis. For example, students may be diagnosed with Dyslexia or ADHD with or without a co-occurring diagnosis of DCD, but recognise that they have additional co-ordination difficulties. The diagnosis of Dyslexia may have been given instead of DCD. DCD was not as well recognised 15-20 years ago as it is in schools today and a referral to an educational psychologist at the time may have resulted in assessment of their presenting symptoms which may have been a reading or writing difficulty and resulted in the diagnostic label of Dyslexia. The diagnosis of Dyslexia could be seen to represent a potential "marker" for other specific learning difficulties.

4.3. Recognition, assessment and current diagnostic processes in FE and HE.

Obtaining additional learning support in universities in England and Wales requires completion of an application form from the local education authority to gain the DSA (Directgov, 2008). The DSA allows for specific support by student support services, as well as funding for specific equipment e.g. a laptop computer and software, where appropriate. This process drives the need for a diagnosis and, therefore, an assessment and recognition of a "disability" in order to receive this additional educational help and support.

Guidance from the DfES document (2005) states that:

> "Diagnostic assessments conducted from the age of 16 would be appropriate for the purposes of DSA eligibility. If an assessment was conducted before the age of 16 years, an update of the student's skills in reading, writing and spelling, e.g. a top-up assessment, would be required."
>
> p10.

Recommendations from the Specific Learning Difficulties Working Group (a group set up to advise government on assessment procedures for students in college and university) (2004/2005/DfES) suggested that:

> "In addition to the use of standardised measures of underlying ability, cognitive processing, and attainments in literacy (and numeracy), supplementary methods of information-gathering that inform the diagnostic process may be employed. These might include information concerning conditions such as Dyspraxia/DCD and disorders of attention, drawn from qualitative evaluations of the student's functioning, from assessments carried

> out by other appropriate professionals (e.g. occupational therapists) and from recognised checklists."
>
> p10.

Obtaining an assessment for DCD as evidence of difficulties in those over 16 years of age is currently fraught with difficulties. There are few services across the UK where there are suitably trained professionals either diagnosing or supporting adults with DCD. It is unlikely that one professional will cover all aspects of difficulties in adults with movement difficulties.

Most occupational therapists with experience of working with individuals with DCD are placed in paediatric services. There remain limited resources for children over the age of 11 years and even fewer for those over 16 years of age. The lack of services is mirrored also for adults with ADHD and AS, where the young adult falls in a "no-man's land" , between child and adolescent psychiatry and adult psychiatry (Coghill, 2004). Educational psychologists may undertake assessments but may not include specific motor tests. They may not also have the appropriate training to consider the differential diagnosis of other causes of motor difficulties such as Neurofibromatosis 1 or Joint Hypermobility Syndrome (JHS) (Kirby, 2004), both of which may have longer-term implications in terms of specialist type of support such as problems with JHS leading later to conditions such as fibromyalgia (Gedalia, *et al.*, 1993). Additionally, the psychologist may not be in a position to assess alone for other potential commonly co-occurring psychiatric disorders such as

ADHD or AS which may significantly impact on the student's ability to cope in university. This poses the question of which professional(s) are appropriately trained to assess and support individuals who are likely to have an overlapping profile of difficulties.

Even if students are able to see a professional for assessment, the testing presents some difficulties as there is a lack of standardised tools for the measure of motor impairment in adults. As described in Chapter 3 there are three main tests in general use across the world: The Movement ABC Battery-2 (Henderson & Sugden, 2007) standardised up to 16 years of age and examines motor skills in three areas: ball skills, manual dexterity and static and dynamic balance; The Bruininks-Oseretsky Test of Motor Proficiency-2 (Bruininks & Bruininks, 2005) which has norms up to the age of 21 years and a third test, the McCarron Assessment of Neuromuscular Development (MAND) (McCarron,1982) which has been normed up to 18 years of age.

However, the relevance of some of these tests in adulthood may be questioned where games requiring ball skills can be avoided altogether. It is of interest that a "clap and catch" task in the earlier version of the Movement ABC Battery has shown to be a good discriminator for adults with co-ordination difficulties compared to controls, when used in Cousins & Smyths' study (2003), is no longer in the latest version of the test.

It is unlikely that one test would be able to cover all aspects of difficulties in adults with movement difficulties. DCD in children (and adults) has been seen to be heterogeneous in nature and may present with differing patterns of difficulties. A retrospective study of a clinical population of 136 children with DCD (Movement ABC < 5%) (Kirby, Sugden & Edwards, 2007) showed that 55 % of the children displayed difficulties across all three areas on the test i.e. manual dexterity, ball skills and static and dynamic balance. However, interestingly, 22% of children did not show significant impairment in manual dexterity scores. This highlights the need for tests that are developed to cover a range of areas affecting motor co-ordination and not an approach that only looks at one aspect.

In the context of testing students in university, the one recommended test for Dyspraxia is the Morrisby Manual Dexterity Test (Morrisby, 1991). The Morrisby test only examines manual dexterity in one setting, and this may not transfer well to assess a range of tasks being asked of students. It was also primarily devised for "assessing candidates for small parts assembly, e.g. within the electronics industry." (Morrisby, 1991). However, there are potential flaws in using this test for individuals with DCD/Dyspraxia.

> "To date however, no specific statistical studies have taken place looking into dyspraxia or other similar difficulties and their affect on test performance. There are many reasons for this, but the main factor is that individual differences do vary considerably, so even if a candidate has

> informed us about a diagnosed or reported difficulty, we have no idea of the extent of the problem. The manual dexterity tests may provide an insight into such problems of course, but they were never developed as clinical diagnostic tests."
>
> (Personal correspondence from Sharp on behalf of the Morrisby Foundation, 2008).

There remains a need for ecologically valid tests to be developed for adolescents and adults that relate to activities of daily living and which also consider the educational or work context in which the young adult is being assessed. This fits with theories including dynamic systems modelling (Thelen & Smith, 1994) and Bronfrenbrenner's ecological systems theory (1992).

The drive for a diagnosis in order to receive support ultimately means that the individual has to recognise themselves as disabled and requires the individual to be categorised. Additionally, others working in further and higher education at all levels have to recognise that students with motor difficulties may have difficulties that can impact on their learning.

However, at the current time there is likely to be a differential in recognition and provision for students with DCD and those with, for example, Dyslexia. The Higher Education Statistic Agency reported frequencies for 2006 (HESA) do not currently have a specific coding to count students with DCD or Dyspraxia. There are codes for

Dyslexia and Autism Spectrum Disorders, as well as for blind and partially sighted, wheelchair/mobility, personal care, mental health (an unseen disability), multiple difficulties, other disability and no known disability. Interestingly, 42% of the total reported disabilities in 2006 were attributed to Dyslexia and only 7.8% were attributed to Autism Spectrum Disorders.

UCAS (Universities & Colleges Admissions Service) only describe Dyslexia and Autistic disorders in their documentation. In the document "Bridging the Gap: A guide to the Disabled Student's Allowances (DSAs) in higher education. Guide for 2007/2008", published by the UK government, the terms used are 'specific learning difficulties' and 'disability' and Dyslexia and Dyspraxia are mentioned as examples of specific learning difficulties. The National Union of Students (NUS) does not mention specific learning difficulties in its disability information section but uses the terms 'disabled' and 'mental health difficulties'. However, it does provide case studies of students with Dyslexia, Dyscalculia, and Dyspraxia.

In order to gain an understanding of the potential level of support directed specifically to students with either a diagnosis of DCD or Dyspraxia offered by universities and colleges student support services, a randomised sample of 20 out of 309 universities and colleges across the UK, including England, Wales, Scotland and Northern Ireland, were selected to check for their provision or guidance. Information was attempted to be obtained through their websites only (full details of all 20 universities are in Appendix E). Only six out of the 20 colleges and universities selected, mentioned anything about Dyspraxia and none mentioned the term DCD. The University of Sunderland, in a document called "Policy and Code of Practice For students with Specific Learning Difficulty (Dyslexia, Dyspraxia, Dysgraphia, Dyscalculia)", were one of the few universities or colleges to describe provision in more detail in their booklet to students and make reference to increasing numbers presenting with Dyspraxia:

> "The majority of students registered with the university's Disability Support Team are students with dyslexia although the number of students with dyspraxia is increasing"
>
> p2.

There remains some confusion over the definition of Dyspraxia :

> "Dyspraxia: difficulty with spatial orientation, confusion with left and right and a problem with directions. Students may appear to be uncoordinated and clumsy due to some impairment of learned voluntary acts"
>
> p 5.

4.3.1. The implications of disclosure and developmental disorders.

Once an individual has recognised that he or she may have difficulties requiring additional support the individual may be a need to come into contact there with others, for example in student support services and disclose their difficulties. There has been no work in the field of DCD on feelings about disclosure by students but there has been some research in the area of Dyslexia. Blankfield (2001) reported negative experiences of students who disclosed that they were Dyslexic while on work placements. Morris and Turnbull (2006), in interviewing 18 nursing students, also found 6 students had not disclosed their Dyslexia because of reticence in doing so. However, in the case of DSA there is obviously a balance of gains and losses in disclosing. Madaus *et al.* (2002) found this balance when surveying 89 ex-college students with dyslexia to establish the level of self-disclosure to their current employer and the reasons for this. Reasons for disclosure included the need for additional time, more detailed direction and to better enable the use of work-based technology. Job security and fears of a negative impact in the workplace were cited as reasons for non-disclosure.

Some students may arrive at university or college without a diagnosis and are only diagnosed once they have arrived there. This could potentially result in a change in their perception of themselves either positively or negatively. Riddick (2000) described the complex relationship between labeling and stigmatization with special reference to Dyslexia. Dyslexia is described by her as a hidden disability and many students may hide their difficulties from others. In contrast, DCD is a more visible problem with handwriting and co-ordination difficulties harder to hide from others. Examples of stigmatisation of children with DCD include terms such as: "spaz"

(oral communication with an adult), and "un-co" (oral communication with a parent of a child with DCD in New Zealand). Childhood experiences may have a profound influence on how the young person emerges in adulthood and their willingness to explain or tell others of any difficulties. These past experiences may particularly colour how they may act when arriving at FE or HE.

At the present time students with motor difficulties require identification in order to receive support. Riddick (2000) highlights the difficulty in providing a system without having specific measures and definitions. However, the current perception by the public of particular diagnoses may encourage or discourage the individual to share their difficulties with others. Parent organizations in the field of Dyslexia have championed a number of successful individuals using terms such as "bright " and "sporty" and listing successful adults with Dyslexia including Winston Churchill, and Steve Redgrave (Direct Learning, 2008). In contrast, there have been fewer flag bearers in comparison in Dyspraxia or DCD. This may make students with motor difficulties more reticent to tell others than those with Dyslexia, as there may be greater negative connotations attached to this than Dyslexia and lower levels of knowledge (Kirby, Davies & Bryant, 2005). Recently Daniel Radcliffe, star of Harry Potter films has disclosed he has Dyspraxia and this has stimulated some interest in the media.

Barga (1996), in a qualitative study in the US of nine students with learning disabilities, found they reported that a label was useful to them if it helped to make sense of their difficulties and enabled them to get help. He also interestingly described some of the positive coping techniques the students had used. These included relying on others to help them, implementing self-improvement techniques, and learning to use particular strategies and management skills to aid their academic work. In contrast, the negative coping techniques were described as "passing". These techniques were used to avoid disclosure of their disability and to get through school. This was achieved by using a number of strategies in order to not let others know that they had difficulties, but were seen to create tension for the students because of having to hide their difficulties.

The voice representing the student with motor difficulties has only grown in the last few years. The first group representing adults with Dyspraxia, rather than parents and children was a part of the parent support organization, The Dyspraxia Foundation. This group later separated from the Foundation and formed a separate identity and named themselves interestingly Developmental Adult Neuro-Diversity Association (DANDA). This was registered as a separate charity in December 2003 and the reason for this was given (2008):

> "as it became clear that most people connected to the Group did not have dyspraxia alone. Most, in fact, had AD (H)D (Attention Deficit (Hyperactivity) Disorder, Aspergers Syndrome or dyslexia as well. It was the norm rather than the exception"

It is fascinating that the adult movement has recognised overlapping patterns and the range of presentations more readily than many establishments and professionals working in the field.

4.3.2. Models of disability.

The challenge in working in the field of DCD is whether DCD is seen by students and others as a medical or educational difficulty, condition, disorder or label. Is the individual impaired or has society disabled them? In order to discuss this it is of value to describe some of the models of disability and impairment. There are a number of different definitions of impairment. Thomas (1999) describes how disability and impairment are not fixed phenomenon by are changing with time and social context.An interpretation of this is that society today may not only have a different positioning for different specific learning difficulties than perhaps ten years ago but could also portray one difficulty as more 'severe' than another. A diagnosis of AS, for example, may result in greater negative views than one of Dyslexia. Goffman (1968) draws a distinction between "discrediting" and "discreditable" stigma and makes the point that societies' attitudes towards disablement vary, depending on how obvious the " differences" are from the main group and what is expected in that society. Therefore, this opens up: the debate whether different disabilities in a place and time have differing "social implications" (Shakespeare, 2002). This move away from an acceptance of the individual and how they are, to maximising each individual's function is a shift from the more rigid social model of practice, which then clearly places the burden on society to change.

Goffman's position is of particular interest in the terms of the individual with DCD, as athletes such as football players are seen as socially desirable and given status in society compared with professionals or academics who may be less regarded as attractive and interesting by young people. Coverage on television and income received are two markers of this.

What does impairment mean in the present day context? One more recent example is:

> "Impairment is often differentiated by two main characteristics: type and severity. Since different abilities are required for different activities of daily living (ADLs) and instrumental activities of daily living (IADLs), individuals with different types of impairment may experience different types and degrees of activity limitations, disability and impairment"
>
> Van Naarden Braun *et al.*, 2008, p1.

This also implies that impairment is not a stable phenomenon but changing depending on the context, the task, or activity the person is being asked to do and the result that one person may be impaired in one setting but not in another. This sets the impairment outside the person. This fits in with a social rather than medical model of disability.

The medical model stems from a belief that the 'problem' of disability lies within the individual and secondly it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from the disability. This is a deficit model in terms of what the individual has not got, or cannot do, rather than society's role in failing to provide sufficient access or differentiating teaching or support to meet the needs of those with differences rather than disabilities. The rigid medical model in the past saw the individual as different from the norm and so he or she was marginalized. The individual was seen to be in need and required help or in need of being cured of their condition. This model stems partly from the late 18th century when the physicians started to define ill health and apply a categorization. At this time the physician catalogued a number of symptoms and signs and even applied their own name to this grouping such as Bell's palsy or Huntingdon's Chorea. Even into this century this continued, such as Asperger Syndrome, named after the German physician Hans Asperger. Early models of disablement are linked to disease or trauma and the individuals were seen as victims (Nagi, 1965). The Nagi model was a linear model starting with pathology leading to impairment leading to functional limitation and finally leading to disability. Environment and personal factors were not seen as part of this model.

Even today the training of doctors leads the doctor to be encouraged to diagnose and to treat the individual, and continues to see the difficulties lying within the individual although there has been increased acceptance of the interplay between the environment and the individual an the cultural and social variables. The dominant discourse among many psychiatrists in the field of ADHD discusses the role of medication and sidelines psychological approaches to supporting the young person and their family.

The doctor-patient relationship in the past was a paternalistic approach to doctoring where the patient was diagnosed and the doctor would decide and tell the patient what needed to be done to become well. There was also a belief that well meant "normal", so that the disabled person did not want to be in their present state or was less valued and would prefer to become like others. This directs the doctor to consider what treatment or rehabilitation programme could be used in order to work towards the individual achieving this state. In reference to the student with ADHD, there is a continuing need for the student to have a doctor-patient relationship, especially if they are receiving medication. They need to be in contact with a doctor in order to be monitored and receive a prescription, if this is the chosen treatment. Baverstock and Finlay's study (2003) describes the issues of managing prescribing once students with ADHD are in college or university. They surveyed 50 undergraduate health centres attached to higher education colleges and universities across the UK. Eighty-two percent responded. Key points from this research were even though 49% of centres were prescribing for students, only 13% of the GPs' had received any recent education about ADHD. Only just over half who prescribed had liaised with student services. The low level of prescribing and knowledge is concerning because a) there are increasing numbers of children growing up with a diagnosis and b) a significant number will also have DCD. They also commented about the NICE guidelines (National Institute of Clinical Excellence) that:

> "long term follow up is recommended into late adolescence and adulthood" p165.

Many services for children with developmental disorders in reality still end at 16 years of age and there remains a lack of recognition by professionals working with adults with these difficulties.

Changing terminology in the field of DCD reflects attitudes and beliefs of the medical establishment. The BMJ leader in 1962 talks of the "backward child" but uses the term "clumsy children" and describes the need for "a study of our backward children so that we can determine whether we can *help* them". Twenty five years on Hall (1988) had some changing views: "there are also dangers in the medicalisation of normal human variation" and reflects upon Illich's (1974) beliefs that generations have been conditioned to believe that a variation from the norm is a marker of 'sickness'.

In contrast to this medical view, the social model of disability was developed in the 1970s' and made a distinction between impairment and disability. Activists from the Union of the Physically Impaired Against Segregation (UPIAS) (1976) developed the model and it was later given credibility by Finkelstein (1980), Oliver (1990) and others.

This places the disability within society and considers what the barriers for the individual are such as access, prejudice, and understanding of others that create the disability. These barriers can be related to society's attitudes to disabled people (e.g. seeing them as objects of pity); economic barriers such as poverty and discrimination in the labour market; physical barriers (e.g. the lack of accessible transport systems); or political barriers relating to the lack of civil rights to counter discrimination.

This considers the effects of others' attitudes and society's beliefs towards disability and where the "blame" lies. This changes the balance of the relationship with the doctor and the patient from a paternalistic approach to one that is about enabling and working in partnership and learning to understand the perspective of the patient rather than considering that all individuals with a disability have similar life experiences.

The social model changes the lines of demarcation between the professional and user and also changes the dynamic between the two rather than one set in a traditional hierarchical model of doctor and patient. This does not diminish the role of the doctor but places him or her alongside the individual in partnership. Foucault's (1970) views were that individuals were "objectivised" and made a subject of others and this was defined by a struggle over power and knowledge. In the context of DCD, the individual would be labelled and defined by others as for example clumsy, unco-ordinated or more medicalised terms would be attached to the individual such as DCD and Dyspraxia. The individual then becomes attached to this model and is then described as "the dyspraxic". In addition, the individual would not be able to have his or her difficulties recognised until a diagnosis had been attached and given by the professional. The social model has been the dominant model in disability research since the 1970s.

There have been moves to discredit the overly rigid social model, and more recently Shakespeare claims that the British social model is outdated (2002) and has seen the disabled as "an oppressed social group." He claims that this model defines "disability" as the social oppression and not the form of impairment. Thomas (1999) discusses a broader vision of "impairment effects" . The present DCD model remains rooted in a medical model, where the family and the individual often have to wait until the diagnosis has been given in order to gain "recognition" and support and intervention.

A relevant, potentially pragmatic, model to consider once the individual leaves FE and HE is one that reflects society's changing needs in the workplace- an economic model. In a society where there are fewer manual jobs and an increasing technology the individual with co-ordination difficulties may have less difficulty accessing work than in previous times. With increasing technology available, the need to write may become less of a core skill once adulthood is reached. With the Disability Discrimination Act (1995; 2005), Special Educational Needs Disability Act (2001) and the Widening Participation Agenda (Lewis, 2002) the employer, HE and FE are being required to address ways of supporting the individual into training and employment. However, the economic reality may well be that where there are low levels of unemployment, the employer may not willingly choose the individual with specific learning difficulties, especially one who may have organisational difficulties. Demands from the economy itself may result in greater power in excluding and including those with additional needs than those from the government themselves. Davis (1999) debates the emergence of a consumer driven, capitalist society further rendering the disabled as "invisible and undesirable". Hardin and Hardin (2004) go further to say that:

> "People with disabilities are blamed for their inability to navigate a world full of barriers or participate in ableist- constructed physical activity"
> p 401.

Shakespeare's (2002) view is one of pragmatism:

> "The priority should be social change and barrier removal .Yet there is no reason why appropriate action on impairment cannot co-exist with action to remove disabling environments and practices"
>
> p 16.

4.4. Conclusion.

The individual with DCD lives within a dynamic and changing setting and the difficulties cannot be seen as a static and unchanging, purely medical or social but set in a biopsychosocial model. The Ecological Systems Theory, renamed as the bioecological systems theory described by Bronfrenbrenner (1992; 2005) provides a framework at differing levels and across time. There are macro, exo, meso and micro levels within this system. The usefulness of this model in the context of the student with DCD is that it sees that system 'failures' can occur at differing levels such as the university not recognising the needs of the individual, or that legislation by government may have an indirect effect on the support an individual obtains and does not set the deficits purely within the person themselves.

Bickenbach *et al.* (1999) describes impairment and disability within the framework of the International Classification of Functioning (ICF) (WHO, 2001):

> "Impairments need not affect a person's activities; but even if they do, no disability will result if the activity is not something a person is expected to be able to do, or to do in one way rather than another. People with impairments and disabilities, moreover, will only be disadvantaged in a social, cultural or attitudinal environment in which having impairments and disabilities (or being perceived to) typically brings disadvantageous consequences" p1175.

In contrast to the medical model, the ICF model is bidirectional, so cause and affect are not as clear cut. There is a focus on achieving a positive outcome and considers both the environmental and personal factors and demonstrates that support may be more than giving a computer to a person that cannot write. This is an important and essential model to consider in terms of DCD and will be discussed in light of findings in Chapter 7 and 8.

The individual with motor difficulties in the context of education has a need to be recognised as existing. This highlights one difficulty. The individual has to be described in terms of a disorder in order to have their needs considered. Changing terminology in the field of motor disorders has led to confusion about the reality of the impairment. This makes it harder to measure need, or knowledge because of this, and then the amount of support provided. While the present system continues to support a 'labelling' approach it will be necessary to clearly categorise the student with motor difficulties and outline their needs. This makes it more important to answer some of the key questions in this thesis to start this process; otherwise there is a chance of not offering appropriate support, having inadequate assessment processes in place. This is clearly both a waste of time and resource.

CHAPTER 5: METHODOLOGY AND RECRUITMENT.

CHARACTERISTICS OF ADULTS WITH DCD, AND THEIR PARENTS AND TYPICALLY DEVELOPING GROUP.

5.1 Introduction.

This chapter is divided into three parts:

The first part discusses the rationale for the methodological choices made in designing the study in order to meet the research aims and describes the strengths and limitations of these choices.

The second part of the chapter describes the recruitment process for all the participants to the study including the following groups.

- Recruitment of DCD participants
- Recruitment of controls
- Recruitment of parents

The final section describes the key characteristics of each of the above groups in further detail.

5.2. Methodology.

The struggle in planning a study to answer the key research questions is to consider the best method for collecting information so that it does not get decanted and distilled into figures and then lose the meaning and the rich experiences of the individuals themselves. At the same time there is a need to consider whether some generalisations can be made in order to be able to influence future practice in supporting students with motor difficulties.

> "Quantitative research focuses on answering the questions "what?" ... whereas qualitative research concentrates on answering the question "why?" and "how?".
>
> Kuper, Lingard and Levinson, 2008, p 404 .

In the context of this work, I have tried to achieve a balance of subjectivity and objectivity by seeking out the voices of both the parent and the student with motor difficulties when designing the studies that encompass the social, historical and the individual contexts. There was also a need to understand and accept the changing terminology that has been used in the field of DCD over the last 20 years. Some students may have been diagnosed with motor difficulties and given one label for this but professionals may now be calling these difficulties by a different name. The constructivist approach accepts that reality depends on the perception of the individual and their lived experience. There is a fine balance in how one listens and presents the voices of the students and the researcher potentially 'reinterpreting' them or making their own meaning from them.

In order to achieve some balance, a mixed method approach was chosen. Quantitative methods were first used to understand what the key features of emerging adulthood are and then, secondly, qualitative methods were used to extract key themes from the information from the questionnaires as well as from undertaking in depth interviews with parents and students in order to listen to their voices and gain a greater understanding of their individual lives.

This study has both a cross sectional and a longitudinal aspect to it. Firstly, a cross section of students from further and higher education were asked about their current functioning (they had not been questioned before). Secondly, a cohort of students who had been diagnosed with DCD in childhood (at The Dyscovery Centre) were also asked similar questions. Parents of the clinical cohort were also asked about their child's current functioning. Case notes on each of these students were available from the time when they were seen in childhood, to be able to compare and contrast the changes in time .i.e. longitudinally. This sequential method has been used in the field of study of adolescence for over 40 years (Baltes, 1968) and is one approach to increase the reliability of the findings. This also allowed a comparison of the self referred group to the clinical group to see if there were consistent or different patterns emerging in their lives and how they functioned.

5.2.1 Personal and professional bias.

As the observer, I am coming with a set of biases which are grounded in my own personal and professional experiences as cited in the introductory chapter. These are positioned also in my social, cultural, political and economic perspectives and also are determined by my training as a doctor. Armstrong (2003) discusses how views are influenced by the present day and related concerns.

The researcher's involvement in the story giving is a contributory factor in the way that the story is told. Blumer (1962) describes how meaning is gained through social interaction. In my case, being a parent of young person with DCD who is at university, with its own day to day challenges and having clinical contact with young people and adults with DCD in a number of different contexts as outlined in the introduction influenced my views before I even started to decide upon the focus of my work. It also had an effect on choosing the methodological approach. It may also have coloured the expectations of histories that might have been told to me. To counteract these potential biases I have used different and objective analytical techniques such as SPSS software and discussed my results with other colleagues to limit the effects of this on my interpretation of the results. Development of coding dictionaries, for example, where other researchers inputted also helped to ensure external checks were made and consistency of approach taken.

5.2.2. Research approaches chosen.

A mixed method approach was chosen in order to explore themes, and test their validity. In order to achieve this, different research techniques were employed:

- Questionnaires were constructed for both students and a cohort of parents containing open and closed questions – paper based and web based
- Interviews were undertaken over the phone with students with motor difficulties and a cohort of parents
- Retrospective analysis of case notes of a cohort of individuals was undertaken from a clinical cohort of children seen in childhood who were now emerging adults in order to compare and contrast past parental concerns with present concerns and explore persisting, resolving and changing issues.

5.2.3. Value to each approach.

Both quantitative and qualitative methodologies have advantages and disadvantages. The quantitative methodologies allows for a counting and categorisation of the young person with DCD, which allows "others" to recognise patterns and features that are consistent. However, this method may allow us to gain a grand picture of the 'selves' of individuals with DCD and may invest power in myself as a researcher to construct and portray this image. It may result in being able to construct the "average" adult with DCD, but may miss out on the differences in experiences and symptomatology dependent on differing contexts and differing individual profiles. This approach allowed information to be gathered from a larger group of individuals and enabled coverage over a wider geographical spread across the UK, but may have limitations as response is determined by who wants to answer the questions rather than being randomly selected. The respondents, therefore, may represent a biased group. For example, students may have less severe symptoms and so could be more confident in their responses, or the converse of this and want to disclose via the internet as there is a level of anonymity. Robson also states that:

> "respondents may not treat the exercise seriously, and you may not be able to detect this"
>
> Robson, 2004, p 233.

Kramer (2004) suggests, to counter these difficulties, that there is a need to collect information from a number of perspectives and use the "OR rule". This means that combining the responses across informants may provide the best approach to providing an inclusive assessment of functioning of the individual. This approach has been undertaken in this study by using both qualitative and quantitative methods, as well as gathering information from multiple sources such as the parent and the student and from differing student populations: a clinical, self referred and a control group.

Parents and their children may have different views about what constitutes a problem for them. Research undertaken about adults with ADHD has shown evidence that self report is a poor measure of functional ability (Willoughby, 2002). A study of college students with ADHD, where both parent and student completed rating scales, showed that students had reported higher levels of symptoms than their parents. This was attributed to higher cognitive functioning leading to greater insight (Glutting, Youngstrom & Watkins, 2005). Having multiple informants, i.e. taking information from both the parent *and* the young person allows for a more complete picture of the young person's functioning. Cousins (2003) reported that in her study of adults with DCD, those who reported themselves as Dyspraxic thought that they had greater difficulties with fine motor control than gross motor control, and vice versa in the clumsy group. However, on testing this was not supported as the Dyspraxic group were worse on both measures.

The voice of the parent has come to the fore in the past two decades, and in particular in gaining an understanding of the individual with difficulties and their needs in the context of their families and the society they live in. Government documents such as 'Every Child Matters' (DfES, 2004) and 'Improving Life Chances of Disabled People' (Prime Minister's Strategy Unit, 2005) have discussed the role of the carer in a key support role. Parents are now seen as key 'change agents' for their children. Parents may also have a unique insight into the difficulties of their children, as they may also have had a greater chance than the mainstream population of having had similar difficulties in their own childhoods (Emerson & Hatton, 2007). This may be useful or could lead to biased responses.

Qualitative research approaches are especially suited to the study where there are complex interactions, such as those between the individual and the environment (Yerxa, 1991). Furthermore, qualitative methods are considered to be the most effective means of studying the lived experience (Cresswell, 2003).They provide the researcher with an opportunity to understand life experiences from the perspective of the individual (Marshall & Rossman, 1995) and, in this case, from the parents as well. Open ended questions answered by the larger body of students and parents also allowed additional qualitative data to be collected prior to undertaking the interviews. This enabled key themes to emerge which were then further explored in greater depth during the interviews and allowed the results of these initial views to be further tested.

Using different techniques including interviews was a preferred method for collecting data about parents' and students' thoughts, feelings and perceptions (Marshall & Rossman, 1995). Robson (2004) and Yin (1994) discuss also the case study approach as:

> "a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence."

p178.

Robson (2004) also states the view that:

> "Case study is not a flawed experimental design, it is fundamentally different research strategy with its own design"
>
> p180.

This exploratory study of the social behaviours and characteristics of emerging adults required this dual approach in order to gain a sufficient and robust picture.

5.2.4. Trustworthiness.

An important consideration in qualitative research is the issue of trustworthiness. Trustworthiness involves establishing credibility, transferability, dependability and conformability (Lincoln & Guba, 1985). The validity of the findings is questioned in qualitative methodology as to what extent are the findings replicable.

In this study, a mixed method approach was used to increase the trustworthiness of the findings, and was established through the gathering of both larger group data and then comparing this to the more in depth case studies ascertained through the use of semi-structured interviews. Coding dictionaries were also established once themes emerged and these were then checked by an independent researcher, who was a psychologist, in order to ensure accuracy of the research results.

A field journal was also kept by the primary author throughout the study as a way of capturing ideas, thoughts and observations. This was referred to when analysing all the data, as time can change perception and to ensure that degradation in views and understanding did not occur. Transcripts were also sent to the parents and students for checking to ensure that these were accurate and the themes that were considered emerging were agreed by them.

As Bloor (1997) states:

> "Social life contains elements which are generalizable across settings (thus providing for the possibility of the social sciences) and other elements that are particular given settings (thus forever limiting the predictive power of the social sciences)"
>
> p37.

Using a mixed method approach allows for an understanding of both these aspects. Robson (2004) aptly describes that this approach presents a reality:

> "through the eyes of the participants. The existence of an external reality independent of our theoretical beliefs and concepts is denied" and goes onto say that: "the attitude towards theorising emphasises the emergence of concepts from data than their imposition in terms of a priori theory"
>
> p25.

5.2.5. Quantitative Methods.

5.2.5.1. Construction of the questionnaire.

A questionnaire was constructed that had multiple elements that would allow the capture of symptoms relating to childhood, in order to not only meet some of the DSM-1V criteria but also to gather information relating to how individuals as emerging adults with poor motor functioning were living and working compared to students without a past history of difficulties.

The use of both open and closed questions allowed information to be completed quickly by the student but at the same time allowed some additional valuable qualitative information to be gathered, such as the students' perceived strengths and difficulties. Using a questionnaire to gather information from the student cohort has strengths as well as limitations. It allowed larger numbers of students' data to be captured and gained from a wide geographical area. The choice of questions evolved from undertaking an audit of clinical cases of adults who had been seen at the Dyscovery Centre, along with focussing on what is known of difficulties presenting in childhood and from studies completed in adolescence and the very few adult studies. There was a need to establish a difference between attitudes and behaviour in order to ensure the ability for generalising the information (Robson, 2004). For this reason, triangulation of information was undertaken from both the individual and from a small group of parents. However, the attitude of the emerging adult was also important to capture in this study. The open ended questions allowed for rich commentary to be obtained, in addition to the information gained from the closed responses. To avoid ambiguity and to check for consistency, some questions e.g. handwriting and organisation were asked in several different ways. By also having a choice of options for completion, web or paper based, this aimed to increase the accessibility, especially for the target audience who may have both reading and writing difficulties. After the questionnaire was constructed a focus group of occupational therapists, psychology researchers, and an educational psychologist met to discuss the content and language of the questions and this was then tested on a clinical cohort of adults with DCD (with explicit permission) to test for length, and understanding (Robson,2004).

5.2.6. The use of the semi-structured interview.

The use of semi-structured interviews gathered in depth information from a sub set of individuals and allowed for greater understanding of the social and psychological setting of the individual, as well as being able to explore potential resilience factors. This approach was chosen in order to gain more explicit information regarding the motor difficulties experienced not only as a child but continuing into adulthood. This differed from using a fully structured interview with fixed wording and an open ended approach undertaking an unstructured interview which may have allowed for understanding of the individual's beliefs but may have not focussed in sufficiently on the areas being studied. The benefit of the semi structured interview is that it has some predetermined questions, but the order is able to modified as the interview is undertaken. This allowed some flexibility if some of the questions were not appropriate. This approach has been highlighted to be useful when a quantitative study has been carried out and some qualitative data are able to be obtained to further clarify information (Robson, 2004).

Until the past few years, qualitative types of research may not have been viewed as having as great value among some academics as more quantitative methods. Participatory research engages the participants in the process. The telling of "the story" has been seen to enable the researcher to gain a comprehensive picture and be able to inform policy and practice (Goodson & Sikes, 2001). Meek (1991) describes stories as a means for "sorting out the world" (p 100.)

Hearing the "voice" in this study of both parents and students was important for me, to be able to consider the different views and perspectives that were being offered to me and then my interpretation of these. I needed to be careful, that the selection of who spoke to me and who did not, were not influenced by my own experiences and what I wanted to gain from the information. Additionally, how information was taken and then analysed was not biased in the way I expressed it to others. A biased selection can become merely a representational picture and not generalised to be the view of "all". The narrative is a constantly changing picture of the narrator giving a history of the past but from a perspective of today.The narrator recreates and reinterprets the pictures of the past.The narrator and the researcher has a close role as the conversation is guided and modelled by both participants. The narrator in telling their tale is asking "who am I, where am I going?" Oakeshott's (1933) views were that when we gather an account of the past we are not only looking at the "facts" that are represented but also with the position the historian has to those "facts". Collingwood (1961), thirty years later described how writing about the past is a re-enactment but given in the present time. Armstrong (2003) more recently has discussed how constructing the story is a process in its own right, as it has to engage with the present time in doing so.

In deciding who would be interviewed, the individuals were asked whether they would be willing by postal questionnaire or email to be interviewed. In doing this, I was not able to choose who may have been "better" to be interviewed or give specific views and ideas.

Goodley *et al.*, (2004) describes how life story research should prompt positive social change and often raises more questions than answers. It should aim to "render the familiar strange" (p 57) and contest normative assumptions. Bannister *et al.* (1994) argued that qualitative research is a part of an ongoing debate surrounding the epistemological position of the author and what theory and philosophical orientation the author is positioning him or herself. This approach is certainly not seen as an easier route as there is a constant "struggle over power, subjectivity and knowledge" (Goodley *et al.*, 2004). There are limitations. It is accepted that stories impose:

> "constraints that confine perceptions of those involved within the boundaries of their own stories"
>
> Armstrong, 2003, p 33.

In order to gain a greater in- depth understanding of the parents' and students' views and lived experiences, a sample of parents and students were interviewed from the index groups. The method used was a qualitative approach using semi structured in-depth interviews (McCracken, 1988). Using qualitative research methods is especially suited to the study of complex interactions such as those between the individual and their environment (Yerxa, 1991).The interviews are the preferred method for collecting data about people's thoughts, feelings and perceptions (Marshall & Rossman, 1995).

Interviews are a negotiation between two people (the researcher and the participant). Fontana and Frey (2000) describe the relationship that is formed in this interaction and how this can have significant impacts on the types of stories that people tell. However, by using a semi- structured rather than totally open interview approach, the voices of students and parents could also be compared to the group study. This may have limited the potential for exploring areas that may not have been considered relevant to the author but at the same time asking questions as determined relevant in order to answer the research questions. As Baker (2004) so cogently states:

> "the sticky problems of bias (on the interviewers part) and truth telling (on the witness's part) come to the fore"
> p168.

In order to capture the voices and individual stories of parents and students audio taping over the phone was chosen as a method of data collection. This was seen to be fit for purpose as interviewees were from a wide geographical spread and allowed for a flexibility working with the participants when they could be interviewed and ensuring this would take place in a setting where they felt comfortable and at ease. This also was achievable within the time frames of the study.

The telephone interviews lasted between 40 minutes to one hour 10 minutes and were all taped on a digital recorder and then transcribed. All parents and students had completed the initial questionnaire. There was then a gap of between 1- 4 weeks to allow them time to think about what had changed or not with their child or for themselves. They did not have a copy of the questions prior to the telephone interview. They were told during the phone call to arrange the interview time,and that the interview would be an extension of the paper based questionnaire.

All interviews were transcribed verbatim and N Vivo software (2005) was used to assist data management and data analysis. In order to ensure that I, as the researcher, had interpreted the responses correctly and had transcribed the interview accurately, once the interviews had been transcribed they were sent to the individuals for checking in order to ensure that the narrative captured was consistent with the themes discussed. Once agreement had been gained they were then coded for themes and further sub analysis was undertaken. The analyses were carried out iteratively. After initial scrutiny of the data collected from the transcription from the first interview, this then informed the other eleven interviews. From the transcriptions, emerging themes were constructed. The thematic framework was used as a basis for coding the data. Each phrase was analysed separately by interview and then cross analysis was used to group responses to questions. The analysis was undertaken in two stages. A content analysis was conducted first to identify, code and categorize the primary patterns from the data into a manageable classification. This was then coded by a second researcher separately. The second researcher was a graduate psychologist with three years experience. An inductive analysis followed to identify emerging categories, patterns and themes. The categories were scrutinized to determine consistency and contradictions and to uncover the multiple perspectives of parents and the students and to develop an understanding of the differences and similarities of their lived experiences. Alongside the taped interviews, detailed field notes were made by the principal investigator to record the experiences, feelings and thoughts that emerged and any additional comments (Patton, 1990).

5.2.7. Retrospective data analysis.

A third area of exploration was through a database from a clinical cohort from The Dyscovery Centre, based in Wales (an interdisciplinary centre providing assessments for children and adults with developmental disorders, with a specific focus on DCD). Children have been assessed in the centre for the past 15 years and so there was an existing database of children who had been diagnosed with Dyspraxia/DCD in childhood. This allowed for a comparison to be made of parental concerns in the past, with present day concerns. Additionally, this approach enabled a valuable source of young people's views of themselves with regard to their current concerns. This allowed for a comparison of concerns at two time points and allowed for a greater understanding of what had changed and what had resolved among the young people with movement difficulties.

5.2.8. Tools used.

Most studies on adults with DCD have used measures to examine specific movements and have considered some but not all the potential impacts of having the difficulties on every day living. In order to select appropriate tools for this thesis, it was necessary to compare other studies which had examined young people with DCD and to consider if the approaches taken would be useful in answering the research questions. Additionally, information gathered from clinical assessments with adults in The Dyscovery Centre influenced the choices and perspectives taken.

Other authors had previously focussed mainly on the motor ability and had adapted a variety of assessment tools designed for younger children. However, I felt this had limitations for this age group as these had been adapted without the appropriate age norms and focussed very much on motor functioning and less on the social impact of having these difficulties. For example, Geuze and Borger used the TOMI (Test of Motor Impairment) (Stott, Moyes., & Henderson, 1984) and then used an adapted version when the children were 11-17 years of age. Cousins (2003) used some tests from the M-ABC (Henderson & Sugden, 1992). However, at the time of testing it had only been normed up to 12 years of age and not normed up to the age of 16 years as it is today (Henderson & Sugden, 2007). Cousins used a variety of methods in her study, including questionnaire and interviews to explore participants' beliefs about their motor skills and how their difficulties affected their lives. She chose tasks to measure the motor ability of this cohort of individuals in order to examine whether their reported behaviours aligned with their actual responses to different motor tasks. The tasks included tests to measure performance in the stationary environment including manual dexterity tests such as handwriting, both for accuracy and for speed. Some of these tests partly originated from the Movement ABC Battery (Henderson & Sugden, 1992). One criticism other researchers had cited was the discriminatory validity of some of the tasks being used in this older age group (Geuze & Borger, 1993; Losse *et al.*, 1991). Cousins also undertook some tasks with the adults in order to examine how the individual moved through their environment. These latter tests, such as examining obstacle avoidance were devised specifically for the study, along with others such as ‘walking along a line’ which had originated from the Movement ABC Battery (1992).

Cousins (2003) in her PhD Study, also took a staged approach in order to examine the group of adults with DCD (with a mean age of 39 years, and an age range of 18-73 years). Her approach influenced the first stage of the recruitment in this study in attempting to gather information in the following areas:

- Presence (or absence) of specific learning difficulties, in particular motor difficulties
- Exclusion criteria for motor deficits
- Functional performance
- Present position- educational attainment, status, living situation

5.3. Recruitment.

This section describes the methods by which participants were recruited to the project and the procedures implemented in the groups below.

- Recruitment of DCD participants
- Recruitment of controls
- Recruitment of parents

5.3.1. Recruitment of Participants.

5.31.1. Students

Two methods were used to recruit participants.

a) *16-25 year olds with evidence of a formal diagnosis in childhood.*

In order to recruit this group letters were sent out to past clients seen at The Dyscovery Centre, University of Wales, Newport (a specialist multidisciplinary team with an interest in children and adults with DCD). These students were now all aged between 16-25 years and had been given a formal diagnosis of DCD in childhood and were asked if they and their parents would consider taking part in the study. The letter contained information about the study, and the option to complete a paper based version of the questionnaire or to go to the website and complete it online. Parents were also asked to complete a questionnaire. See Appendix C. The questionnaire additionally asked them to indicate if they were willing to undertake a face to face or telephone interview in the future.

b) ***Students at college or university with a diagnosis of DCD/dyspraxia or recognising themselves as having co-ordination difficulties since childhood.***

In order to capture this second group of students from colleges and universities across the UK several methods were employed. The methods used included sending posters and information about the study to universities and colleges across the UK after contacting the disability officers from each college and university through NADO (National Association of Disability Officers). Where disability officers agreed to placing posters, a pack of posters and information about accessing the website was then sent to each centre. A question was printed clearly on each poster asking students: “Do you think you were ‘clumsy’ as a child, or have you ever been given a diagnosis of DCD/Dyspraxia?” Leaflets outlining the project were also sent to so that they could be passed onto the students. It was of particular interest to attract both students with a childhood diagnosis of DCD or Dyspraxia and also those that thought they had been “clumsy” as a child, but were not diagnosed or had been given an alternative diagnosis such as Dyslexia. This was important, as cited in chapter 3, where the issues of overlap of ADHD and DCD and Dyslexia were discussed as well as the issues of assessment and diagnosis of DCD in adults discussed in chapter 4. The students were representative of students that may be attending FE and HE throughout the country.

The rationale for having two groups- a clinical group and a self reporting group was to consider whether their patterns of difficulties were similar or different. Attracting students from across the UK was also important in order to gain an overall perspective on student support provided.

5.3.1.2. Use of the internet.

Additional recruitment techniques were used through "Facebook", an online community actively used by students. Information on the study was placed on the site with an invitation to contact the researchers if they wished to participate or if they wanted further information about the study. Alternatively they could go straight to the website and complete the questionnaire.

After gaining consent, all students completed either a web or a simple pen and paper questionnaire. A website was developed specifically for the study: (http://www.amandakirby.info/page.php?page=movementdifficultiesinadults.php). The site also included information about the author to ensure the credentials were overt for all respondents to access. Background information on the study was also repeated on the website.

An internet-based questionnaire was specifically offered to limit the need to hand write responses as it was likely that some of the students would have some handwriting difficulties (Cousins & Smyth, 2003). It was also used as a technique to increase recruitment of students from across the UK from as wide a range of colleges and universities as possible. The internet has been used as a tool for research since the early 1990s'. The internet mediates and may moderate the responses that would normally be given through other more conventional media such as paper based questionnaires especially for the target audience. Online access makes completing a questionnaire easier for the participant in a number of ways such as anonymity, no need for handwriting, and the user can choose their own time and place to complete it. It also allows information to be gathered from a geographical spread (Markham, 2004).

5.3.1.3. The questionnaire.

In order to decide who was to be included in the study, the questionnaire was constructed into two main sections. This first section was concerned about diagnostic and screening issues, and contained questions to specifically rule in or out applicants to the study. This section will be reported in this chapter.All students were also asked if they had been given a diagnosis of a developmental disorder and by whom. They were specifically asked whether they had been given a diagnosis of Dyslexia, ADHD, AS, Dyspraxia /DCD and other (asked to state). The diagnoses were not specifically used as exclusion criteria as the aim of the study was to capture a cohort of students who believed or had been told that they had co-ordination difficulties. Including them within the study allowed for a representative sample of students with motor difficulties that would be seen in FE and HE.

The second section contained a series of questions enquiring about whether the students had received any professional help or intervention in childhood. Also name and type of university or college and their course chosen, current living arrangements and whether the students were currently in receipt of additional help or allowances was asked. Social and leisure choices, alcohol, drug and driving history were also asked. In order to obtain detailed information about driving abilities a questionnaire was adapted from a driving questionnaire derived by Barkley (2004) and was amended for UK purposes with permission from the author (see Appendix A, B and C).

Students were additionally asked, in an open question, what they perceived were their strengths and remaining difficulties at this time. This question was asked as I thought it may give an insight in how the student perceives themselves and may be seen as starting point to see how support services in FE and HE could support students with DCD.

A full copy of the questionnaire as accessed by participants can be found in Appendix A. In developing the questionnaire a small number of students who were being seen clinically at The Dyscovery Centre piloted the questionnaire but were not included for final analysis. Small amendments were made as a consequence of comments and input from them and from other professionals working in the Centre. It was also read through by members of the clinical team who regularly see adults with DCD and related developmental disorders for their comments and advice.

The term DCD has been used for consistency in reporting results. However, students may also have stated that they had a diagnosis of Dyspraxia given in childhood as this was the common term used ten to fifteen years ago when they would have been diagnosed. It is also still used interchangeably by some clinicians in the UK. For this study the terms DCD and Dyspraxia are being used interchangeably (Peters *et al.*, 2001).

5.3.1.4. Inclusion and Exclusion criteria.

The first part of the questionnaire contained specific questions in order to attempt to mirror the DSM-1V criteria for diagnosis of DCD (APA, 2000). This provided a framework for both inclusion and exclusion to the study.

Inclusion criteria: In order to meet criterion B, i.e. having difficulties interfering with activities of daily living and education since childhood, seven questions in the questionnaire related specifically to past motor difficulties in childhood, either skills deficits or observations by others of their movement skills.

The questions asked were: difficulties with self care tasks such as tying shoelaces, fastenings such as buttons and zips, cleaning teeth; difficulty learning to ride a bike compared to peers; difficulty playing team games such as football, netball, catching or throwing balls accurately; difficulties writing neatly (so others could read it) and/or as fast as their peers difficulties bumping into objects or people or tripping over things more than others; have difficulty playing a musical instrument e.g. violin, recorder; being called clumsy, or having others comment about their lack of co-ordination.

In order to be included in the motor co-ordination group, students had to have scored at least five out of seven on the past difficulties in childhood part of the questionnaire or have evidence of having a diagnosis of DCD given in childhood (such as gained from notes from the Dyscovery Centre).

In order to be included in the other groups e.g. Dyslexia, they needed to report that they thought they were clumsy or had poor co-ordination in childhood and have been given a diagnosis of Dyslexia in childhood.

Exclusion criteria : In order to meet Criterion C which states that the individual should not have any other causes of motor difficulties such as "general medical conditions" (e.g. cerebral palsy) students were specifically asked whether they had any medical conditions that could be a cause of their motor difficulties. Examples were given e.g. muscular dystrophy, stroke, cerebral palsy, polio. All those responding positively to any of these were then excluded from the final analysis.

Criterion D states that: "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." Individuals were not formally tested as it was presumed that as the population were attending university and college in order to obtain higher level qualifications and so it was highly probable that they had *reasonable* cognitive ability.

Additional exclusion criteria: If students were out of the age range of 16-25 years they were excluded from the main analysis.

An additional questionnaire was completed by a subset of students after preliminary analysis of strengths and weaknesses as reported in Chapter 6 (see Appendix B). This questionnaire went into greater detail about daily functioning and self perception of students' ability to do what they wanted and needed to do. The results of this are also presented in Chapter 6.

There are limitations using a questionnaire based approach as the students were not formally assessed for their motor difficulties and for some their diagnosis was self reported and not formally confirmed, apart from those who had been given a diagnosis in childhood of DCD or Dyspraxia undertaken by The Dyscovery Centre. The rationale for not formally testing each student for DCD was similar to current approaches taken to supporting a student in FE and HE as has been explained previously. Students who want help in college and university present themselves for support, and they are not formally assessed using any standardised tests apart from the Morrisby Test of Manual Dexterity which is not specific to DCD (1991).

5.3.2. Recruitment of control group of students.

Control students (coded as TD i.e. typically developing) were recruited from universities and colleges from across the UK attending a range of courses, using a paper based version of the questionnaire. They were asked if they would be willing to complete the questionnaire after the rationale for the study was explained. All students who completed the questionnaire were offered to be entered into a draw for an Apple Nano I-Pod.

Exclusion criteria for the control group: All students who reported two or more motor difficulties in childhood and/or having a known diagnosis of any specific learning difficulty including ADHD, Dyslexia and AS or DCD/ Dyspraxia were excluded from the study.

5.3.3. Recruitment of parent group.

The rationale for the recruitment of parents was that they could give an additional perspective of their children's functioning especially at home. The results of these interviews and completed questionnaires are discussed in greater detail in Chapter 9. Parents were selected for interviews in two ways. A non-probability, purposive sample was used to select individuals from a clinical sample of children with known co-ordination difficulties.

> "In purposive sampling, researchers handpick the cases to be included in the sample on the basis of their ... typicality"
>
> Cohen *et al.*, 2001, p.103.

Parents of children who had been seen at the Dyscovery Centre with a diagnosis of DCD or Dyspraxia and were now in the correct age group were selected from The Centre database. All parents were sent a questionnaire (see Appendix C) to complete and asked if they would ask their children if they would also agree to complete a questionnaire (see Appendix A).

5.3.3.1. Parent interviews.

The parents were also asked whether they would be willing to be interviewed and their preferred method of contact. Those parents that agreed to be interviewed were contacted by e-mail or telephone in order to arrange a suitable and convenient time for the telephone interview to take place. The interview style was semi structured providing a framework for the in depth interviews, (McCracken, 1988) in order to examine the parents' perspectives of their children at the present time and how they perceived changes had occurred during emerging adulthood.

The rationale for gaining multiple viewpoints has been gathered from the research from other developmental disorders. It is common practice and indeed cited as best practice to gain views from multiple informants in order to obtain the diagnosis of ADHD (Barkley, Murphy & Fischer, 2008). This has a practical aspect as the students themselves may not be able to recall early developmental milestones or behaviours. In order to be given a diagnosis, difficulties need to have been present since childhood. A second reason for a parental perspective is that the information gained about social experiences and present functioning from the student may not be the reality of the experience for the family. This has been noted in the field of AS, where students and their parents were both asked about the costs of support. Estimated hours of support were 2.5 times higher than their children's estimates and expenses 8 times higher than their children had indicated. (Järbrink *et al.*, 2007). Variance in parent and student reporting has also been noted in studies in adults with ADHD. One study showed under reporting of the students (Cantwell *et al.*, 1997) but this was in a younger age group of adolescents. In contrast, the study by Glutting, Youngstrom and Watkins (2005) demonstrated students reporting higher rates of difficulties than parents.

From the initial parents' questionnaires, information was collated to establish whether they would be willing to be interviewed and their preferred method of contact. A time was agreed with the parent to undertake the interview. All interviews were undertaken by the author over the phone. The telephone interviews lasted between 40 minutes to one hour 10 minutes and were all taped on a digital recorder and then transcribed. A similar process was undertaken for the students who were interviewed.

5.3.4. Student interviews.

The selection of students for interview came from a sub set of the students that had completed the online questionnaire and who agreed on their questionnaire to being interviewed over the phone. This aspect of the study was seen as important in order to drill down further and gather information about their lived experiences of the motor co-ordination difficulties group and to explore additional issues that had not been highlighted from the questionnaire and additionally to gain further qualitative information. Consent was gained from each student to tape the recordings. All interviews were then transcribed before being coded using N-Vivo software (2005). Manuscripts were sent out for comment to each student once transcribed in order to check for accuracy. Students were asked to make amendments if necessary. The results of much of this information are explored further Chapter 6-8.

5.4. Methods of Data Collection.

Information about the project and questionnaires were sent to Disability Officers based in colleges and universities. Questionnaires were also posted out to the database of clients from the Dyscovery Centre who were aged between 16 to 25 years. A stamped addressed envelope was sent to each client. The questionnaire was posted twice, each time with a stamped addressed envelope to increase the response rate (Edwards *et al.*, 2002). All students were offered a £10 book voucher once the questionnaires had been returned. Of the 122 postal letters sent out to clients and parents there were 46 responses from this (38% response). Of these 46 responses, four were decisions not to participate, resulting in 34 % agreeing to enter the study.

5.5. Characteristics of Participants in the Index Group.

5.5.1. Characteristics of Student Participants based on the results of the Questionnaire.

After screening procedures were completed, 284 questionnaires were completed in total; 166 in the motor difficulties group and 118 from the typically developing control group.

The following describes the characteristics of each group.

Table 5A: Background details for questionnaire; student respondents in movement difficulties group

166 questionnaires completed

Paper - 46 ▼

Web -120 ▼

	Male	Female
DCD only	26	18
Other	48	61
No diagnosis	3	10
Total	77	**89**

Out of the 166 who completed the questionnaire with motor difficulties, 66 were excluded from the study for the following reasons:

Exclusions (n= 66)

- Over the age of 25 or no age given (n= 32)
- Medical conditions reported (n= 14)
- Had 4 or fewer childhood motor related difficulties and a potentially unreliable DCD diagnosis source or an unknown diagnoser (n= 16)
- Less than 5 childhood difficulties and no diagnosis (n=1)
- Resident and attending University outside of the UK (n=3)

Table 5B: Medical conditions reported.

Medical conditions reported	**n**
Stroke	5
Meningitis	3
Left hemiparesis	1
Asperger's syndrome **and** childhood epilepsy	2
"Inturned femurs"	1
Head injury as a child	1
One leg shorter than the other	1
Total reported	**14**

The childhood epilepsy cases reported were BECCTS syndrome (Benign Epilepsy of Childhood with Centrotemporal Spikes) and has been associated with motor difficulties (Scabar *et al.*,2006) but were excluded because of a known neurological condition.

5.6. Characteristics of the Motor difficulties groups.

There were 100 students in the final sample, with 57 males (57%) and 43 females (43%).

Individuals were then subdivided into four groups:

1. DCD (those reporting " just" a diagnosis of DCD)
2. DCD + (those reporting another diagnosis in addition to DCD)
3. Dyslexia and Dyslexia + (those reporting a diagnosis of Dyslexia and one individual with Dyslexia +ADHD, but not DCD)
4. Movement difficulties present but given another or no diagnosis

The rationale for dividing the students in this way was to examine whether there were differences between groups that related to their given diagnosis in childhood and to explore whether those in particular with a diagnosis of Dyslexia were, in fact, a different or less severe group in terms of their motor functioning.

Table 5C below shows the characteristics of the groups subdivided into those who reported a diagnosis of DCD (and additional developmental disorders), and those who were diagnosed in childhood with Dyslexia, and did not receive a diagnosis of DCD in childhood but reported that they thought they had poor co-ordination.

Table 5C: Characteristic of motor difficulties group by age and gender

Group Numbers		Male %	Female %	Age range	Overall mean (SD)	Male mean (SD)	Female mean (SD)	% 16-18	% 19-25
DCD only	31	67.7	32.3	16-25	20.13 (2.49)	19.81 (2.71)	20.8 (1.87)	29	71
DCD plus	42	52.4	47.6	16-25	19.76 (2.13)	19.23 (2.0)	20.35 (2.16)	28.6	71.4
Other/no diagnosis	3	100	0	17-25	21.33 (4.04)	21.33 (4.04)	n/a	33.3	66.7
Total motor group	76	60.5	39.5	16-25	19.97 (2.34)	19.63 (2.48)	20.5 (2.05)	28.9	71.1
Dyslexia and Dyslexia+	24	45.8	54.2	17-24	21.13 (1.87)	21 (2.15)	21.23 (4.04)	8.3	91.7

A further breakdown was undertaken of those with a diagnosis of 'DCD plus'. It is interesting to note that more students with a diagnosis of 'DCD plus' were recruited than DCD only. This may reflect the reality that DCD is often seen overlapping with other developmental disorders or may be a bias in recruiting in that those with persistent difficulties are likely to be individuals with more overlap with other developmental disorders. DCD and Dyslexia were the commonest overlap seen. In the DCD only group the ratio of males to females was approximately 2:1 compared to the Dyslexia and Dyslexia+ group, and the DCD+ group where there were approximately similar numbers of males and females. The latter were reported mostly having DCD and Dyslexia as a combination. This may reflect that females may be less likely to be recognised if they have solely motor difficulties.

Table 5.D: DCD + by reported diagnostic breakdown

DCD +	(n=42)
DCD + Dyslexia	21
DCD + LD	5
DCD + AS	3
DCD + ADHD	2
DCD, ADHD + AS	1
DCD + other	1
DCD, Dyslexia + LD	4
DCD, AS + LD	1
DCD, LD + other	1
DCD, Dyslexia, AS + Other	1
DCD, Dyslexia ,ADHD, AS + LD	2

Table 5D demonstrates the breakdown of the reported diagnosis in those that stated they had DCD plus another diagnosis.

(LD indicated learning difficulties. This was reported by individuals and not specified what this was)

Table 5.E: Number of participants reporting Dyslexia, "other" and no diagnoses

Other (n)	
Dyslexia	23
Dyslexia + ADHD	1
No Diagnosis	2
ADHD	1

Table 5E shows the breakdown in the "other" group, i.e. those that reported a diagnosis that did not include DCD. As the no diagnosis and ADHD diagnosis were a small group, it was decided that in any further analysis only the Dyslexia and the Dyslexia plus group would be compared with the other two groups.

The group were also divided into whether there was information available from assessments undertaken in childhood (i.e. from the Dyscovery Centre) or were self reported.

Table 5.F: Breakdown of the motor difficulties group

Group	Number	Male %	Female%	Mean Age (SD)
Dyscovery Centre diagnosis	33	75.8	24.2	19.33 (2.51)
Self-reported external source	43	48.8	51.2	20.47 (2.11)

Table 5F shows the source of the 76 adults in the motor group, 33 had been seen at the Dyscovery Centre and 43 were self reporting. However, many of these students also stated that they had received a diagnosis in childhood. All students cited where they perceived they had been given a diagnosis apart from nine who did not know and two who failed to answer the question. The self-reported diagnosis responses came from a variety of external sources including University support services, Specialist Dyslexia/Dyspraxia services and a variety of medical/education professionals. As previously noted, individuals with fewer than four reported childhood difficulties and a potentially unreliable diagnosis source were previously excluded.

5.7. Characteristics of the Control group (Typically Developing)

The control group have been referred to as the Typically Developing (TD) group in the study. This term has been used commonly in children's literature and as emerging adulthood is also seen as a developmental phase it was felt still to be an appropriate term.

There were more females who participated in the research than males. This may be attributed to the type of data collection using online questionnaires and a willingness to participate in research

Table 5.G: Table of breakdown by gender of the TD group

N= 118	**Male**	**Female**	**No gender given**
TD group	41	67	10

Out of the 118 individuals who completed the questionnaire 35 were excluded from the study. Twenty two were over 25 years of age, five reported more than three difficulties on the questions on motor difficulties relating to childhood and were excluded as they may have undiagnosed motor difficulties, two reported having "another diagnosis" but gave no description of this and a further six stated that they had been diagnosed with Dyslexia.

After all exclusions were undertaken, the following table describes the gender and age range of the TD group. Most of the TD group were from further education. It was difficult accessing students from further education. There were greater numbers of females than males in this group.

Table 5.H: Table of breakdown by gender of the TD group after exclusions removed

Group Numbers	Male %	Female %	No gender %	Age range	Overall mean (SD)	Male mean (SD)	Female mean (SD)	% 16-18	% 19-25
TD= 83	38.6	59.0	2.4	16-25	20.71 (2.0)	20.94 (1.81)	20.51 (2.13)	7.2	92.8

Table 5H shows the breakdown of the TD group by gender and age.

5.8. Comparison of reported motor difficulties in childhood between different categories.

DCD is a developmental disorder where difficulties are present from childhood. It was important to compare the three groups: DCD, Dyslexia and TD groups as it would be expected that those with a diagnosis of DCD would have the highest responses to questions relating to motor difficulties in childhood. One reason for students giving a low level of response could have been that the individuals may have had difficulties recalling childhood behaviours and may have needed it to be corroborated by a parent or guardian. For the purpose of this study, this was not undertaken. However, parent and student concerns were compared in the clinical cohort and are reported in detail in Chapter 9.

A comparison of the responses from the questions on the seven questions relating to reported motor difficulties in childhood was undertaken in the following three groups:

1. Those with a diagnosis of DCD (including those with other difficulties as well i.e the DCD+ group)
2. Those reporting a diagnosis of Dyslexia or Dyslexia plus another disorder but not DCD
3. The control group of students. (TD)

The mean number of reported childhood difficulties in the DCD group was 5.52 and in the Dyslexia group was 3.22. As the data were ordinal and not normally distributed, this excluded the use of parametric statistics. Non parametric statistics were employed for analysis using SPSS version 15 software (2007). The analysis was undertaken to explore whether there were differences between the groups on their reported difficulties in childhood and if so how they distinguished themselves.

Figure 5A demonstrates the differences between the DCD groups, Dyslexia and TD groups on all measures. There were significant differences between th groups on all questions.

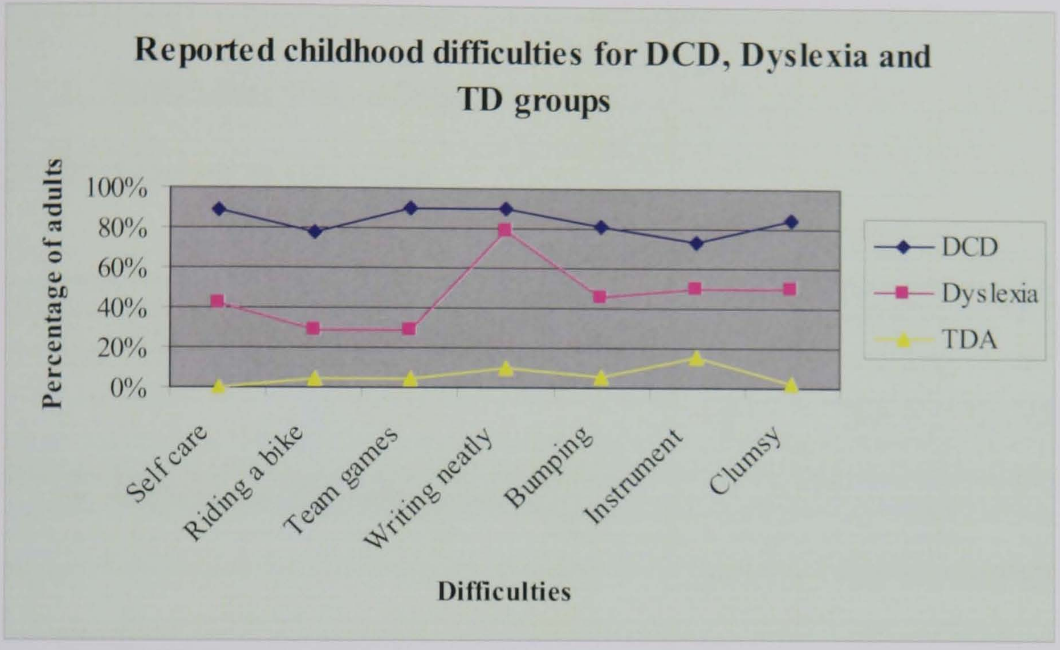


Figure 5.A: Diagnostic breakdown of DCD, Dyslexia and TD group

5.8.1. Differences between the DCD and TD groups.

Students were asked to respond to a dichotomous response. There were significant differences between all questions between the DCD and TD groups as seen in Table 5J. These questions clearly differentiate the two groups.

Table 5J shows significant differences on all questions relating to childhood experiences comparing the DCD to the TD group.

Table 5.I: Group differences between DCD and TD groups

N=146 (and 9 missing data)	DCD N=63 %	TD N=83 %	χ^2 (df=1)	p
1. Difficulties with self-care	89	1.2	125.75	<0.01
2. Learning to ride a bike	78.1	4.8	86.71	<0.01
3. Difficulties with team games	90.4	3.6	117.68	<0.01
4. Difficulties with writing neatly	90.4	9.6	101.63	<0.01
5. Bumping into objects	80.8	6	89.81	<0.01
6. Difficulties with playing a musical instrument	72.6	15.7	52.22	<0.01
7. Comments from others about their lack of co-ordination or clumsiness	84.9	2.4	104.1	<0.01

Table 51 demonstrates the different responses by group and clearly shows that the TD and DCD group are significantly different in all questions asked.

Post hoc analysis on the clinical DCD group was undertaken in order to compare their responses to the total DCD group showed there were no significant differences between these two groups on responses to the questions.

5.8.2. Differences between DCD group and Dyslexia group.

A comparison was made between the DCD group and those reporting motor difficulties but having a diagnosis of Dyslexia. There were significant differences between the two groups on all seven questions as seen in Table 5K. Sixty eight percent of individuals reported writing difficulties in the Dyslexia group compared to 87% in the DCD group. This is not a surprising finding as there has been extensive work (Berninger, 2001) linking writing difficulties with Dyslexia. Berninger, in later work, showed that some children with dysgraphia have problems specific to transcription skills–handwriting and/or spelling–without reading problems, but some children show an overlapping pattern of dysgraphia and dyslexia (Berninger, 2006). However, she did not distinguish whether these children had other generalized motor difficulties. This is an important distinction, as the Dyslexia group see themselves as clumsy. On further questioning, this relates more to fine motor actions such as writing difficulties. Even though the two groups were significantly different in responses, there is certainly overlap in their difficulties, with 48 % reporting that "comments from others about their lack of co-ordination or clumsiness" compared with 74% of the DCD group.

Table 5J: Group differences between DCD group and Dyslexia group

N=87	Dyslexia N=24 %	DCD N=43 %	χ^2 (df=1)	p
1. Difficulties with self-care	41.7	89	23.12	<0.01
2. Learning to ride a bike	29.2	78.1	19.25	<0.01
3. Difficulties with team games	29.2	90.4	36.38	<0.01
4. Difficulties with writing neatly	79.2	90.4	2.11	n/s
5. Bumping into objects	45.8	80.8	11.01	<0.01
6. Difficulties with playing a musical instrument	50	98.6	4.59	<0.05
7. Comments from others about their lack of co-ordination or clumsiness	50	84.9	12.18	<0.01

5.8.3. Differences between Dyslexia group and TD group.

An analysis of the differences between the TD and Dyslexia group was undertaken and there were significant differences on each of the seven questions. The questions seem to effectively distinguish all three groups from one another i.e. DCD, Dyslexia and TD. This may be a useful starting approach when considering the differing needs of a predominant movement difficulties group from one that has more predominant literacy based difficulties.

Table 5 K: Group differences between Dyslexia group and TD group

N=107	Dyslexia N=24 %	TD N=83 %	χ^2 df=1	*p*
1. Difficulties with self-care	41.7	1.2	37.73	<0.01
2. Learning to ride a bike	29.2	4.8	11.78	<0.01
3. Difficulties with team games	29.2	3.6	14.14	<0.01
4. Difficulties with writing neatly	79.2	9.6	47.70	<0.01
5. Bumping in to objects	45.8	6	23.20	<0.01
6. Difficulties with playing a musical instrument	50	15.7	12.01	<0.01
7. Comments from others about their lack of co-ordination or clumsiness	50	2.4	36.64	<0.01

5.8.4. Differences between the Clinical DCD group from The Dyscovery Centre compared to the self reporting group.

Analysis of responses was also undertaken between the clinical motor difficulties group (those seen in childhood at the Dyscovery Centre) and those self reporting a diagnosis but without documented confirmation by testing from the clinical team at the Dyscovery Centre. There were no significant differences between groups on all questions apart from one. This lack of difference between the groups makes the combination of sources feasible as they are representing individuals with apparently similar characteristics.

There was a significant difference in reporting between the clinically diagnosed group on one question: "others commenting about their lack of co-ordination or clumsiness". Seventy-five percent of the former group responded compared with ninety two percent of the self-report group ($\chi^2=4.39$, $N=76$, $df=1$, $p<0.05$).
This was a surprising result as it would be expected that those being seen in a clinical setting may have had poorer co-ordination and so noted more often than those from the self report group. However, many of the self report group had been diagnosed elsewhere and so may in fact have a similar level of motor difficulties.

These results show that apart from 'others commenting about clumsiness' the two groups were not significantly different on reporting their past childhood difficulties.

This is important as it demonstrates that it is likely that the self report group have similar characteristics to the diagnosed group and indeed did have DCD in childhood and strengthens the trustworthiness of the informants. It also strengthens the ability to generalise when combining all the data.

5.8.5. Gender & childhood difficulties.

There were also significant gender differences in reported difficulties in childhood within the whole group. Fifty three percent of males reported difficulties with self-care compared to 34% of females ($\chi^2=6.44$, N=180, df=1, $p<0.01$). Forty seven percent of males reported difficulties with bike riding compared to 31% of females ($\chi^2=5.11$, N=180, df=1, $p<0.05$). Fifty two percent of males reported that others commented about their clumsiness or lack of co-ordination compared to 36% of females ($\chi^2=4.91$, N=180, df=1, $p<0.05$). Gender differences have been noted in organised sport favouring males compared to females (Coakley,1998). Sixty five percent of males reported difficulties with writing neatly compared with 40% of females ($\chi^2=11.29$, N=181, df=1, $p<0.01$).

5.9. Parent, child and student cohorts.

Information about the study was sent out to the database of parents of children who were seen at the Dyscovery Centre in childhood and who were now aged between 16- 25 years of age. From this as previously stated, 35 parents responded and 34 children also returned their questionnaires. All 'children' were aged between 16 and

25 years. Children had been selected as they had a diagnosis of motor co-ordination difficulties in childhood. In the study they responded to the questions on their past childhood difficulties. The responses were in the range of three to seven (with a maximum possible score of seven), with a mean score of 5.68 (SD=1.47). The mode was seven (14 adults out of the 34 reported this number of difficulties). The second most common number was six, with eight of the 34 children reporting this number of childhood difficulties

Table 5.L: Characteristics of the Parent group

	Parents	***Child***
Males	*1*	*27*
Females	*31*	*8*
Both Parents	*2*	
Grandparent	*1*	

Table 5.L describes the gender of the parents who completed the questionnaires and the corresponding gender of their children.

This was further analysed in the following pairings:

- 24 questionnaires from female parents attached to sons
- Seven questionnaires from female parents attached to daughters
- One questionnaire from male parent with attached daughter
- Two questionnaires from both parents with attached son

- One questionnaire from a grandfather with an attached grandson

It is of interest to note parental gender; there were far fewer males completing the questionnaires. The voices of fathers have only been recognised of importance in recent years. Carpenter and Towers (2008) in a paper "Recognising fathers: The needs of the father of children with disabilities" discusses this in depth and cites the Every Children Matters Green Paper (DfES, 2003) as one that mentions the father as well as the mother as having an important role. This may be especially true in the process of emerging adulthood. Especially, this may affect individuation and identity formation as the presence of the father may be important in this process. Fathers may be less likely to have had contact with their child's school and so may not be able to recall difficulties that occurred during that time. More children with DCD have been described as boys and so some of the fathers may also have had difficulties in childhood.

Twelve parents volunteered to be interviewed over the phone and these were:

- Nine mothers with attached sons
- One father with attached daughter
- One grandfather with attached grandson
- One set of parents with attached son

Intergenerational relationships remain important and so it was of interest to have one grandparent who had agreed to be interviewed and to hear his involvement with his grandson. The support role grandparents can provide especially with young and divorced parents (Ferguson, 2004) may also be important to understand. In this case, the child and mother were living with the grandparents and no father was present. Much of the work on the role of grandparents with children with learning difficulties has come from the US. A review of work in this field has been recently undertaken by Mitchell (2008). One area highlighted is the potential for sharing skills between grandparent and child, such as teaching IT skills and teaching driving skills. This may be a useful association at a time of emerging adult in DCD where confidence needs to be gained in acquiring new skills in order to achieve independence. The grandparent may have more time and patience to do this.

5.9.1. Characteristics of children whose parents were interviewed.

Table 5M below gives the characteristics and diagnosis given in childhood for the children whose parents were interviewed. The children were aged from nine to 17 years of age when first seen at the Dyscovery Centre for an assessment and were at the time of the study between 17 and 23 years of age. Parents of eleven males and one female were interviewed. The table also shows a comparison of the parental concerns given at the time of referral to the Dyscovery Centre and the current parental concerns as gathered from initial questionnaire prior to interview. The 'diagnosis' column was the diagnosis given to the individuals in childhood.

Only one parent did not express any concerns currently for their child. There is a general trend in the type of concerns expressed by parents at this stage of emerging adulthood around independence, organisation and self confidence. There is less focus on specific motor concerns such as handwriting and not surprisingly, dressing skills. Terms such as

"Moving forward to adulthood" and *"lack of preparation for the job market"* describe some of the concerns over this time of transition to adulthood. Concerns such as *"Self awareness when in the outside world"* and *"Getting along 'socially' with people"* give some clues to some of the potential difficulties. These are explored in greater depth in an analysis of the interviews with the parents described in Chapter 9.

Table 5.M. Characteristics of children whose parents were interviewed, along with parental concerns at the time of the referral and current concerns.

Gender	Age when first seen	Age now	Parental concerns at time of referral	Current parental concerns
Male	10 years	18 years	• About to start secondary school, advice and assistance for transition.	• "Not very good with the word NO"
Male	10 years	17 years	• Physical demands of handwriting • Copying correctly • Forgetfullness and poor organization • Immature behaviour • Invasion of the personal space of others	• Lack of support within education, i.e. extra time, lap top as there are pupils worse than him
Female	10 years	18 years	• Under pressure at school • Difficulty in making friends • Struggling to keep up with the speed of written work at school • Taking a long time to dress after PE • Frequency of 'tellings off' by others for 'accidents'	• Moving forward to adulthood without any major issues
Male	15 years	18 years	• General clumsiness • Time taken to dress • Problem solving and mathematics • Sequencing • The need to have instructions repeated • Obsession for	• None

			routines • Social skills	
Male	11 years	18 years	• Inability to put thoughts on paper • Low self-esteem • Fear of new physical activities • Difficulties with reading, handwriting, spelling and mathematics	• Self-awareness when in the outside world
Male	15 years	17 years	• Social behaviour (easily distractible or upset) • Organizational skills • Keeping up with work demands • Mathematics • Night time enuresis and soiling • Friendships	• Time-keeping • Coping with job demands • Organization • Getting along 'socially' with people.
Male	13 years	18 years	• Handwriting and co-ordination • Organization • Self esteem	• Organisation without any help • Ability to transfer thought to paper
Male	13 years	18 years	• A deterioration in handwriting skills identified at annual optometry review	• Living skills, e.g. switching things off, cooking, getting from A to B, not getting enough sleep
Male	17 years	23 years	• Low self-esteem and planning/organizational skills are a problem ahead of starting a university degree course	• Lack of self-esteem, depression, lack of situational awareness
Male	12 years	19 years	• Persistent difficulties in areas including motor skills, self-esteem/confidence and organization but	• Very naïve for age and easily manipulated • Only a

			lack of any formal diagnosis	couple of good friends; concerns that people feel he is weird
Male	11 years	17 years	• Guidance on imputing an education plan to assist persistent reading, writing and spelling skills • Improving eye tracking • Improving ability to multi-task	• Driving • Untidiness
Male	9 years	17 years	• Pervasive difficulties mot fully understood. In need of guidance and support for both mum and child	• Lack of preparation for the job market • Adult independence, socialisation, coping alone, situational awareness

5.9.2. Characteristics of the students interviewed.

Ten students were interviewed by telephone. Eight students were from higher education, two from further education. Six were males and four males. Table 5P describes the characteristics of the group, the courses being studied and their relationship and living status. The relationship between living at home with parents and going to college and university is discussed in Chapter 8. The type of courses chosen by the overall motor difficulties group is also presented.

Table 5N: Characteristics of students interviewed

Case	Age (years)	Course	Status
Case 1 Female	21	Politics- 3rd year	Single, in rented accommodation with others
Case 2 Male	22	Strategic business management- 3rd year	Single ,in rented accommodation with others
Case 3 Female	19	African Studies with Development- 2nd year	Single at home with parents
Case 4 Male	19	Law- 2nd year	In relationship, in rented accommodation with others.
Case 5 Female	20	Drama with Spanish- 2nd year	Single at home with parents
Case 6 Male	18	A levels: Biology, Chemistry, Environmental Science	In a relationship, living at home with parents
Case 7 Male	22	Business Computing & IT- year- 4th year	Single in hall of residence
Case 8 Male	24	BTEC First Diploma in ICT- 1st year	Single, living at home with parents
Case 9 Female	20	Social Policy- 1st year	Single in hall of residence
Case 10 Male	25	Geology- 3rd year	Single ,in rented accommodation with others

It was harder to recruit 16-18 year olds to be interviewed and this may be because of finding it harder at this stage to articulate to others about their difficulties or lacking confidence talking to someone on the phone. Using a blog or online group may have been an approach that could have been taken to encourage information sharing and views.

5.10. Conclusions.

This chapter contains both the methodology and the recruitment processes and presents the initial baseline descriptions of the groups being studied and how they were selected. The Dyslexia group (those with a diagnosis of Dyslexia but considering themselves as poorly co-ordinated) were a surprise group, and were not considered in the initial study design. However, this was of particular interest in terms of provision in further and higher education and the implications of this have been explored in more detail in Chapter 8. The seven questions relating to childhood difficulties discriminated well between the three groups: DCD, Dyslexia and the TD group.

This study provides several different opportunities to listen to the voices of emerging adults with DCD with both longitudinal, as well as cross sectional data and multi-informant reporting from parents and a grandparent. Interviews from parents and students additionally provide rich examples of some of the emerging themes gained from the initial questionnaires which will be described in the following chapters.

CHAPTER 6. DISTINGUISHING CHARACTERISTICS OF STUDENTS WITH DCD SINCE CHILDHOOD.

6.1. Introduction.

This chapter presents the findings of a subgroup of students that had met the criteria for DCD as noted in Chapter 5 through the recruitment process.They are compared to the control group of students without difficulties. The first part of the chapter explores the strengths and weaknesses and pattern of difficulties of emerging adults with DCD. The information was obtained in two ways. The first way was to ask in the initial survey when recruiting students with DCD to report their perceived strengths and weaknesses. This was undertaken in an open question in the motor difficulties group, and then coded as seen below and only undertaken in this group. When the students were recruited initially for the motor co-ordination group, as stated in the previous chapter, a second group emerged, and these were students who did not have a diagnosis of DCD but rather had been given a diagnosis of Dyslexia but still thought of themselves as being "clumsy" or having poor co-ordination. This group also reported their strengths and weaknesses, and this data is reported alongside those with a diagnosis of DCD to present what appears to be another group.

The second part of this chapter then compares and contrasts the social and behavioural characteristics of the DCD subgroup of students with a cohort of students without difficulties.

6.2. Statistical analysis.

As the data were ordinal and not normally distributed, this excludes the use of parametric statistics, non parametric statistics were employed for analysis using SPSS version 15 software (2007).Where appropriate the two groups were compared with each other against a set of variables. The variables included strengths, weaknesses, questions from the current functioning and activity and participation questionnaire.

6.3. Reported strengths and weaknesses of students reporting a diagnosis with DCD and those with Dyslexia.

All participants were asked in an open ended question what they thought their strengths and their remaining weaknesses were in order to examine whether there were differences between groups. A coding dictionary was developed to analyse this data. Examples of some of the responses are included in Table 6.A.

Responses were coded into five main themes: motor skills, in order to capture continuing difficulties with co-ordination; executive functioning, as DCD commonly co-occurs with ADHD and executive functioning is a cornerstone of the diagnosis (Kaplan *et al.*,1998); social and communication skills, as this has been highlighted as a problem for children with DCD (Skinner & Piek, 2001; Dewey *et al.*,2002);

creativity, as a Dyslexia group was analysed alongside the DCD group and creativity has been associated with Dyslexia, it was thought to be of interest to see if these students differed from the DCD group. Creativity and dyslexia have been linked, for example, in art students (Wolff & Lundberg, 2002). The DfES website (2008) also states that:

> "dyslexic learners may possess, or have developed, more positive talents such as:creativity,thinking laterally and making unexpected connections being able to see the 'big picture', good visual spatial skills and being able to think easily in 3D, problem-solving skills, good verbal skills, good social skills. "

The final theme was determination, in order to try and gain a picture of potential resilience factors that may be related to the success of this group reaching further and higher education. The determination groups were also considered to be a potential marker for self esteem.

Table 6A: Coding dictionary with examples of responses

CATEGORY	Examples of responses included.
Motor	*Motor ability, sports ability, handwriting, drawing ability, dancing ability, ability to play musical instruments, writing ability, clumsiness, co-ordination, fine motor, gross motor, tying shoelaces*
Executive functioning	*Time management, memory, organization, planning, decision making, thought management, preparation skills*
Social and communication skills	*Social skills, team work skills, leadership skills, empathy, public speaking, sense of humour, communication skills, verbal abilities, personality, social confidence, social competence, listening to others, friendliness, oral presentations*

Creativity	*Creative writing, song writing, arts and crafts, practical work*
Determination	*Determination, ambition, ability to commit, motivation, always try hardest, willing to try*

Table 6.A. describes the themes in the coding dictionary with some examples of some of the students' responses in each section. The coding dictionary was checked with three other raters apart from the author. Two other raters were psychology graduates working in research assistant posts and one was an occupational therapist with extensive clinical experience of working with individuals with DCD. Inter - rater reliability was excellent. Pearson's correlation coefficient was 0. 97.

6.3.1. Reported weaknesses.

Students were asked what they considered their weaknesses to be. These were then coded using the above coding dictionary. They were not specifically asked to rate all the areas by level of concern and were not prompted to consider specific areas.

Table 6B: Weaknesses reported by percentage of each sub group using the coding dictionary

Group	% Motor Weakness	% EF Weakness	% Social Weakness	% Creative Weakness	% Determination Weakness
DCD (N=50)	54	44	20	2	7.8
Dyslexia (N=22)	45.5	22.7	13.6	0	4.5

Table 6B demonstrates that 54% of adults with a childhood diagnosis of DCD reported continuing motor difficulties in adulthood .Some individuals gave some possible explanations for this: *"My eyes don't converge probably"* and the impact of having these difficulties e.g. *"Unable to do practical tasks"*

There were no significant correlations between those experiencing writing difficulties as a child and motor difficulties as an adult in the DCD group.

It is interesting to note that 32% of those with DCD stated handwriting was a motor weakness. 63% of those reporting motor weaknesses in the DCD group specified fine motor difficulties. This may reflect the ability to avoid sports all together when adulthood is reached e.g. *"keeping handwriting tidy at the same time as writing quickly"*. Another student reported: *"Remembering stuff, writing lecture notes whilst listening, reading to understand - have to read a difficult page 8 times"*.

Other examples of motor difficulties reported were:

"clumsy; tying shoelaces"; "Having to drive an automatic car"; "Poor co-ordination"; "Unable to do practical tasks".

One student described himself as: *"very clumsy, difficulty in movement "* highlighting the difficulties with gross motor function and another student described his difficulties as {I}" *struggle to understand things at first, clumsiness, my body not doing what my head wants to".* Another student with DCD described the anxiety: *"The fear of other people thinking I'm thick when they see my writing"*

Examples of executive functioning weaknesses in the DCD group were as follows: *"My organisation, timekeeping is poor"* and: *"Information is hard for me if I am disinterested in the subject".*

An example of social skills weaknesses in the DCD group was:
"I can find it difficult to work well with colleagues";

Examples of lack of determination in the DCD group:
"My self esteem from time to time can be very low, and I get into my Negative Syndrome of saying I'm no good, or believing I'm no good".
Another reported: *"I am rather young and immature for my age and lack confidence and self esteem. I have a very negative outlook".*

The range of weaknesses reported for students with motor difficulties were not solely related to motor functioning. Poor social skills were reported in 20% of students with DCD. This will be compared in Chapter 9 considering the reports by parents. Whereas 54% of students with motor difficulties described a motor difficulty as a weakness, this still leaves 46% where this was not mentioned as a main concern. This is encouraging. However, 44% of students with motor difficulties did report EF skills as being a problem compared with a lower level of 23% in the group with Dyslexia. This was interestingly the key difference between the two groups. Low self esteem in the DCD group was also reported, indicating that insight into having difficulties including social difficulties may be evident in some students in this group and may indicate some have a 'theory of mind'.

6.3.2. Reported strengths.

Students were asked what they considered their greatest strengths to be. These were then coded using the previous coding dictionary in order to establish whether individuals with DCD displayed different strengths to the Dyslexia group.

Table 6C: Strengths reported by percentage of each sub group using the coding dictionary.

Group	% Motor Strength	% EF Strength	% Social Strength	% Creative Strength	% Determination Strength
DCD (N=49)	6.1	18.4	44.9	16.3	28.6
Dyslexia (N=21)	4.8	38.1	38.1	19	23.8

Table 6C shows that approximately 45% of adults in the DCD group reported social skills to be strength of theirs, compared to only 38% of individuals with a diagnosis of Dyslexia. However, this did not reach significance on statistical analysis. There were no significant differences between the DCD and Dyslexia groups on any reported strengths including creativity.

Examples of the few individuals who perceived them self as having a motor strength in the DCD group included: "*Tae Kwon Do*" and "*I am a talented pianist, at a grade 5 level, who is still taking lessons*". One individual commented that: *Now enjoy sport. Was demoralised [for] many years till around 14 years*". Interestingly, executive functioning was stated as being a strength in 18% in the DCD group with examples such as "*well organised*". Examples of the type of comments relating to determination reported by the DCD group include: "*persistence to the point of bloody mindedness*"; "*dedication to work*"; "*hard working, conscientious*" and "*obsessive about things that matter*". In particular, several students also cited "*memory*" and "*intelligence*" as strength.

Examples of social strengths for those with DCD are as follows: *"Verbal communication and interacting with other people"; "Good team worker and social skills."; "kind and, caring"; "communicating and public speaking" and "ability to relate to others well"* Examples of creative strengths for those with DCD are as follows: *"Can think outside the box" "I am great at writing in a surreal manner"; "I am a good composer"* and *"seeing patterns".*

6.4. Current functioning.

In order to gain a diagnosis of DCD (meeting the DSM-1V criteria) there is a need to have difficulties in independent living skills. Despite this, there have been anecdotal evidence and small scale studies into the functioning in adults (Kirby & Drew, 1994; Cousins, 2003). In selecting the questions it was important to attempt to examine if these difficulties continue in emerging adults and how this presents at this stage of life. Additionally, many of the questions asked also "tapped" into executive functioning skills (EF) because of the known and common overlap between DCD and ADHD (Hellgren *et al.*, 1994). Persisting difficulties in EF have been strongly associated with adults with ADHD. In the latest book by Barkley, Murphy and Fischer (2008), they go further and describe ADHD symptoms in adults and have a group of questions specifically relating to executive functioning (p181). As EF and daily functioning difficulties emerged from the reported weaknesses in the DCD group, some additional questions were added in and asked of a sub set of students with DCD (N=20) compared with the TD group (N=26). Mean age of the DCD group was 20.35 years and TD group was 20.5 years. There were 65% males and 35% females in the DCD group and 35% males and 65% females in the TD group.

The following represents the results from these questions. The questions chosen examined daily functioning in greater detail, activity and participation.

6.4.1.Results.

There are distinct and significant differences on a large number of behaviours reported between both groups and this reflects the wide disparity between those with DCD emerging as adults compared with the TD individuals.The following two tables describe, firstly, the students reported current functioning and secondly their perception of the pace, compared to peers, in which they undertake a variety of tasks.

6.4.1.1. Current functioning.

The following table represents the percentage of individuals responding that they were able to undertake the tasks asked of them.

Table 6.D: Items showing signficant differences on the questions relating to current functioning taken from the questionnaire

(Numbers shown relate as allocated in the questionnaire – see Appendix B)	TD % N= 26	DCD % N=20	χ^2	*p*
1.Self care tasks such as shaving or make-up (where appropriate)	3.8	30	6.00	<0.01
2. Eating with a knife, fork or spoon	0	15.8	4.24	<0.05
3. Writing neatly when having to write fast?	15.4	80	19.21	<0.01
4.Writing as fast as your peers	7.7	84.2	26.78	<0.01
5.Reading your own writing	0	20	5.70	<0.05
6.Copying things down without making mistakes	0	45	14.06	<0.01
7. Organizing /finding your things in your room	7.7	50	10.50	<0.01
8. Finding your way around new buildings or places	12	50	7.81	<0.01
9.Others called you disorganised	15.4	26.3	-	ns
10.Have difficulties sitting still/fidgety	23.1	35	-	ns
11. Do you lose or leave behind possessions	11.5	40	5.03	<0.05
12. Would you say that you bump into things, spill or break things?	4	25	4.24	<0.05
13. Are you slower than others at getting up in the morning and getting to work or college?	7.7	35	5.36	<0.05

14.Longer than others driving	0	42.9	-	Too small a response
15. Do others find it difficult to read your writing?	3.8	55	15.34	<0.01
16. Do you avoid hobbies that require good co-ordination?	3.8	60	17.58	<0.01
17. Do you choose to spend leisure time more on your own than with others?	4	47.4	11.56	<0.01
18. Do you avoid team games/sports?	8	75	21.22	<0.01
19. If you do a sport, is it more likely to be on your own, e.g. going to a gym, than with others?	8	68.8	16.63	<0.01
20. Did you tend in your teens/twenties or currently to avoid going to clubs/dancing?	8	66.7	16.40	<0.01
21.Preparing a meal from scratch	11.5	20	0.627	ns
22. Difficulties with packing a suitcase to go away	3.8	40	9.39	<0.01
23. Difficulties with folding clothes to put them away neatly	7.7	60	14.61	<0.01
24. Difficulties with money management	42.3	75	4.92	<0.05
25. Do you have difficulty to perform two things at the same time (e.g., driving and listening)?	7.7	65	16.89	<0.01
26. Difficulties with planning ahead	11.5	70	16.58	<0.01
27. A loss of attention in certain situations	15.4	63.2	10.93	<0.01

Table 6D shows significant differences in responses on 23 out of the 27 questions asked to the DCD and TD groups. Several of the questions relate to organisational and executive functioning difficulties, especially functioning under time pressure or dual tasking, and planning an activity ahead of time. Even tasks such as packing and folding, while having a motor element, also require planning skills. Five items indicated significant difficulties with writing skills in the DCD group compared with the TD group. Writing difficulties continue in many students with DCD, especially when writing at speed with 84% of students in this cohort reporting difficulties and 45% having difficulties copying things down compared to none of the TD group reporting difficulties with this. This has implications for further and higher education, for example when notes need to be recorded in lectures and at examination time.

Interestingly 'preparing meals' was not significantly different between the two groups. The question perhaps should have been different and stated preparing a *hot* meal from scratch. Everyday tasks, which may have been practised over time, may, for some, have been accomplished such as self care tasks. However pace may still be an issue as 35% of the DCD reported never or seldom washing and showering at the correct pace compared with eight percent of the TD group. This again exemplifies the intra group differences in the DCD group.

Comments from parents re-iterated some students that had difficulties in these areas and are elucidated further in Chapter 9.

6.4.1.2. Activity and Participation Questionnaire Responses.

The purpose of this second part of the questionnaire was to try to learn about how individuals with DCD perceived themselves managing their time at home and with family, as well their leisure activities outside the home. Students with DCD and TD students were asked to rate how they thought they performed the activities and if this was at an 'expected pace'. The higher the percentage scores the better their perception of their performance.

As seen in Table 6E, out of 21 questions asked in the activities and participation section of the questionnaire (see Appendix B, Section 2), fifteen questions were significantly different between the TD and DCD groups. Pace, timing, sequencing, and organisation did seem to be a problem for the DCD group. One question, "completing jobs/tasks you take upon yourself" was approached significant and this may have been because of the language of the question, not having time implications, like some of the other questions that separate the two groups.

Table 6.E: Responses to the Section B, Activity and Participation Questionnaire

The activity	TD (%)	DCD (%)	χ^2 (df=1)	p

	N=26	**N=20**		
1. Getting up from bed in the morning	73.1	42.1	4.39	<0.05
2. Going to the bathroom	88.5	68.4	-	ns
3. Washing your face, brushing your teeth and hair	88.5	68.4	-	ns
4. Getting dressed	88.5	65	3.66	<0.05
5. Your meals	80.8	80	-	ns
6. Washing/showering	80.8	55	3.55	<0.06
7. Organising your bag	88.5	40	12.08	<0.01
8. Following instructions	76.9	40	6.47	<0.01
9. Getting ready to leave the house	80.8	50	4.87	<0.05
10. Preparing different assignments	53.8	30	2.62	ns
11. Filling jobs you get	61.5	27.8	4.86	<0.05
12. Completing jobs/tasks you take upon yourself	76.9	50	3.61	<0.06
13. Arranging your room and work areas at the proper pace	57.7	20	6.62	<0.01
14. Finding objects around the house	65.4	30	5.66	<0.01
15. Getting organised for an activity which was planned in advance for a specific hour (e.. a ride, meeting , an event)	84.6	40	9.92	<0.01

16. Getting organised for socialising with friends or family members at the proper pace	88.5	35	14.24	<0.01
17. Planning leisure activities at the proper pace	84.6	35	11.94	<0.01
18. Getting organised for a class or a meeting at the proper pace	80.8	45	6.37	<0.01
19. Getting ready for sleep	69.2	55	-	ns
20. Performing activities which are required from you at work or school	73.1	40	5.1	<0.05

The final part of the questionnaire (The Daily Living Questionnaire, see Appendix B, Section 3) was completed by the same sub groups and they were asked to rate their satisfaction levels around ability to think, function and what they needed and wanted to do. This was undertaken to gain an understanding of the impact and concern the difficulties have on the individual's satisfaction around how they function. Table 6F shows increased levels of dissatisfaction among the DCD group compared to the TD group on all the questions asked. This was especially true for the questions asking about ability to think and do what you need to do. This shows some awareness in some students about their difficulties. Although the converse of this was also true and some students were satisfied in some areas. This displays, again, the variability in a group of students with DCD.

Table 6F: Satisfaction rating of daily functioning by TD and DCD groups

FUNCTION RATING % response	Ability to think (N)	Ability to do function (N)	SATISFAC-TION RATING % response	Ability to do what you need to do? (N)	Ability to do what you want to do (N)
Excellent DCD	5 (4)	5 (1)	Satisfied DCD	26.3 (5)	29.4 (5)
Excellent TD	0	0	Satisfied TD	42.3	50
Very good DCD	15 (4)	15 (3)	Somewhat satisfied DCD	26.3 (5)	23.5 (5)
Very good TD	26.9 (9)	26.9 (7)	Somewhat satisfied TD	53.8 (14)	34.6 (9)
Good DCD	35 (7)	40 (8)	Neither satisfied or dissatisfied DCD	21.1 (4)	17.6 (3)
Good TD	65.4 (15)	65.4 (17)	Neither satisfied or dissatisfied TD	0	0
Fair DCD	40 (4)	40 (8)	Somewhat dissatisfied DCD	26.3 (5)	29.4 (5)
Fair TD	3.8 (1)	3.8 (1)	Somewhat dissatisfied TD	0	11.5 (3)
Poor	0	0	Dissatisfied DCD	0	0

DCD					
Poor **TD**	**3.8** **(1)**	**3.8** **(1)**	**Dissatisfied TD**	**3.8** **(1)**	**3.8** **(1)**

6.4.2. Gender differences.

Fifty four percent of males in the DCD group reported difficulties with keeping still or appearing fidgety compared with none of the females (χ^2=5.79, df=1, N=20, p<0.05). The hyperactivity may be associated with ADHD- like symptoms and seen more often in males than females.

Males (33%) in the TD group reported difficulties with planning ahead compared to none of the females (0%) (χ^2=6.41, df=1, N=26, p<0.01). There were additional gender differences overall between groups, also on several questions relating to planning, including: more males reported losing or leaving behind possessions than females (41% compared to 8%, respectively; χ^2=6.69, df=1, N=46, p<0.01). Males (32%) also reported more difficulties with packing a suitcase than females (8%) (χ^2=4.02 df=1, N=46, p<0.05). More males (59%) also reported difficulties with planning ahead than females (17%) (χ^2=8.87, df=1, N=46, p<0.01).

Gender differences were also noted in handwriting. The question: "thinking that others had difficulty understanding their handwriting" had differing responses. Forty one percent of males compared with 13% of females responded to this question (χ^2=

4.80, df=1, N=46, $p<0.05$). Also more males (18%) reported difficulty with reading their own handwriting than females (0%) (χ^2=4.78, df=1, N=46, $p<0.05$).

6.5. Conclusions.

This chapter has highlighted the differences in everyday functioning between those motor difficulties and the TD group . It has also highlighted, in the first part of the chapter, the differences between those students with a diagnosis of Dyslexia and DCD in their reported strengths and difficulties.

The reporting of social and communication skills as a strength in 45% of the DCD group was a surprise finding. This may reflect a level of resilience in those students that successfully get to higher education or alternatively may show lack of insight into their true skills. However, on the satisfaction rating, the students do show some awareness of limitations.There may also be a bias in the sampling as those that have greater confidence may be more likely to respond to a questionnaire than those who are currently failing. It may also be because of the manner of questioning. Students were asked what they saw were both their strengths and weaknesses. They may have stated that the motor and executive functioning were at the fore of their current concerns and not considered the social difficulties as worth commenting on. In Chapter 7 social habits are described and show that the DCD group are more socially isolated and not participating in similar hobbies and activities compared with other students without difficulties. Interestingly, creativity, recognised by some as a trait of Dyslexia, was reported at the same level in the DCD and Dyslexia groups. The theme determination was sought in order to look for potential resilience factors in the DCD group compared to others. Terms such as" *intelligent";* " *communicating ambition"; "keeping going"* and *"hardworking"* reflect the determination in some of the students with DCD. These strengths may also be linked to students having good family support providing early opportunities for gaining skills (Masten, Glantz, & Johnson, 1999). Students were not specifically asked about what or who may have contributed to having these strengths. An alternative explanation could be that high levels of support recieved by professionals in childhood may have taught skills to these individuals, such as good time management.

One striking result seen in this chapter is the marked level of difficulties relating to planning and organisation and the frustration reported relating to this in the DCD group.There may be an explanation why motor skills are not so obviously noted at this time because everyday skills will have been practiced over many years and finally accomplished, adaptations made or avoidance strategies taken. However, novel situations requiring planning, even those at a daily functioning level, such as folding clothes and packing a suitcase., are seen to be more problematic. Another explanation is the evidence in childhood of overlap between ADHD and DCD, cited previously, and that many of the persisting difficulties may be more related to ADHD - like features. Barkley, Murphy and Fischer (2008) describe the close relationship between ADHD and EF skills and have proposed that questions relating to specifically to EF are included in a proposed DSM V criteria for adults. Denckla (2007) noted the heterogeneity within the EF domain and that individuals and different developmental disorders may demonstrate differences in their clustering, and in DCD there may be differences in patterns of EF skills deficits within the group as well as individual variation.

These differences between the TD and DCD group demonstrate the persistent and pervasive nature of DCD in emerging adults affecting both home and the 'workplace' whether at school, college or in employment. However, it is apparent from responses that one of the difficulties perceived by the DCD group compared to the TD group is when individuals need to function under time pressure.

CHAPTER 7. SOCIAL CHARACTERISTICS OF STUDENTS WITH REPORTED DCD.

7.1 Introduction.

There have been very few studies in DCD until now focussing on the stage of emerging adulthood and the social behaviours and characteristics of this group compared to students without a diagnosis of developmental disorders. Chapter 2 describes the current knowledge of emerging adulthood in general and Chapter 3 then elaborates on current knowledge in DCD and related developmental disorders. I am particularly interested in the impact of motor difficulties on the individuals and how students with these difficulties behave as a consequence of this.

Cousins in her PhD (2003) described some of the quality of life issues relating specifically to motor function in her adult study and demonstrated that more than half of those interviewed reported gross motor difficulties, riding a bike as an example of a balance task was reported as remaining as a difficulty. Also, 44% of individuals reported that they thought that their dancing skills were poor, although some did describe themselves as competent. This study was generally an older age group in their thirties. However, I am particularly interested in the impact of not being able to do some tasks on social behaviour i.e. if you can't do something, how does this then limit what you do socially with others of your age? For example, if you can't dance do you then avoid going clubbing?

This chapter reports on the results from questionnaires and interview data from students from college and university who have reported motor co-ordination difficulties since childhood and/or who have received a diagnosis of DCD in childhood when compared to equivalent age matched controls from a college and university setting. Their social behaviours including their drug and alcohol usage, choice of leisure pursuits, hobbies and interests and driving histories are described.

7.2. Method.

The recruitment procedures for both the control and the motor group have been described in detail in Chapter 5. There were both open and closed questions contained in the questionnaire (see Appendix A). Additional qualitative and more in depth information has also been included in this section, where appropriate, from interviews from ten students. Emerging themes from the group data drove the direction of further in depth questioning.

As the data was of a mixed nature, both quantitative and qualitative, the results reflect this and where appropriate statistical methods have been employed along with examples of the emerging themes that have been taken from the transcripts and additionally from participants who have completed the open ended questions relevant to that area. This provides an opportunity to consider common themes but understand the reality of the lived and individual experiences of the students being studied.

7.3. Statistical analysis.

As the data were non categorical and not normally distributed chi square was employed for analysis using SPSS version 15 software (2007). An association analysis (chi-square) was used, where appropriate, to compare the two groups with each other against a set of variables: mean number of reported difficulties, including: social behaviours, leisure choices, driving behaviours. Where qualitative analysis was undertaken, N Vivo software (2005) was used to code themes and extract subthemes.

7.3.1. Participants.

In this chapter, the individuals with motor difficulties and a diagnosis of DCD were compared to TD students .The group with a diagnosis of Dyslexia (and considering themselves to also have motor difficulties) and the group with no or another diagnosis as described in Chapter 5 are not included in this chapter, as the focus of the study is on emerging adulthood in specifically the motor group. It was considered that analysis should be only with those with a diagnosis of DCD or Dyspraxia.

7.4. Results.

The number in each group varies within this section because of response rates from both the TD group and in the DCD group. Where there are fewer figures in either group this was because of non responders.

7.4.1. Marital status.

The DCD group were significantly more likely to be single than the TD with 76% of DCD group reported being single compared to 50% of TD group ($\chi^2=7.48$, N=101, df=1, $p<0.01$).

7.4.2. Alcohol, cigarette smoking and illegal drug usage.

7.4.2.1. Alcohol and cigarette smoking.

Students were asked if they drank alcohol and smoked cigarettes or used illegal substances and, if so, at what age did they begin to do this. There is extensive literature on the social behaviours in adults with ADHD (see chapter 3). In the past, substance abuse has been associated with ADHD but more recent studies have teased this apart and it is clearer that this is more closely linking Conduct Disorder as one of the major factors (Barkley, 2006). Adolescents with ADHD have increased vulnerability to becoming cigarette smokers. A largely linear relationship has been shown with the severity of symptoms of ADHD conferring additional risk of smoking with hyperactivity/impulsivity symptoms being a better predictor of lifetime smoking than inattentive symptoms (Kollins, McClernon & Fuemmeler, 2005). It is for this reason that a specific focus of questioning was directed at smoking and alcohol consumption to compare and contrast behaviours of students with DCD with what is known about ADHD and a comparison with TD students. This is also pertinent in the light of the literature demonstrating overlap of DCD and ADHD, as described in Chapter 3.

Table 7A: A comparison of drinking and smoking behaviour between the DCD and TD group

Activity	DCD	TD
Average age began drinking (years)	16. 2	15.63
Average age began smoking (years)	14.88	15.65

There were no significant differences between groups for age starting to drink

The control males smoked on average 8 cigarettes per day as compared to males with movement difficulties who smoked on average 4 cigarettes per day, differences were not significant but small differences may reflect less social opportunity in the motor difficulties group.

Overall, males were reported to drink more units of alcohol per week on average than females (t (49) = 2.89, $p<0.01$). Eight individuals with DCD responded 'yes' to smoking and 23 TD students. Twenty five students with DCD reported drinking compared to 64 TD students.

7.4.2.2. Illegal drug usage.

There was not a significant difference between whole groups for age when starting drug usage. However, 21% of the TD group reported taking drugs compared to 6% of DCD group. There were gender differences in usage in the TD group with males in the TD group significantly more likely to engage in drug taking behaviour than females (48% and 2% respectively, $\chi^2=23.54$, $N=76$, $df=1$, $p<0.01$) in comparison to those with movement difficulties, where behaviour was approximately similar for both males and females (5% and 10% respectively).

When an overall analysis of all students was undertaken, there were gender differences seen in drug taking. Overall, 30% of males reported drug taking compared to 4% of females ($\chi^2=13.7$, $N=108$, $df=1$, $p<0.01$).

The conclusions from the drug, cigarette and alcohol usage were of interest as the DCD group was quite different from the reported research from the comparative ADHD literature, as they were not smoking or using drugs in greater amounts than the control groups. In fact, the DCD group were less likely to report to have used drugs. This may be related to less social opportunity. One third year student described school day experiences as a back drop to being slower at actively socialising at university:

> *"I was later than most of my peers in starting to experiment, starting just a few weeks before my 18th birthday. I didn't really have a lot of people to go out with, and I didn't usually enjoy it when I did because it simply seemed to be a less controlled extension of the social dynamics of school... i.e. I was outcast to varying degrees. Now, at university, I definitely don't drink more than some, but I'd say I was about average for my peer group at the moment".*

A second year student with motor difficulties also recalled his early experiences:

> *"I certainly remember when I was at school; some of my friends did go out to pubs/clubs a couple of years before being 18. I never did though. I only went out with them, the night of the day the A-Levels results came out. I also didn't go out again, despite being at uni, until that Christmas. It was after prize night in my school, and just went out with my old school friends again after. At university, I didn't go out until the end of the second semester in 1st year, last year. So in school and university I have been going out later than my peers."*

7.4.3. Leisure time and hobbies.

A comparison was undertaken of responses to the question “What are your favourite ways of spending your leisure time?”

Students were given a choice: Bar, Reading, Films and TV, Club, Sport and were also allowed to submit “other” and then give a specific choice if this differed from the choices given. They were able to choose more than one option.

Mean scores for each leisure time choice were entered into a two factor ANOVA. There were a number of significant differences between the two groups on a range of variables as follows:

The results of the choices of hobbies and interests showed a clear picture that adults with DCD avoided situations requiring good co-ordination and were more socially isolated. Their choice of hobbies may have also been further limited by their co-ordination difficulties.

Examples of types of hobbies that students with DCD chose included playing on computer games: spending time with friends, listening to music, writing a journal, cooking for people/cleaning and one individual did salsa dancing.

Specific examples were: *"I like swimming"; "I like reading about cars"; "Cycling and walking and occasionally to the gym."*

Some students specifically described liking and being involved in a range of physical activities. One student described this as: "*I love singing, dancing, acting, creative writing, the arts type*" and another student also liked dancing: "*I really want to get into the practice of swimming and there is a dance society at Uni and my salsa which I am on a committee of starts tomorrow so I can get back to doing salsa*"

The control group reported a significantly wider choice of leisure pursuits than the movement difficulties group. Mean number of choices was 2.72 for the control group compared to 1.88 for the movement difficulties group (t (67) = -2.54, $p<0.01$). Sixty percent of the DCD group reported avoiding hobbies requiring good co-ordination compared with 4% of TD group ($\chi^2=17.58$, N=46, df=1, $p<0.01$). A t test was used on the number of choices of pursuits because this data was nominal, and in contrast a χ^2 test was used for the choices of hobbies analysis as this was categorical data.

If the DCD group chose sports then these tended to be ones they could do alone. 69% of the DCD group reporting a preference for individual sports compared to 8% of the TD group ($\chi^2=16.63$, N=41, df=1, $p<0.01$.).

Avoidance of team playing was reported, with 75% of the DCD group reporting avoiding team games or sports compared to 8% of TD group (χ^2=21.22, N=45, df=1, p<0.01).

The control group were also significantly more likely to choose sport as a favourite way to spend leisure time than movement difficulties group (χ^2 =8.14 ,N=70, df=1,p<0.01).

The DCD group presented as more socially isolated, either by choice or as a result of their difficulties, reported significantly higher rates of spending leisure time alone compared to the TD group (47% of the DCD compared to 4% of TD group respectively) (χ^2=11.56, N=44, df=1, p<0.01).

This was additionally demonstrated in choices of activities, with 67% of the DCD group reporting an avoidance of clubs and dancing compared to 8% of the TD group (χ^2=16.4, N=43, df=1, p<0.01). None of the females in the movement difficulties group chose clubbing as a favourite leisure pursuit.

Suggestions from student interviews for reasons for not choosing clubbing as an option were as follows: *"Bars – not a problem, clubs I wouldn't go into. I felt unsafe, I felt out of my depth, I felt the socialising obviously the thoughts of noise, not that I have hearing difficulties, but with lots of noise I felt quite disoriented so I didn't feel very comfortable and I wouldn't like to be involved really".*

And: *"The crowds and the fact that if you go it's not cheap, £15 a night and it's just a bit daunting"*.

And a lack of experience: *"I have only been clubbing three times."* Some described how things could have been improved: *"if I had gone with some friends it would have been better"*.

One student described school day experiences of socialising demonstrating that social difficulties were an extension of earlier experiences: *"Socially (at school) I tended to be isolated, but this was partly me trying to isolate myself from those who were not understanding. I ate my lunch inside classrooms, spent breaks in the library etc. anything I could to keep away from people. Throughout my entire secondary school experience I had about four friends, and they were all outcasts of one form or another, thus my group of friends were quite understanding and ignored my 'quirkiness'. I think finding people who can empathise is very important, and is possibly the only reason I survived school at all."*

7.4.3.1. Amount of reported exercise undertaken.

Students were asked whether they did any physical sport regularly, how often and what type of sport. There was no significant difference between the number of respondents reporting undertaking exercise and the amount of sessions per week that they did (N=43). 65% of the movement difficulties group undertook exercise (mean number of sessions per week = 3.18) compared with 67% controls (mean number of sessions per week = 3.41). However, when an analysis of the choice of activities was undertaken significant differences appeared. The DCD group chose more solitary activities as described below.

7.4.3.2.Sporting choices.

On analysis of the type of sport chosen and there were 30 different activities reported by the two groups. Fifty three percent were likely to be undertaken with someone else e.g. squash, rugby, kickboxing, and paint balling in comparison to swimming, yoga, walking, going to the gym, and running that could be undertaken alone.

Of those that reported sporting choices, eighteen of the controls reported choosing joint activities preferentially compared with five of the movement difficulties group. Only three of the movement group took part in team games such as rugby, hockey or football compared with thirteen of the controls.

Sporting choices may be limited by continuing motor difficulties and they may also be related to poor experiences of sport when in school, and lack of choice in schools of the sports that individuals with DCD may like to do. One individual described his experiences at school: *"I liked swimming, but the annoying thing was that you only got to do that for about 6 weeks of the whole year but they let me, the school was quite good because we had a swimming club every week and that meant I could improve my swimming"*.

Some students reported the reasons why they thought that they might not be so good at sport: *"Dancing. Though they are going too fast now I can't learn the routines"* and another: *"My physical abilities have always been poor. I get tired extremely easily and I cannot do much physically-intensive activity such as heavy lifting. There are days where simply moving around is difficult"*.

These results highlighted that the movement difficulties group had different social behaviours and were likely to be more socially isolated compared with controls. The social difficulties are reinforced by parental reports in Chapter 9.One student described the gains from making friends and going out: *"I actually met up with someone there [in a club] which is good because it gave me some more self confidence"*.

Some of the choices of activities in the DCD group also highlighted how they were undertaking quite different types of activities compared with other students e.g. one person chose to play the guitar, play on the computer, listened to music and watched films as preferred leisure activities.

Difficulties with organisation as well as co-ordination difficulties may have been an additional reason for not joining in activities with others. This may be because of difficulties first in planning and perhaps choosing an activity and secondly, organising themselves to be ready to be in a place at a given time. Results as cited in more detail in Chapter 6 demonstrated the specific organisational difficulties especially when planning activities at the proper pace which is expected of them. Also 89% of the TD group reported being able to get organised for playing with friends or family members at the proper pace, which is expected of them, compared to only 35% of DCD group ($\chi^2=14.24$, N=46, df=1, $p< 0.01$). This did seem to cause some frustration among those in the DCD group; 50% of the DCD group reported 'always' or 'usually' reacting angrily when not being able to conduct activities at the expected pace compared to 8% of TD group ($\chi^2=10.49$, N=46, df=1, $p<0.01$).

7.4.4. Driving.

Much has been written in the literature in the past few years about driving skills and ADHD, but Cousins and Smyth study (2003) were one of the first to discuss this in the specific area of DCD.

In the current study, some of the participants were under the age to be able to start driving, so they were excluded from the analysis in both the movement difficulties and TD groups.

A series of questions were asked about driving behaviour and the responses are described below. These had been amended to be suitable in a UK context (with permission from Barkley's driving survey used in studies in adults with ADHD).

7.4.4.1. Have you learnt/are you learning to drive?

It was of interest to explore whether students with DCD avoided learning to drive.

Table 7B: Percentage of students learning to drive.

Group	Yes %	No %
TD (79)	82	18
DCD (40)	53	47

Fifty three percent of students with motor difficulties had learnt to drive compared with 82% of the control group. A chi-square test indicated that this difference was significant ($\chi^2=11.75$, N=119, df=1, $p<0.01$).

7.4.4.2. Reasons given for not driving.

Reasons given in both groups were for financial reasons. However, the DCD group did show some distinct differences. One male in the DCD group gave the reason for not driving: *"Because I consider myself a liability and wouldn't trust myself to be able to control the car say if there was a crash"* and a second stated that: *"I had a block of lessons in 2005. I found it very difficult and I didn't get on well with the* *instructor. I couldn't afford the lessons. Since moving to London I haven't felt the need to learn because public transport is so good."*

Some students did give other reasons for not driving, for example: *"I hope never to buy a car, well mainly for environmental reason, for safety and the expense".*

In the control group no-one reported having co-ordination difficulties as a reason for not driving.

One student in the motor difficulties described the long process in learning to drive:

"I have stopped and started a number of times, I tried manual at first but I couldn't get on with the clutch and then I moved onto automatic and then the driving instructor had problems with the car and I was getting behind with my school work and everything so I stopped and then I went back to automatic again and then I stopped again cos I was going to Uni and then I started up again properly".

One student described his attempts at learning to drive compared to his sister: *"I am taking longer to learn than let's say my sister because she has already passed but she is two years younger than me."* Another individual described some of the barriers and some feelings about potentially not being able to drive: *"When I lived with my dad, my dad tried to teach me when I was seventeen and I got very, very wound up over things and I now realise because of my dyspraxia I couldn't co-ordinate everything together. I was permanently stalling the car; I got very, very* *panicky driving the little roads with things coming towards me. I do intend to try again at some point, I know I have to take a test first to see if I'm allowed to and then I will get a disability driving instructor and I do think that when I do learn I think I will try an automatic, I don't think I will try anything more complicated than that but if I don't learn to drive I will just have to put up with it I guess. My boyfriend drives and most of my friends do so."*

Another reported that he felt it was likely to be a long- term difficulty: *" I don't think I am ever going to be comfortable with long journeys or anything like that."* One student reported his pattern of trying to learn to drive and how alternative approaches, such as learning on an automatic car, were chosen: *"I have been learning on and off for a number of years. I originally tried learning with a manual gearbox but experienced problems with clutch control (little wonder due to my dyspraxia). I have been learning in an automatic for a while, but, as yet have yet to pass my test. I always come close but I experience difficulty with controlling speed and judgement."*

Another student reported having been given some conflicting advice: *"the driving instructor, he told me that I didn't need an automatic but he was always moaning about my clutch control."*

7.4.4.3.Driving behaviour.

Driving behaviour was compared between the TD and DCD groups by enquiring about the length of time the students have been driving, the number of theory and practical tests, and the average number of miles driven per week. The number of lessons was not asked and in reflection this may have been additional useful information to gauge whether there were differences between the two groups.

Table 7C: Length of time driving (in months).

Group (n)	Months (mean/SD)
TD (60)	39 (23.85)
DCD (16)	22 (26.01)

Table 7C shows the difference between groups with the TD group reported driving for a longer period than DCD group (*t* (74)=-2.603, p<0.01). The N values for each group represented the number of students who responded to the specific question.

Table 7D: Number of times taking theory test.

Group (n)	Times (mean/SD)
TD (63)	1.43 (1.33)
DCD (16)	1.69 (1.3)

There was no significant difference between the TD or DCD group in number of times taking the theory test as seen in Table 7D. One student with DCD reported: "*I* *failed my theory test the first time. Now I have to do it again for the third time because my certificate ran out. I booked my test twice and cancelled it twice.* " The N values for each group represented the number of students who responded to the specific question.

Table 7E: Number of times taking practical test.

Group (n)	Times (mean/SD)
TD (60)	1.82 (1.02)
DCD (16)	1.31 (1.45)

Table 7E shows the number of times taking the practical test in both groups. There were no significant differences between the TD or DCD group in the number of times taking the practical test. This was a surprising result. One question was omitted and would have been of interest was the number of lessons taken before passing the test.

Indication of successful driving was given by some students: *[I drive] "an automatic car which I am getting on well with great"*

Table 7F: Average number of miles driven per week.

Group (n)	**Miles (mean/SD)**
TD (54)	149 (101.02)
DCD (13)	79 (97.08)

Table 7 F shows that the TD group reported driving significantly more miles in an average week than DCD group (*t* (65)=-2.25, $p<0.05$). This may be possibly related to social behaviour with the TD group going out more. The N values for each group represented the number of students in each group who responded to the specific question.

7.4.4.4. Accidents and reckless driving.

Additional information was gathered about behaviour on the road on a day to day basis including accidents and reckless driving. This again was asked because of the literature from ADHD studies on driving behaviour as cited in Chapter 3.

Table 7G shows the differences in a range of behaviours between the two groups. DCD adults were significantly more likely to report having difficulties with distance estimation than TD group ($\chi^2=9.4$, N= 45, df=1, $p<0.01$).

Table 7G: Comparison of percentage of accidents and reckless driving between DCD and TD groups.

% YES	TD (N=62)	DCD (N=19)	χ^2	p
Driving without a valid license	9.5	0	0.2	ns
License revoked/suspended	3.1	0	0.6	ns
Accident	48.4	36.8	0.8	ns
Struck a pedestrian or cyclist	1.6	0	0.3	ns
Been reported for reckless driving	4.8	5.3	0.01	ns
Driving intoxicated	0	0	n/a	n/a
Speeding ticket	22.6	5.9	2.4	ns
Parking ticket	38.7	21.1	2.0	ns
Difficulties parking	11.1	42.9	3.2	ns
Difficulties with distance estimation	16	60	9.4	<0.01

There were no significant differences between the groups in other areas. The control group were more likely to have had a crash but there was not a statistically significant difference between the two groups. The DCD group described bumps and collisions that had occurred, such as: "*many knocks and bumps, many scratches. I have needed my car re-spraying twice*", and: "*one week after passing practical [test] I was driving down a hill after heavy rain, rushing and I couldn't slow down, then the car in front suddenly braked to turn right, I panicked and went straight into their boot. My car was written off, theirs was ok. Also, have judged space between wall, my car and another car badly*".

Another student described difficulties with distance perception and spatial awareness: "*Parking is still tricky. Distances are rarely as they seem. One car was written off, the police were behind me with lights and sirens on, this took my concentration and I crashed*" and similarly other students described: "*judging the distance between the cars because I either drive too close to one side or too close to the other*" and: "*spatial awareness. I really have severe problems with spatial awareness especially when I'm a pedestrian crossing roads; I find that really hard*".

Another student described some issues with control: "*when driving with my instructor (5 years ago) I accidentally reversed into a tree as I momentarily forgot to* *turn the wheel as I was reversing"*. These difficulties were not true of all students with DCD: *[I] "didn't find much problem with parallel parking."*

Difficulties with spatial awareness and control appeared to be the main problems described by students with DCD.

7.4.4.5. Speeding and parking offences.

The final comparison of driving behaviours related to speeding and parking offences between the TD and DCD group. It was uncertain whether the DCD group would be more or less like students with ADHD who had a history of increased rate of speeding offences.

Table 7 H: Speeding and parking offences.

	% Received speeding ticket	**Mean no. speeding tickets (Mean/SD)**	**% Received parking ticket**	**Mean no. parking ticket (Mean/SD)**
Movement difficulties	5.9	1 (0.0)	21.1	2.5 (2.38)
Control	22.6	1.62 (0.96)	38.7	2.14 (1.42)

Table 7H.shows that greater number of students in the control group had received parking tickets than movement difficulties group, however it was not significant.

Fourteen TD students received speeding tickets compared to one of the DCD group. Of these, as seen in Table 7K there were no significant difference between groups on the numbers of speeding tickets issued.

7.4.4.6. Gender & Driving.

There were general gender differences in driving behaviour. Overall, 17% of males have driven without a license compared to 0% of females ($\chi^2=8.52, N=81, df=1, p<0.01$). Males in TD group were significantly more likely to have driven without a valid license than females (25% and 0% respectively) ($\chi^2=10.52, N=62, df=1, p<0.01$).

7.5. Mental health difficulties.

Psychological and emotional difficulties were not specifically asked about in detail and standardised assessment tools were not used. Students reported spontaneously in their 'weaknesses' mention of mental health difficulties. Associated anxiety and depression has previously been described in Chapter 3 with regard to increased anxiety in the study by Sigurdsson *et al.* (2002). This was only reported in a small number of participants in the DCD group and was not asked specifically in the TD group as seen below in Table 7C.

Table 7I: Reported mental health difficulties in motor difficulties group.

Illness type	**Number**
Depression	8
Eating disorder	1
Anxiety/stress disorder	3
OCD	1
Total	**13**

Table 7K shows the type of mental health difficulties reported in the motor difficulties group. In those that responded, females with DCD were significantly more likely to have or have had a mental illness than males with DCD (44% and 10% respectively; $\chi^2=8.25$, N=54, df=1, $p<0.01$). However, as this was a small percentage of the total group it may be difficult to fully interpret these results and it would be prudent to follow this up with a further study using specific depression measures.

However, a number of DCD participants did report symptoms that may indicate some mental health difficulties when they were asked about their "weaknesses". Some comments reported included the following: *"Tendency to depression"* and *"My self esteem from time to time can be very low"* and *"OCD, over-emotionality"* and *"Anxiety. This happens to the point where I begin to feel physically ill and unable to work through challenging circumstances- i.e. job interviews"*.

The presence of mental health difficulties in students were also reported and described by parents of students with DCD in some detail and are described in

Chapter 9. It is difficult from this sample to be sure of the prevalence rates as compared to the general population.

It may be postulated that this may be higher as ADHD has been associated with high levels of known psychiatric comorbidity, and as DCD commonly overlaps with ADHD, but it is an area that requires further exploration. Student support services may need to consider the presence of mental health difficulties in students with motor difficulties in further and higher education. Specific referral may need to be given to both help prevent mental illness especially at times of increasing pressure in order to use techniques such as cognitive behavioural therapy and medication where required (March *et al.*, 2004).

7.6. Conclusions.

This chapter has shown as in previous chapters the social consequences of having a motor difficulty. The overall picture is that social behaviours such as drinking and alcohol in young people with motor difficulties appear to begin at a similar age to their peers. However, there is less opportunity to experiment and drink to excess as there are fewer opportunities because of greater social isolation. This could be described as a want but not the will. This is supported by the fact that students with motor difficulties are not going out and participating in social activities such as clubbing compared to peers and choosing more solitary leisure pursuits. There was a difference in drug taking between groups, with the DCD group using drugs less than the control group and, again, this may be related to a lack of social opportunity or being more risk averse.

Leisure choices appeared to be different in the two groups with only three of the movement group reporting taking part in team games such as rugby, hockey or football compared with four times the number of the controls. This behaviour may be a continuation of childhood with avoidance of team sports (Poulsen, Ziviani & Cuskelly, 2006). Alternatively, at this stage the individual may have chosen sports that he or she can participate in.

Driving is an important rite of passage. It is not surprisingly cited as a problem for many individuals with DCD with a suggestion that driving an automatic car seems to be a better bet than even starting to learn in a manual car. Driving behaviour in the motor difficulties group seems to be more cautious than in the control group with fewer miles travelled. It is of interest to note that reckless driving, in the past associated with ADHD, is now thought to be a more associated condition with conduct disorder. It is now reported that impairments in attention, distractibility, and slower and more variable reaction time, as well as difficulty in competing with different sensory information may be the key factors at play interfering with driving ability in young adults with ADHD. Difficulties with driving in students with DCD may turn out be a combination of poor motor control and executive functioning problems. Additionally, spatial awareness did seem to be a reported problem with difficulties parking the car. The difficulties with attention may be important information to give to emerging adults with motor difficulties that they need to consider ways of reducing the number of variables to increase their ability to concentrate effectively on their driving. This may be one factor why a number of students have chosen to drive with an automatic car as well as the control difficulties.

Driving behaviours in the motor difficulties group were different from the control group. They were seen to be driving fewer miles per week and this may be associated with the pattern of their social behaviours as described earlier in the chapter where the individuals with DCD were less likely to be going clubbing and dancing compared to TD group (67% compared to 8% respectively). They were also less likely to be speeding and had difficulties with distance estimation. This picture, along with the descriptions given, paints a picture of generally more caution and social isolation apart from a few individuals who portrayed a different picture. This may be learnt behaviour i.e. individuals recognise they have co-ordination difficulties and are therefore more cautious when driving. The DCD group were also more likely to choose solitary hobbies and not play in team games and so may generally not be going out as much as other students so resulting in them not needing to drive as much as their peers.

There were two cases where, interestingly, where the individuals both scored at least six out of seven positive responses on the past difficulties in childhood list of motor difficulties questions, but did not have a diagnosis of either ADHD or DCD. They did have a different and distinct pattern of behaviour compared with others and may be suspected of having an ADHD-DCD profile. One was a first year male of 25 years of age studying banking. He had driven for seven years and took his practical test six times, and his theory test six times. He had his license revoked due to excess alcohol consumption. He described experiences of having accidents: *"Parking is still tricky. Distances are rarely as they seem. One car was written off, the police were behind me with lights and sirens on, this took my concentration and I crashed"*.

He started drinking at seven years and had now stopped due to excessive consumption. He had also started smoking at ten years, and had stopped in the previous Christmas. He also started taking drugs at ten years of age! He also reported suffering depression & anxiety. He was not currently receiving student support but recognised he needed it.

The second individual was a male of 22 years of age. He had driven for three years. He took his theory test three times and practical test three times. He reported driving without a valid license. He started drinking at 16 years, drinks 30 units per week and started smoking at 18 years and smokes 20 per day. He started taking drugs at 17 years. He did not receive help as a child and has not asked for help in university. He was a 3rd year student and was studying strategic business management.

7.6.1. Limitations of the questionnaire approach in assessing driving skills.

When comparing the movement difficulties group and control groups there were equal numbers of females and males in the control group but not in the DCD group. This may have some influence on social choices among the two groups. Although there were not significant differences in learning to drive demonstrated in the number of times theory and practical test taken, the students were not asked how many lessons they had taken before taking the test nor the time (months) from starting to learn to passing their test as they may have delayed sitting the test until they were certain they were going to pass it. However, it was of interest to note the number of students with movement difficulties who had chosen not to drive or who had stopped driving after trying to do so.

These results are also limited by the fact that students reported their difficulties rather than actually being tested on their driving abilities and further studies need to be undertaken with driving simulators or with cameras in real time actually recording and assessing difficulties.

A recent study in the field of ADHD (Fischer *et al.*, 2007) examined the performance of young drivers and showed there were more slower and more variable reaction times, greater errors of impulsiveness (false alarms, poor rule following), more steering variability, and more scrapes and crashes of the simulated vehicle against road boundaries than in controls. A meta-analysis by Jerome *et al.* (2006), examining the effects using long – acting methylphenidate with young drivers with ADHD, showed a normalization of dysfunctional driving behaviours on a driving simulator and during on-the-road driving when they receive treatment with long-acting methylphenidate compared with treatment with other stimulants and non stimulants. Future research in drivers with DCD may need to consider whether there is a case for trying medication with this group and seeing whether this improves driving skills or determining further whether the difficulties noted are mainly because of executive functioning and attention difficulties and it is this that should be identified in this cohort.

Corroboration of reported behaviour in this study would have also been valuable if it had also been gained from parents. Recall of motor difficulties in childhood may not be entirely accurate. However, if the young person is attending for an assessment as an adult in a college or student setting he or she is likely to be asked these types of questions without any corroboration from parents and so is consistent and reflects current practice. Routine practice gaining a history from another informant such as a parent would improve the diagnostic process.

CHAPTER 8: IDENTIFICATION AND SUPPORT OF STUDENTS WITH DCD IN FURTHER AND HIGHER EDUCATION.

8.1. Introduction.

This chapter presents findings describing some of the experiences of students with motor difficulties in further and higher education and the type of support that they have received. Examples of their experiences have been included from the transcribed and coded interviews. Qualitative comments from students from the larger data set are also included where appropriate. Differences in numbers between groups from the whole group represented in Chapter 5, is where a subset of students have responded to information. However the exclusion and inclusion criteria remains the same throughout the study.

This chapter also discusses the implications of these findings for Further and Higher Education in planning assessment and support services. Additional information from parent interviews and questionnaires (further described in more detail in Chapter 9) is included in this chapter where relevant to both support and compare the comments that students had made with those of parents.

Arriving at university or college is a marked transition from the 'safety' of school. Up till this point, liaison about the student's needs would have included the parent in the discussion. This may be the first point where the parent is no longer included and the individual has to be fully independent. This may present difficulties as it may result in less or even no support being sought if the young person lacks the confidence to ask for help or the ability to navigate the processes required to receive it. The parent, acting in a role as an advocate, may confer advantages in ensuring support for their child especially in a college setting in further education (Morris, 2002). A new start for some individuals offers the ability to present themselves in a new light without the 'tags' of disability attached to them or misconceptions about them from others. Bullying experiences in school were a theme obtained from the student interviews and this may have an influence on the social confidence in the movement difficulties group and how they behave when first arriving.

8.2. Results.

The selection process and characteristics of each of the groups were described in detail in Chapter 5. The student groups of DCD, TD and Dyslexia are described and data presented. In some areas it was more relevant to compare either DCD with TD or DCD with Dyslexia groups.

The DCD group were those individuals with a diagnosis since childhood, the Dyslexia group were those diagnosed as 'dyslexic' but had entered the study as they considered themselves having co-ordination difficulties and the TD group of students were those with no reported diagnosis of specific learning difficulties. Thirty seven (56.9%) of the students in the cohort with motor difficulties were reported attending university, whilst 28 (43.1%) were attending college or in the sixth form. Where Disabled Student's Allowance is discussed this is in reference to the university rather than college students as this is not applicable in that setting.

Year of study	DCD only (N=16)	DCD + other (N=21)	Dyslexia (N=23)
1	43.8%	47.6%	30.4%
2	18.8%	28.6%	39.1%
3	25%	19%	30.4%
4	12.5%	4.8%	-

Table 8A. Year of study at time of completing the questionnaire of those in university.

Table 8A shows the pattern of year of study of the cohort of students in university with an additional sub division between the DCD and DCD+ group. This demonstrates that both the DCD and DCD+ group are similarly distributed across years one to three, with 12.5% of the DCD group in year four at university. In the Dyslexia group more students who completed the questionnaire were in year two, than in years one and three. Not all students completed this information.

It is useful to reflect on current functioning by considering what level of support students recieved while in school. It would be logical to consider that those who required assistance at school may continue to need some assistance in college or university. In order to measure this, students were asked if they had recieved any professional help for their difficulties in childhood by either health or educational professionals.

8.2.1. Support received in childhood.

There was a significant difference between the total DCD group (i.e. DCD and DCD+) and the Dyslexia group with respect to receiving help in childhood. Sixty two percent of students with a diagnosis of DCD reported receiving help in childhood from a health or educational professional compared to 33% of students with a diagnosis of Dyslexia ($\chi^2 = 5.26$, N=55, df=1, $p<0.05$). There was also a significant difference with the DCD group compared to the TD group with 62% of the DCD group compared to 7.7% of the TD group ($\chi^2 = 19.26$, N=57, df=1, $p<0.01$).

Of the total cohort, 62% of males received help compared to 27% of the females. A chi square test indicated that males were significantly more likely than females to have received support as a child ($\chi^2 = 15.13$;N=123, df=1, $p<0.01$).

This demonstrates that those students who had been diagnosed with DCD received more help than those with a diagnosis of Dyslexia alone and males were also more likely to receive support than females.

8.2.2. The need for continuing support from parents.

In order to move away from home to go to college or university, the student needs to have acquired some independent skills such as being able to travel independently from home, manage their finances, and plan their week. Some insight was gained about the level of continuing support needs from the interviews with parents of children with movement difficulties. Parents described their children's journeys into further and higher education, both positively and negatively. They described the gains from moving to a new environment but also their concern for their child's ability to cope.

Arrival at college or university may be the first time individuals with DCD may have had to negotiate help for themselves. One issue that arose was that parents were no longer part of the discussion about needs and that they were not often included in any meetings with student support services:

> *"The main problem we came across with helping X with College was that he is responsible for all communication once he is 16 years."*

It was clear from several parents that there remained a lack of understanding of the needs of the individuals:

> *"The support is inadequate and there is little understanding of what X's needs actually are. The help to X has been minimal in terms of his development."*

Parents of the 16-18 year old group also described the difficulties for the students coping with increasing work in the college setting such as:

> *"X is finding A levels very challenging. May have to take A Levels over three years"* and: *"learning for him is a great challenge at the A level standard."* and *"I worry about him getting course work etc completed in time."*

These responses, as well as those additionally discussed in greater detail in Chapter 9, demonstrate that the parent may need to be a part of the process moving through this major time of transition, especially for students with social and communication difficulties. It is interesting to note differences in perception of difficulties. Twenty percent of students with DCD reported social and communication skills as a weakness compared to 50% of parents reporting their children had social and communication difficulties (as gathered from the cohort of parents that completed questionnaires. This contrast between parent and child perception again highlights the need for parental involvement, at least at the beginning of starting at college or university with agreement with the student in order to gain a complete picture of needs. However, there is a fine balance between over concern and the need to protect and to let go and watch failure occur.

8.2.3. College and university changes.

The first few weeks of college or university can be an anxious time for most students, having to navigate their way around a campus, make new friends, care for themselves and often learn new subjects. It also offers an opportunity of presenting oneself in a different light. One student described this new start and the opportunity to present himself differently:

> *"At university I could start all over again, no one knew who I was and therefore their opinion was not clouded by a view of me when I was at my most clumsy."*

College or university may also offer the student new opportunities for support that may have been lacking in a secondary school setting. Some parents described the benefits of moving into a further education setting:

> *"New college provided some support for him but local comprehensive didn't offer much at all."*

And:

> *"Support at college Y has been 100% and continue to bring up new ideas - he has totally changed since leaving school and this is due to the encouragement required".*

Another parent described the specialist support that her son was receiving:

> *"Now receives support (mainly out of class) in a learning support centre attached to his sixth form college".*

Parents described some of the types of support received such as exam allowances: *"B has benefited from allowances in exams for his Dyspraxia"*. Another parent stated that help was: *"listening support one hour per week"*. One parent described their child was: *"at a specialist FE college from where he attends mainstream college with support."* It was evident that there were different models of support and these did not seem to be prescriptive in terms of the diagnosis had been given. However, in some cases there remained a: *"lack of appropriate support"*. Variability and lack of transparency in the provision may cause confusion when considering which college or university to choose.

8.2.4. Place of residence while in college and university.

Students were asked where they were currently living during term time. Analysis of the place of residence was undertaken in order to compare the behaviour of students with DCD to those with a diagnosis of Dyslexia and the TD groups and to consider whether this was a potential 'marker' of independence. Living away from home with other students would require a level of both independent and social skills. If students with DCD were continuing to require a high level of parental support then this may have been potentially seen compared to TD students. However, during the study there have also been changes in the way students are funded and so some students may be selectively staying at home because of financial reasons and not because of a specific support needs. Students were asked whether they were living at home with parents, renting with others or living in halls.

Table 8.B: Comparison of current living arrangements by percentage and by group.

% (N=63)	DCD	Dyslexia	TD
Home with parents	65.3	21.4	50
Renting with others	22.4	71.4	50
Living in halls	12.2	7.1	-

Table 8B shows that 65% of the DCD group reported living at home with parents compared to 21% of Dyslexia group (χ^2=8.5, N=63, df=1, p<0.01). However, there were not significant differences between the TD and DCD groups. There were no significant differences in those choosing to live in halls of residence between the DCD and Dyslexia group and no TD students were living in halls of residence. Students with Dyslexia (71%) were significantly more likely to be renting accommodation with others compared to those with a diagnosis of DCD (22%) adults (χ^2 = 11.75, N=80, df=1, p<0.01).

Two of the interviews with first year students gave some greater insight into reasons students with motor difficulties choosing to stay at home:

> *"I was thinking about moving away from home but decided in the end that I would see how I got on with first year, then if I wanted I could move away in second year. I thought that due to my problems it would be easier to stay at home".*

In contrast, another student recognized the need to move out:

> *"I didn't particularly want to stay near home as I thought it would make an easier transition to adult life, staying in halls. It was a good way to grow up a bit and start to take a bit more responsibility".*

Further analysis of the data demonstrated an interesting association in that significantly more adults without a mental illness in DCD group (79%) reported living at home with parents than adults with a mental illness (18%)($\chi^2=13.9$, $N=49$, $df=1$, $p<0.01$). This may indicate increased social isolation or difficulties with home relationships that leads to those with mental health problems leaving or the converse that being at home affords a protective environment for students and reduces the risk factors for mental illness. There is certainly some evidence linking self esteem and a nurturing stable parental environment and the notion of connectedness. This is that the individual can remain connected with the family while at the same time going through the process of individuation (Grotevant & Cooper,1998). There are limitations in interpreting these figures as the sample size is small. Standardised questions screening for anxiety and depression may be a useful approach to gain a true estimate of the level of mental health difficulties.

There was no relationship between living at home with parents and whether the individuals with DCD chose to go to clubs or choosing bars or clubs. This may further demonstrate that separating from your parents can still occur while living at home and it was not this that was a barrier to the young people in choosing their social activities.

8.2.5. Arrival at university.

As has been described in Chapter 6, students reported organisational difficulties. One area of difficulty highlighted was 'finding your way around new buildings or places'. Fifty percent of students in the DCD group reported difficulties as compared to 12% in the TD group. All students, whether with or without additional learning needs, have to learn to get around a campus and get to different lectures and meetings on time.

It could be predicted from responses from the questionnaire that orientation around the campus for the student with motor difficulties may be difficult. Some students described the arrival at university and the type of problems that occurred. The examples cited mainly related to the landscape of the campus and difficulties finding their way around it.

> *"Everything was like all over the place it was a bit like daunting at first because French was separate over from IT".*

And:

> *"easy to get into a panic with things like time tables were done beforehand and they would clash something".*

And:

> *"if you are always at different campuses, you are tired".*

Students also described what had helped them to navigate their way around: " *all the labs are in the same place* " ; and *"there are signs everywhere"* and *"it's difficult to try and get my bearings so I like to try and have some kind of benchmark as it was, something to remember".*

In order to provide support for the individual with motor difficulties, not only do the individual's specific areas of difficulties need to be addressed but also there is a need to make sure that the environment is adapted to meet the needs of that individual. It is a duty of the further and higher education establishments to be proactive in their practices under the DDA (Learning and Skills Council, 2004). Clearly, signage around all areas of the campus would be of help to individuals with motor difficulties. They are likely to benefit other students as well. Induction programmes for students with DCD prior to attending the college or university could also be of help with an option, at some point, of parental involvement.

8.2.6. In receipt of government support.

As described in Chapter 4, student support in university is linked to gaining a disability student allowance. Students were asked if they had received or were currently receiving Disability Student Allowance (DSA) or Disability Living Allowance (DLA). None of the TD group received any support. The following table describes the support the students in university received.

Table 8C: Levels of government support by diagnostic groups.

%	**DCD (N=37)**	**Dyslexia (N=23)**
DLA	5.4	4.3
DSA	67.6	69.6
None	29.7	26.1

There were no significant differences between DCD and Dyslexia groups on the type of benefits received. The DCD group contained both individuals with DCD only and those with DCD+ other specific learning difficulties including Dyslexia. The Dyslexia group contained students with Dyslexia alone. However this does not divide the students into DCD alone, DCD and Dyslexia, DCD and other specific learning difficulties, and Dyslexia alone in terms of being in receipt of DSA. When this is undertaken there are significant differences between groups.

Table 8D: In receipt of DSA by diagnostic category.

Diagnosed difficulty	**Number**	**Percentage in receipt of DSA**
DCD	31	29%
DCD and Dyslexia	21	61.9%
Dyslexia	23	65.2%
DCD and Specific Learning Difficulties	21	23.8%

There was a significant difference between the DCD only and DCD +Dyslexia group for receipt of DSA ($\chi^2 = 5.54$, N=52,df=1, $p<0.05$). There was also a significant difference between the DCD only and Dyslexia only groups ($\chi^2=7.0$, N=54,df=1, $p<0.01$). However, there was no difference between the DCD + Dyslexia and

Dyslexia only groups. Differences in levels of student support seem to be related to a diagnosis of Dyslexia and this could be for a number of reasons; it may be due to lack of awareness of schools in preparing students with DCD to apply for DSA. The application process has several hurdles which require good organisational abilities including obtaining the forms, completing relevant sections which have to be handwritten, sending them to the appropriate department, and getting to an assessment in a place that is unfamiliar to the student. Just the form filling exercise may be harder for individuals with handwriting difficulties. The student may be 'put off' completing these necessary forms. Universities and colleges may not be promoting services specifically to students with motor difficulties /Dyspraxia/DCD. It is evident that there is significantly more information on the websites about Dyslexia. In the randomized sample of 20 universities websites that were examined this was certainly the case. Student support services may also have low levels of awareness of DCD and may not know how to recognize the signs and symptoms and feel ill prepared at supporting this specific group of students (see Appendix E, page 449).

Only one student with Dyslexia reported to be in receipt of Disabled Living Allowance. This latter result is not surprising as students with Dyslexia would not be eligible for disability living allowance unless they had difficulties with independent living or physical difficulties.

8.2.6.1. Having a disability

Once the student has been assessed and diagnosed, then he or she will be in receipt of a Disabled Student's Allowance and receive support, specialist equipment and special exam arrangements, immediately differentiating them from their peers. This opens up the debate over when, and if, to disclose difficulties to others. One student described why he disclosed:

> *"I do tend to tell others who take the micky sometimes but usually due to jealousy because of the disability allowance so I take it in my stride".*

Another student described how he did not need to do so:

> *"Most people know to be honest, as a fair few people off my course are also dyslexic and we all take out exams in the early starters room, I don't see it as anything to be ashamed of but I also don't want to be seen as having a disability, it's just the way I am".*

One student interestingly described his difficulties especially with regard to spelling. He described this in a context of English as an additional language. This is an example of how the environment may make a change to others perception of your difficulties. In this case one student was perceived as not having difficulties because other students could not write English as well:

> *"When I changed uni, I informed them so I'd get the extra minutes for exams but as my department is predominantly international, I'm not really at an advantage. I just mention it if people ask me to proof read for them, in case my spelling isn't top notch".*

In this setting, the other students having English as an additional language were at a disadvantage, and they sought help from him not realising he had difficulties of his own.

It is interesting to note that in order to receive the *disability* student allowance you have to be declared as 'disabled'. This highlights the persistence of a medical model of disability in further and higher education.

8.2.7. Courses currently studied in reported motor difficulties group.

It was of interest to consider whether there was any trends in the type of courses that students with DCD chose compared to those with Dyslexia.
The table below compares the choice of courses by diagnostic category

Table 8E: Choice of course at college or university by reported diagnosis.

	DCD **(N=64)**	**Dyslexia** **(N=24)**
Social Science	18.8	16.7
Humanities	10.9	12.5
Arts, Media and Design	9.4	8.3
Health	1.6	12.5
Business	10.9	12.5
Physical Science	10.9	16.7
Education	3.1	12.5
IT	3.1	-
Vocational	18.8	8.3
A levels	12.5	-

Table 8E shows that students with DCD in this sample were less likely to be studying health related studies and education. Higher levels of vocational courses were recorded in those with a diagnosis of DCD compared to those who reported a diagnosis of Dyslexia. This may be indicative of lower academic achievement. Additional information was not obtained about their GCSE or A level attainments. There may also be limitations in interpreting this data, as the sample sizes for each of the diagnostic categories was relatively small. However, a comparable study by Riddell, Tinklin and Wilson (2005) shows students with Dyslexia were less well represented in veterinary science, agricultural science and information science and had greater representation in creative arts and design courses.

The recognition that a student receives DSA leads onto the student then having a further specialist assessment to determine their specific support needs. In an ideal setting this should result in a specific package relating to the needs of the individual student. It would also be expected that students with one specific developmental disorder may need similar types of supports and these may differ to some degree with other developmental disorders. For these reasons, a comparison of reported support was undertaken between the DCD and Dyslexia groups.

8.2.8. Type of support provided by college/university for DCD and Dyslexia groups.

Analysis of the type of support reported as being offered.

Table 8F: Type of support reported to be provided in college or university.

%	DCD (N=46)	Dyslexia (N=20)
Extra exam time	89.1	95
Laptop	52.2	55
Note-taker	21.7	5
Mentor/coach	26.1	30
Other	21.7	15
Student Support	75	90

There were no significant differences in the types of support between groups. However, there were more note takers being provided in the DCD group (21.7%) compared to the Dyslexia group (5%). This is not a surprise and can be attributed to the degree of handwriting difficulties persisting in this group.

Examples of "other" support cited included the use of Dictaphones, attending catch-up programmes, and class notes being photocopied. One student mentioned that a: "*quiet study space recommended but not yet sorted*".

Further exploration of the usefulness of this provision was not undertaken and would be an interesting area of research to pursue. Despite different profiles of difficulties, support being given did not differ. This is a surprising finding and questions the need for the many hurdles that students with DCD and other developmental disorders have to climb over in order to receive support. These also have considerable costs and time implications for all involved.

8.2.9. Diagnosis in university or college.

Students may arrive at college or university with a diagnosis of learning difficulties. This may be DCD or could be another diagnosis such as Dyslexia. Other students may arrive, having gone through school aware of difficulties but not being formally assessed and therefore not having a 'label' for their difficulties. One female student described why she believed she had not been recognised:

> *"I had no diagnosis at all until I was 19, it wasn't until I had deferred from my first year at uni and was in therapy that I was diagnosed. My parents had thought there was something wrong since I was first at school and didn't get on as well as anyone else, but they kept being told, for years, "she reads so well, she can't be dyslexic (no-one ever even mentioned dyspraxia, even though I was so totally uncoordinated, I think most people who dealt with me hadn't heard of it). The reason I read so well is because I LOVE reading so I forced myself to do it".*

For some students, having their needs identified and labeled results in a variety of feelings .One student described feelings of surprise: *"I thought I might have slight dyslexic tendencies. Turns out no I'm not actually dyslexic I'm dyspraxic, completely unexpected."* and another student described feelings of relief: *"I've always wondered and things have been a struggle. It was a relief and on the other hand it was a hindrance".*

One student described what it felt like to her having a 'disability' as an emerging adult and possibly seeing herself as different from before.

> *"I know that I've now got a disability".*

Another student described being diagnosed at this time as not being a major change in his life.

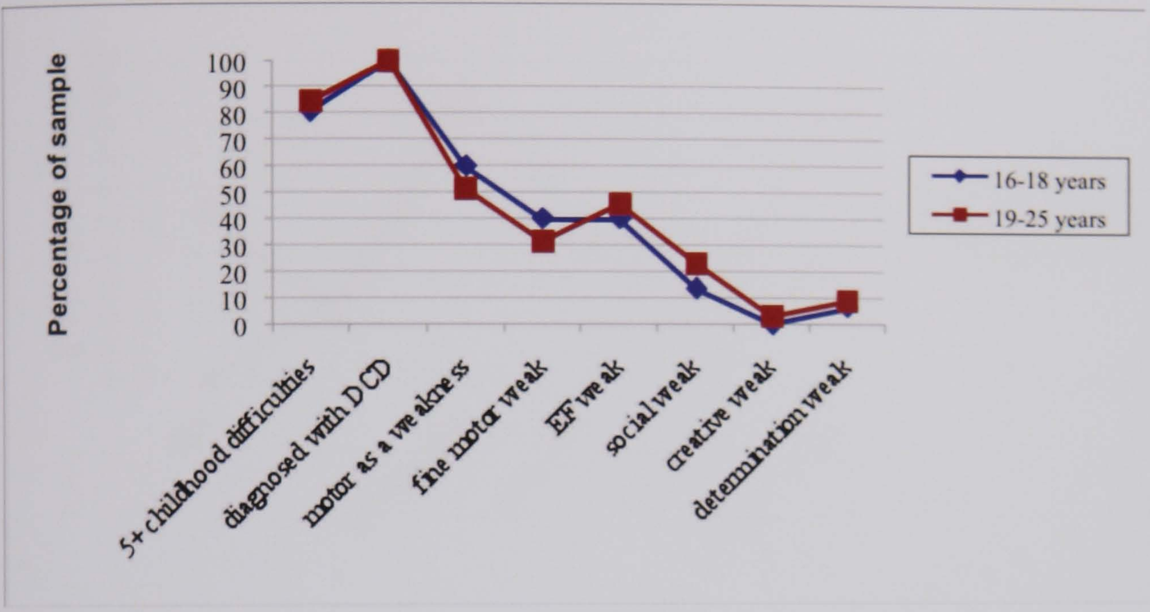
> *"I was diagnosed at university; it was no big deal or great revelation. It was interesting to tell friends about all the psychometric tests".*

The need to have a diagnosis in university specifically before support can be given drives the persistence of a medical model. A formalised process for assessment in contrast means that identified students can seek help and appropriate support. However, this support is currently linked to being 'disabled' and carrying this badge may potentially drive some students away from seeking the help they need as they may not want to see themselves as being disabled but, alternatively, that the environmental demands are disabling them.

8.3. Differences between support for 16 to18 year olds and 19 to 25 year olds with motor difficulties.

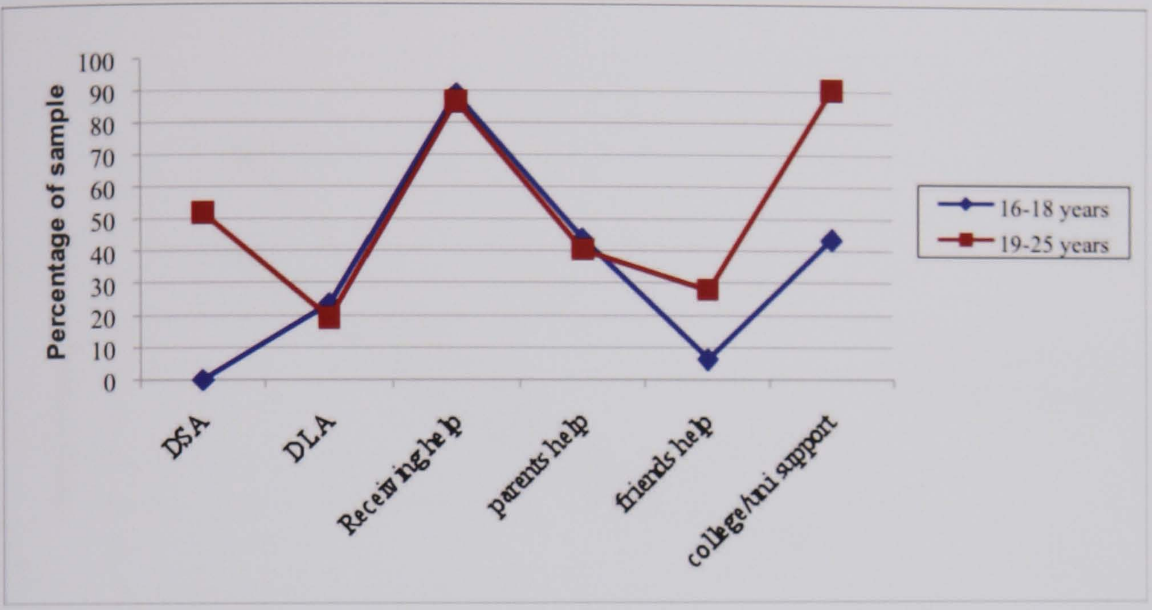
Support was compared for both the 16 to18 year old group and the 19 to 25 year old group, both with motor difficulties, to see whether there were similarities or differences in characteristics. Figure 8A shows that, for many of the reported characteristics, the two groups were very similar. A comparison was made of reported difficulties in childhood, whether they had been diagnosed and the pattern of reported motor weaknesses. As can be seen below, there were few differences between the two groups.

Figure 8A: Comparison of characteristics between 16 to18 year olds and 19 to 25 year olds with motor difficulties.



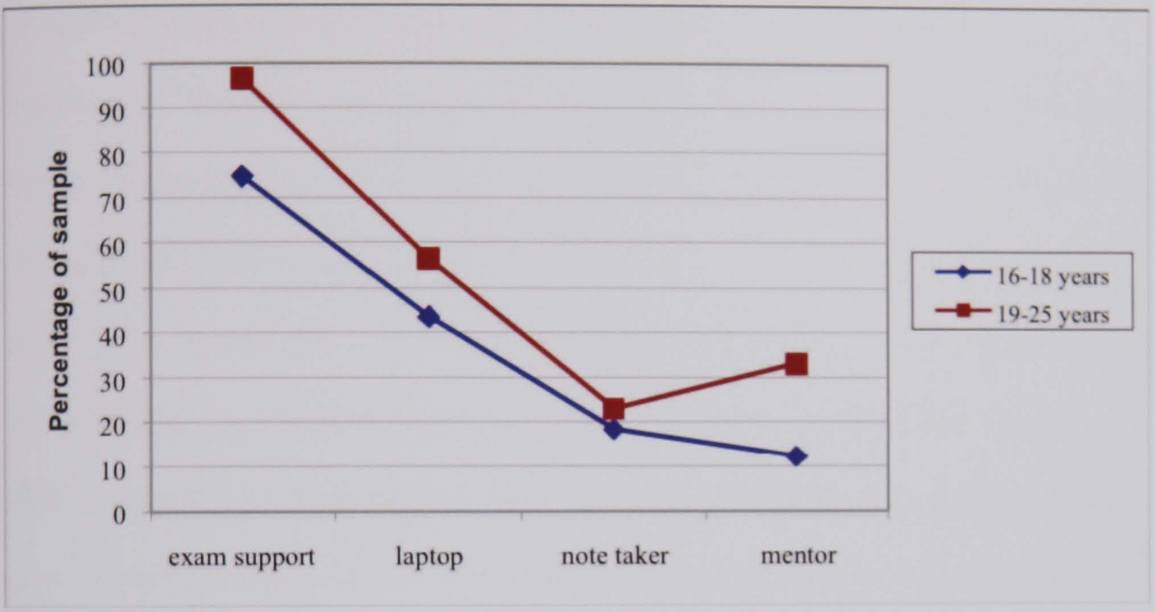
A comparison was made of the two groups comparing the type of support they were receiving and whom they were receiving it from (see Figure 8B). DSA was not being provided in any of the 16 to18 year olds students, as expected, as they were not at university. There were no significant differences between the two groups for type of support being given by parents for the 16 to 18 year olds (43.8%) compared with the 19 to 25 year olds (40.6%). Even though help had decreased a little in the older group, it was still at quite a high level. University student support services were more often accessed than college support, with 91.7% university students accessing support compared with 60.9% of the college group receiving support. However seventy five percent of the latter cohort received help of some sort. This may be related to awareness and access arrangements.

Figure 8B: Comparison of government support by age group of students with motor difficulties.



Further analysis was undertaken regarding the specific support being given in the college and university settings. Figure 8C shows a discrepancy between the two groups, in exam provision,laptop provision and note takers and mentoring support.The latter being offered more in the older age group.

Figure 8C: Comparison of student support given between 16-18 year olds and 19-25 year olds with motor difficulties.



Despite similar profiles between the two age groups, provision given varies depending on the context where that help is being received and does not seem to be based on the needs of the individual or even at a group level. This demonstrates, at the present time, a clear inconsistency in practices.

8.4. Discussion.

There are clear differences in provision at several levels as demonstrated in this chapter, for example by age, by diagnosis and by gender. Even before arriving at college or university, identification and support may be different for girls and boys with motor difficulties. This may be because of overlap with ADHD. The ADHD literature has shown in recent years that girls have been shown to be more commonly an inattentive type of ADHD and are more likely to internalise their difficulties, whereas boys externalise their difficulties (Gershon, 2002). Less hyperactive, "dreamy" girls may be less disruptive (Haines *et al.*, 2002). It may be the externalising behaviour in males that brings their additional motor difficulties to the attention of the teacher or parent (Vollebergh *et al.*, 2005). This may result in girls having equally poor motor skills but being able to sit at the back of the class not being noticed. An additional factor in identification may be associated with the ability to partake in physical participation. Playing sports may have greater social currency in boys and so parents and teachers may be more alert in identifying the poorly performing boy in PE and games sooner than the females.

Arrival at college and university is a key step in the process of emerging adulthood with an opportunity for individuation as well as potential separation from parents. The difference in this study between the TD and DCD groups was not significant for the two groups for those who were currently living at home with parents in term time. This may be due to sample size or changing economics with increasing numbers of students deciding for financial reasons to stay in their home town. Students with DCD were also noted to be more likely to be living at home than those with a diagnosis of Dyslexia and this may reflect the need for continuing support from parents. In a study by Holdsworth and Patiniotis (2005), 22.7 % of students who responded to their survey lived in the parental home, and with more men (25.1

%) living at home than women (21.5 %). Interestingly, students in the study who were living with parents tended to take courses such as mathematical sciences, business studies and IT, engineering and the physical sciences. Further analysis of the data in this study was undertaken to check if there were similarities in the DCD group. Students studying business, computer, IT, engineering and physical science were compared to students studying other courses, and there were no significant differences found between the groups.

Students will arrive at university needing support but presenting in several ways. Some students arrive with a diagnosis of Dyslexia but may in fact also have DCD but have not had it formally diagnosed (29.2% of those diagnosed as having Dyslexia also reported having at least five difficulties out of seven on the past motor difficulties checklist). It could be conjectured that this presentation may be related to the age they received their diagnosis of Dyslexia. Ten years ago, when they were likely to have been in primary school, awareness of DCD would have been less than today and so referral for concern for difficulties with writing, for example, may have resulted in a primary diagnosis of Dyslexia.

These results have demonstrated a clear bias towards support for those with a diagnosis of Dyslexia. Those with a diagnosis of DCD (without Dyslexia) were more likely to have received support in childhood but were significantly less likely to receive Disability Student Allowance (DSA) in university, despite more being in receipt of Disability Living Allowance, than those with a diagnosis of Dyslexia. Post hoc analysis was also undertaken on the group who could be potentially missing out on support.

As previously described two students who described themselves as poorly co-ordinated but had "no diagnosis" were also characteristically different on a number of different variables to the main DCD group, apart from them both reporting having had significant motor difficulties in childhood. The first student had to take his practical and theory driving tests six times, and had his license revoked due to excess alcohol consumption. He had a number of accidents: *"One car was written off, the police were behind me with lights and sirens on, this took my concentration and I crashed"*. He reported starting to drink very young and had stopped because of excessive consumption. He also started smoking at ten years and had stopped the previous Christmas. He also reported taking drugs. He liked the gym, running rowing and skiing. He had reported also being depressed and anxious and wanting some help. The second individual had taken his theory and practical test three times and had driven without a valid license. He also reported drinking at 16 years, and drinking 30 units per week, started smoking at 18 years, and smokes 20 per day and started taking drugs at 17 years of age. Both were studying business degrees. It is interesting to conjecture what is different in character and behaviour to the other students with motor difficulties and why both these individuals have not been identified or supported despite having difficulties.

The provision of DSA at the present time is dependent on a diagnosis and so favours a medical model of disability rather than a social model and highlights an inequality in terms of provision, where those who are diagnosed receive greater support. It also highlights to the individual that they are 'disabled' and this may potentially change the way they consider themselves or others view them. This is seen in this student's description below:

> *"I found out at university. It was quite a relief to know that there were reasons for why I was slower than 'normal' people so I gave myself a mental break and started taking it easy on myself. I treated myself to extra breaks and did as I was told by my mentor which helped tremendously. I do tell others usually my lecturers who sympathise and are more helpful if I have difficulty understanding what others grasp quickly".*

One way to potentially provide fair and equitable student support is to identify and allocate resources according to need. An alternative assessment framework would need to be used, such as the International Classification of Functioning (ICF), Disability and Health Model (WHO, 2001). This provides a framework for assessment, considering the individual's limitations in participation and takes into context the environment the individual is in. It also reflects on the changing nature of developmental disorders where the level of support may depend on the context. For example, a student moving from a hall of residence into independent living may have increased demands to self organise and then plan and get to college or university. This may have a secondary impact on their capacity to study and this may result in 'tipping the balance' in coping on their course. However, there are training implications for using the ICF such as considering how this would be measured.

There are also clearly training needs around the knowledge base of student services and universities about DCD and this needs to further examination how training should be put into place. This need has been recognised in the field of Dyslexia by Pollak (2003):

> "The importance of staff awareness is further underlined by the introduction of the Disability Discrimination Act Part IV, the Special Educational Needs and Disability Act (SENDA) that came into force in September 2002. The Act makes it a legal requirement for educational institutions to introduce "reasonable adjustments" for dyslexic students and consequently many institutions are now reviewing policies and putting improvements in place. In this situation, informed decisions need to be made. Hence the need for raising staff awareness regarding dyslexia has become even more pressing." p100.

CHAPTER 9 - PARENTAL CONCERNS

9.1. Introduction.

In order to gain a full perspective of the life of the emerging adult with motor difficulties it is important to have information from key additional informants. The parent or guardian who has observed their child's behaviour over many years, is an essential person, and is likely to be the only one able to give a developmental history and recognize the changes that have occurred in their child over time.
Studies in adults with ADHD and AS have shown the importance in gaining a multi-informant picture to be sure of the true pattern of behaviours and difficulties occurring (Barkley, Murphy, & Fischer, 2008; Järbrink *et al.*, 2007).

This chapter presents information gathered from two sources; firstly, a questionnaire completed by a cohort of parents whose children had been diagnosed with DCD in childhood. This longitudinal information allows a comparison of symptoms over time. Additionally, it gives information about the parental concerns when the children first presented in childhood and a comparison with the present time now their children are aged between 16 and 25 years. Secondly, a more detailed insight is gained from a subgroup of these parents who were interviewed and themes from these interviews are also presented in this chapter.

Understanding the differing perspectives, both from the child and the parent, allows a unique understanding of current and past issues. The latter part of this chapter presents results comparing parental concerns at the present time to the students concerns in the same time frame to illuminate some of the similarities and differences in their concerns. This is gathered from questionnaires completed by both parent and child pairings. Finally, parents describe some reflections on what they believe has changed for their child and what they might have wanted to be different from services providers along the way.

Only a few studies on DCD have considered the views of the parent (Missiuna *et al.*, 2006; 2007) and these have mainly listened to the views of parents of younger children not of those in this emerging adult age group.

Parents have a unique viewpoint of their child's development. They are able to provide a perspective of their child's daily experiences and are able to reflect on educational experiences that have occurred over time. In a study by Missiuna *et al.* (2006), thirteen mothers were interviewed in order to gain their views of their children with DCD. They participated in one-on-one interviews with a researcher. Four open ended questions were initially asked in an attempt to explore parent's perceptions of their child and insights gained over time (e.g. "Tell me about your child"). Further questions probed areas of interest such as coping strategies, environmental factors and specific descriptions of experiences. Further questionnaires concerning developmental history and demographics were gathered.

as well as the use of the Strengths and Difficulties Questionnaire (Goodman *et al.*, 2000). The mothers later participated in a follow up interview. Parent's discussions highlighted strengths as well as challenges encountered over time. Central themes focussed on issues arising within school, outside of school, the relationship with the educational system in general, as well as considering which teachers were supportive. Given an open ended question, most parents initially volunteered positive information about their child, such as temperament and intelligence. However, parents also volunteered information concerning children's difficulties, such as avoidance of fine motor tasks and being unnoticed or misinterpreted by teachers. Many parents expressed concerns about their child's self concept and poor ability to socialise with their peers. In addition to discussing difficulties experienced by their child, parents discussed their own difficulties, in particular a lack of support and recognition.

The importance of needing to listen to the voice of the parents in helping their child with decision making has come to the fore in recent years. This may happen less frequently as young people move from childhood to adulthood.

In the SEN Code of Practice (2001)

> "Parents hold key information and have a critical role to play in their children's education. They have unique strengths, knowledge and experience to contribute to the shared view of a child's needs and the best way of

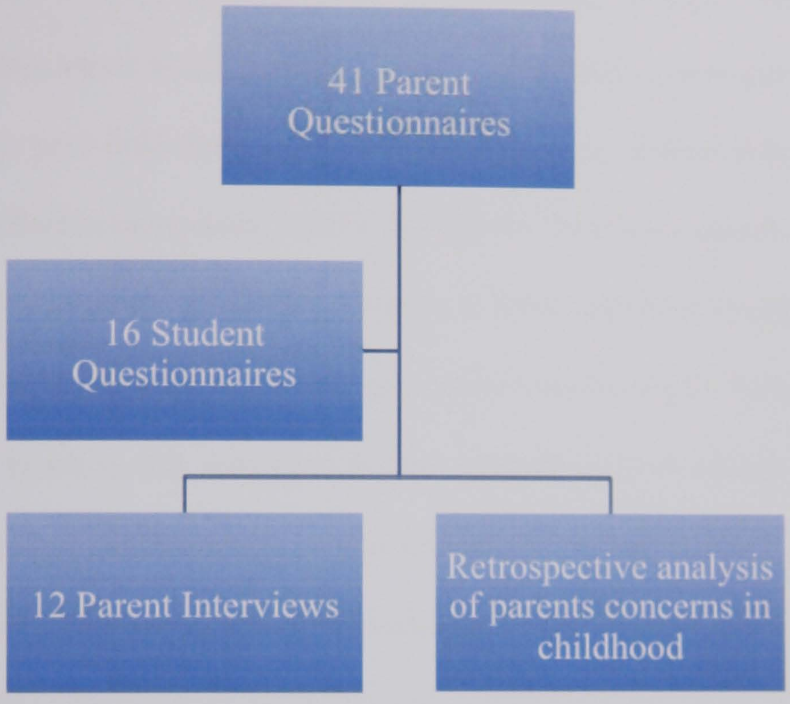
> supporting them… All parents of children with special educational needs should be treated as partners"
>
> *(2.2).*

The process of when the parent 'bows out' of the support process remains somewhat cloudy and how this should be undertaken with the emerging adult.

9.2. Results.

The following plan displays the sources of the results in this chapter and describes this pictorially. Participants were recruited from the clinical cohort from The Dyscovery Centre. This is described in greater detail in Chapter 5.

Figure 9A: Plan of sources of information



Forty one parents completed paper based questionnaires (see Appendix C). From this group of parents, a cohort of 12 parents agreed to complete telephone interviews. All children had been seen in childhood and had been diagnosed with motor difficulties.

The parents were representative of 32 males and nine female children. One of the 41 children presented had a diagnosis of ADHD, despite having motor difficulties and scoring high on the checklist for past motor difficulties. All others had been given a diagnosis of DCD or Dyspraxia in childhood.

The following presents a table of the parents' responses from information gathered from the questionnaires with regard to their concerns at home and school/college or university. This is presented to demonstrate the variability within a group of emerging adults with DCD and related difficulties. Sixteen out of the 41 parents did not express specific concerns relating to problems at school, college or university. Parents may be less aware at this stage of specific difficulties occurring at college or university as they have little direct contact unlike the primary school years. Specific themes are described in more detail later in the chapter. Nearly all parents, apart from one, did have concerns about their children at home and these mainly related to independent living skills, social skills and poor organisational skills. Parents were able to report as much as they wanted to of their concerns. It is of interest to note that some parents had extensive and varied concerns. For example case 20 was a 19 year old with a diagnosis of DCD and other developmental disorders. His parent described concerns relating to motor difficulties, emotional immaturity described as '*living in a dream world*' and '*led astray*' and '*gullible*', time management and organisational difficulties. There is a feeling of persistence in the reports being given with terms such as: '*never learns from mistakes*' and '*shows no remorse for actions*'.

Table 9B: Characteristics of the 41 students (age and gender) with the reported parental concerns at home and in education.

ID	Gender	Age	Reported Diagnosis	Parent opinions of remaining problems/concerns at home.	Parent opinions of remaining problems/concerns at school/college.
1	Male	20	DCD & LD's	• Cannot organise himself so needs help sorting things out-cannot sort clothing or live independently in any way which makes him very angry at home. • Often depressed and withdrawn, feeling he is a failure at everything. Always wants reassurance and goes nearly everywhere with me (mum).	• Sometimes does not want to go to school because of what others say to him.
2	Male	20	DCD, Dyslexia & LD's	• Probably the main area is memory which he can work at it but we support him with.	• One of the lecturers treats X differently due to his difficulties-not in an encouraging way. • The main problem that we came across was X was responsible for all communication at college when he turned 16 years of age-college rules.
3	Male	18	DCD & Dyslexia	• Still has serious organisation problems.	• Still has organisation problems which lets him down as he is so bright.
4	Male	20	DCD & Dyslexia	• General absent mindedness but this may be perfectly normal for a 19 year old boy. • He has not started driving yet, it may not be a problem but with his co-ordination skills it may be difficult. • A difficulty in reading people and social situations at times.	• Not reading signs and therefore walking into dangerous situations or perhaps not walking away from them as he hasn't picked up the clues. • Illegible handwriting, it's not always possible to type.
5	Male	19	DCD & Dyslexia	• Very difficult behaviour at times. • Concerned about speech skills.	• Speech. • Finds simple tasks

				• Concerned about organisation skills.	hard to follow.
6	Male	19	DCD, ASD & LD's	• Anything outside of his usual routine brings on panic and frustration. • Finds basic things like peeling vegetables and drying dishes a slow and frustrating process. • Needs time to organise himself, we cannot announce that we are leaving the house in ten minutes. • Routine is still an obsession, making decisions for himself almost non-existent.	• None.
7	Male	19	DCD, Dyslexia, ADHD & ASD	• General lack of confidence in public (shopping, finding way about, filling out forms). • Lacks social skills. • Co-ordination much improved but still poor at certain skills like using a can opener. • Organisation still quite poor, needs help and support though he seems to be improving a little.	• Relies on laptop a great deal, still finds writing difficult.
8	Male	18	DCD & ASD	• Gets very angry and frustrated and then hits and bites himself a lot. • Lack of initiative and needs constant prompting. • Poor independent living skills. • Can't occupy himself for very long, no social life outside of home. • Movement generally immature.	• Lack of appropriate support-poor mock GCSE performance but school unable to offer study skills advice. • Poor independent study and learning skills. • Forgetfulness. • Lapses in concentration. • Poor handwriting.
9	Male	19	DCD & ASD	Independence in life skills such as cooking, washing clothes, shaving, cutting nails etc. • Learning to drive. • Crossing Roads. • Dealing with change, new spaces etc.	• None.
10	Male	18	DCD	• When tired cannot function its as if all systems start closing down.	• Organisational skills. • Handwriting.
11	Male	18	DCD & Dyslexia		• Very disorganised. • Paperwork. • Poor presentation. • Finding A levels very challenging may have to take them over three years. • Poor memory and

					concentration means he finds deadlines for coursework difficult to keep. • He is often seen as different.
12	Male	18	DCD	• Organisational skills could still improve. • Handwriting remains difficult to read.	• None.
13	Male	19	ADHD	• Impulsive • Lacks stability for daily living skills, e.g. difficulty in pouring a drink in a controlled way. • Starts another task before completing first. • Holds himself in awkward position when running.	• Lack of concentration. • Easily distracted. • Listening skills. • Cannot write in a legible way.
14	Male	18	DCD & LD's	• Still disorganised. Swimming has greatly helped but when his exercise levels fall his co-ordination greatly reduces and stomach muscles become much more relaxed. • Great difficulty in riding a bike. • Language disorder can be a barrier.	• None.
15	Male	20	DCD	• He needs to concentrate and have peace and quiet to carry out every day tasks. • Lacks confidence in his abilities and will not try new methods encase he fails.	• If he has a job that involves organisation and neatness he may struggle a little when he finds a routine.
16	Female	19	DCD & ASD	• Needs lots of support. • Lacks confidence. • Anger issues.	• Hates groups feels like everyone is looking at her. • Low self-esteem. • Lacks confidence.
17	Male	19	DCD	• Has few friends and is very solitary. • Disorganised. • Very young for his age. • Worry as to whether he will be able to lead a fully independent life-still very dependent on us.	• Getting coursework completed on time. • I worry that he will not achieve the grades he needs in exams.
18	Male	20	DCD	• Can still be difficult and intolerable. • Easily annoyed.	• Organisation. • Prioritisation.
19	Male	19	DCD	• Writing skills.	• None.
20	Male	19	DCD, Dyslexia, ADHD, ASD & LD's	• He lives in a flat and cannot manage himself or his money and is in major debt. • Remains clumsy, constantly dropping mobile phones, spilling drinks etc. • Very immature, child like. • Goes from relationship to relationship. Concerned he has no friends, has a girlfriend (apparently pregnant). • Led astray by others-used/taken for a ride, he is very gullible. • Cannot keep a job, currently looking for	• None.

				job 18. Gets job (puts on show) then gets sacked when they see the real him or he gets bored. • Poor time-keeping. • Struggles with short-term memory. • Creates chaos wherever he goes. Shows no remorse for actions-is emotionally distant. • Cannot organise money/life/time in general. • Lives in a dream world and has unrealistic expectations, is not accepting of his issues. • Never learns from mistakes, repeats over and over again, e.g. obsessed with mobile phone so debt collectors after him. • Neglects health, dental care-will not accept advice.	
21	Male	18	DCD	• Co-ordination-avoids ball games • Currently learning to drive. Wanders around the road but this may simply be due to inexperience.	• None.
22	Female	19	DCD, ADHD, LD's	• Can fall over easily. • When cooking needs to be kept on target.	• Slow when asked to write.
23	Male	18	DCD	• Very poor memory. • Tiredness. • Organisation problems. • Writing.	• Lack of organisation.
24	Female	19	DCD	• None to write about, very slight.	• Slight social difficulty making friends. • Immaturity.
25	Female	23	DCD & Dyslexia	• Is withdrawn and angry at times • Organisation is abysmal, can't seem to get things together to sort herself out e.g. dental appointments, finances or workload.	• Does not appear to be coping, does not keep up with workload. Expressing giving up course. • Finds it difficult sharing a house.
26	Male	25	DCD	• May still have problems with organisation as much due to the quantity of information and interests that engage him as due to Dyspraxic information filing/retrieving.	• It may be due to factors of personality but he wants to go off in a number of different directions at once taking on more than anyone can reasonably manage and losing not momentum but 'ground'.
27	Male	17	DCD	• Panics if a situation is not structured.	• None.

28	Male	22	DCD & ASD	• Used a laptop at school and never wrote so consequently finds it very difficult, e.g. filling in forms. • Still untidy and has difficulty organising his things, he often loses his possessions. • Social skills are very poor.	• None.
29	Male	19	DCD, Dyslexia, ASD & OCD	• OCD means he spends a lot of time checking/rechecking switches, doors, taps etc.	• Coping well at university but becomes anxious when coursework etc is to be presented. • Still has difficulty organising his thoughts and presenting them on paper. • Cannot take notes in lectures and absorb what is going on, therefore he has scribes for lectures.
30	Male	23	DCD	• Sleeps most of the day and procrastinates so much that he is not productive, until he becomes stressed. • Lack of social skills. • Oversensitive, can be manipulated in relationships. • Needs constant support particularly with money management.	• Misses lessons because of time management • Becomes confused, puts off assignments and then rushes them and does not achieve potential.
31	Male	22	DCD, Dyslexia & LD's	• Personal hygiene. • Co-ordination. • Organisational difficulties.	• None.
32	Female	21	DCD & LD's	• All aspects. Especially social & understanding of the outside world, life and people. • Organisation and poor memory which sometimes seems better and you have bad days again. • She is not structured in everyday life at home. • No concept of time, her perception of it is very poor. • Can count money but has no understanding of it at all. • Easily distracted • Social skills with peers poor they do not accept her. Interrupts conversation, uses	• None.

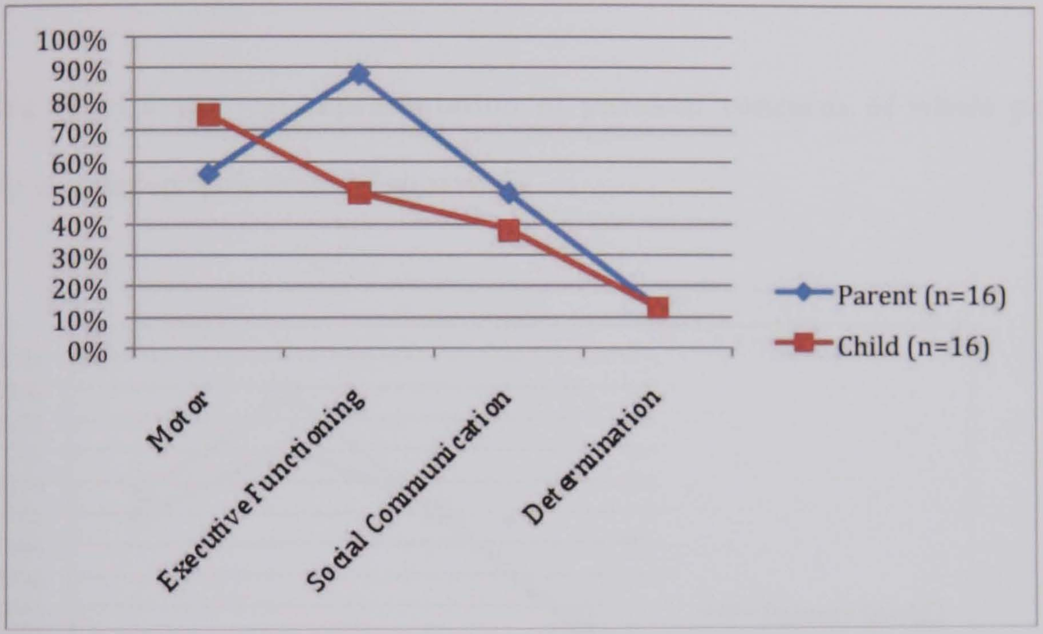
				inappropriate topics at wrong times, over friendly at wrong times-wants to be liked. • Vulnerable at all times, cannot read appropriate behaviour from others • Will do certain things but wants reassurance but cannot accept guidance and takes it as being criticised or put down.	
33	Male	17	DCD & ADHD	• He still has a lot more problems than he is willing/able to recognise as almost all problems he had as a child remain. • Still clumsy (but says he isn't). • Completely unable to tidy his desk and room so he has a clear space to work, ditto clothes.	• Organisation, getting assignments done on time and to required standard. • Remembering equipment, times etc.
34	Male	24	DCD	• Managing time and money. • Unable to concentrate for any length of time.	• Has failed all courses since leaving school.
35	Female	19	DCD & LD's	• Independent travel, finding her way around unfamiliar places. • Short-term memory difficulties. • Time-management. • Can be rather heavy handed and clumsy.	• None.
36	Female	19	DCD	• Personal hygiene is still poor • Poor assessment of direction and speed of traffic. • Fearful of crossing road and taking public transport or driving, i.e. learning to drive.	• Still lacks social skills, which permit her getting on with her peers-she has no close friend.
37	Female	23	DCD	• Still struggles at work despite help available. • Particular difficulties with the handling of her son of 15 months	• None
38	Male	22	DCD	• Organisational skills remain a challenge	• None
39	Male	19	DCD	• He is intelligent but often disappointed by his exam results, feeling that his peers are doing better	• None
40	Female	21	DCD	• Finds it very difficult to hold family conversations • Relating to people at work • Confidence	• None
41	Male	22	DCD & ASD	• Handwriting • Coordinating cutlery	• Finds it difficult to deal with stress when doing academic work

9.2.1. Parental concern compared to student concerns at the present time.

Of the 41 parents who expressed their current concerns of their children, 16 students correspondingly reported their concerns. These 16 students were matched with their respective parents in order to compare and contrast parental and child concern in emerging adulthood.

Graph 9 A demonstrates the differences that 16 parents and their matching children reported as their main concerns when these are coded using the same coding dictionary used in Chapter 6, reporting self reported student's weaknesses and strengths. However, creativity was not included in the table below as there were no responses from either parents or students relating to this when asking about concerns. The four main areas coded were: motor, executive functioning, social and communication, and determination.

Figure 9 A: Categorical differences in concerns between parents and their children.

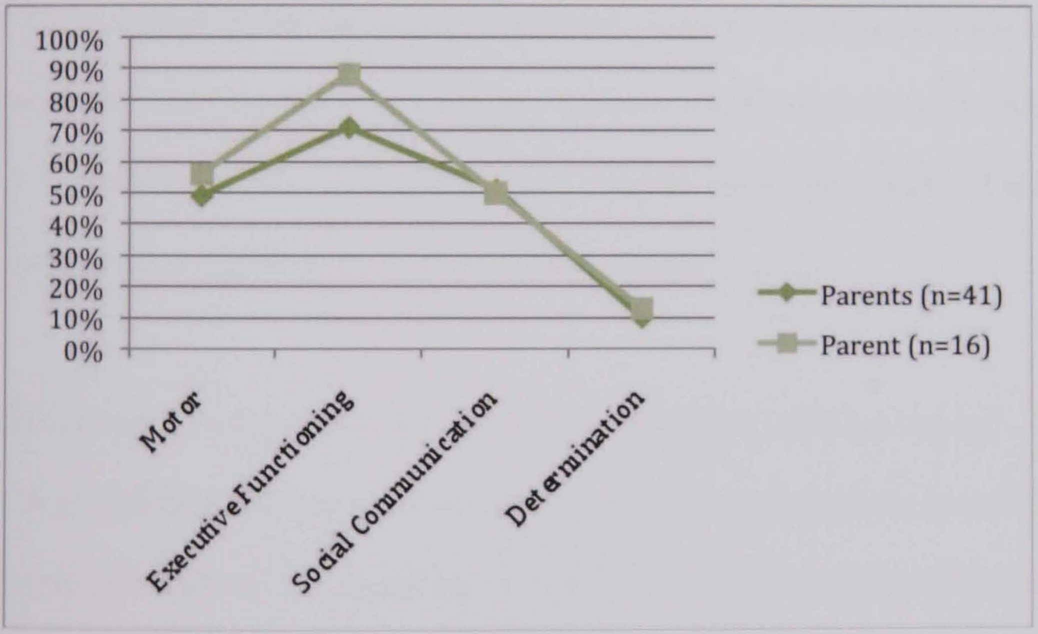


Graph 9A shows the differences in response by percentage comparing parents to children and demonstrates that parents have greater concerns about their children's organisational abilities and executive functioning than the children themselves. There was a significant difference between adults and children in reporting of executive functioning as a problem concern was seen ($\chi^2=5.24$, df=1, N=32, $p<0.05$). This is an important finding as it validates the need to have multiple informants in gaining a true picture of functioning in emerging adulthood in this group as has been seen in other developmental disorders.

9.2.2. Parental concerns of the 16 parents compared with those of the whole group.

This analysis was undertaken in order to consider if the subgroup was representative of the larger parent group of young people with motor difficulties

Figure 9B: Categorical representation of parental concerns of whole parent group compared with those of subgroup.



This graph (9B) represents the categorical presentation of a subgroup of 16 parents' concerns/problems compared with group of 41 parents who also reported their concerns/problems. There were no significant differences seen in the overall group between the two groups. This increases the power to generalize this data from the smaller group to potentially larger populations.

Some examples from each of the four key themes that the parents expressed were as follows:

Motor and independent living skills: Parents described some of the specific difficulties such as:
"He lives in a flat, he cannot manage himself or money and is in major debt" and another described: *"Difficulty in pouring drink in a controlled way"*.

Executive functioning: One parent wondered whether behaviours they had seen were 'normally' seen in other young adults: *"General absent mindedness but maybe this is perfectly normal for a 19 year old boy"* Another parent described : *"Lack of concentration, easily distracted and listening skills"*.

Social and communication: One parent described their child has having:
"Very difficult behaviour at times" and *"also concerned about his speech"*. Another parent talked about: *"no social life outside home"*. This was reiterated by another parent: *"Y has few friends and is very solitary"*. One parent posited a reason for this: *"Very immature, child like"* and the result of this [he] *"goes from relationship to relationship"*.

Determination: One example given by one parent of lack of determination was: *"Lack of initiative and needs constant prompting".* This could also be related to executive functioning skills.

From these general themes, further triangulation was undertaken in order to complete a more in depth analysis. This was undertaken taking responses from the whole group and also including in the analysis the transcripts of parent interviews in order to explore the changing nature of DCD in this age group. Additional examples cited from students, where appropriate, have also been included in order to demonstrate similarities or to highlight differences in opinions.

9.2.3. Detailed analysis of parents' and students' views of the changing nature of DCD in emerging adulthood.

Themes emerged from using a combination of the case studies where 12 parents completed telephone interviews (as described in the recruitment process in Chapter 5) and information gained from parent questionnaires.

The interviews were undertaken using a semi-structured questionnaire in order to consistently cover similar areas in each interview. By seeking out common themes, it is possible to generalize about common experiences as well as acknowledging the heterogeneity of the group. The views of the larger group of parents' also acted as an additional source to check against the knowledge gained from the parents interviewed and increases the ability to generalize. There was some flexibility in the interview process in order for parents to add in additional information or extend their discussion in any of the areas.

All interviews were transcribed and then coded using N Vivo software (2005) Additional information was also gathered through a similar process with students who had a childhood diagnosis of DCD or Dyspraxia and, in turn, a number of students were also interviewed and their interviews coded for similar themes.

The following themes describe parents' views and reflections of change, persistence and resolution in their children and what emerges in adults as a continuing problem for the young people, as well as including students' views where appropriate. It also highlights what parents see as positive traits and behaviours in their children.

Much of the treatment and interventions in children with DCD have evolved around focussing on resolving their difficulties rather than seeking out their strengths.

Cantell, Smyth and Ahonen (2003) commented that:

> "There is a risk in concentrating only on the weaknesses in children with DCD, and neglecting the potential inherent strengths and external support systems that have contributed to positive outcomes"
>
> p 427.

There has been increasing interest in a strengths model in the field of psychology. Peterson and Seligman (2004) are some of the key psychologists leading the positive psychology movement. Using this approach along with the Baltes and Baltes (1993), Baltes and Baltes (1999) SOC (selection, optimization, and consolidation) model as described in Chapter 2, are useful frameworks to consider factors that may be affecting a successful outcome. These approaches develop the concept of the individual needing to develop goal setting skills in order to work with their potential strengths, alongside finding strategies to overcome their difficulties. Much of the work in DCD has been about deficits and few studies have focused on the potential positive aspects of having a motor difficulty. For this reason a specific question was asked of parents about what they perceived were their child's strengths so this could also be compared with the strengths reported by students' with motor difficulties themselves, to see if there were common themes emerging.

Parents described a number of different strengths in their children including humour, empathy and caring, good organisational and social skills. Examples of some of these are described below.

Humour was one strength: "*I think relating to where other people are at. I think he is really sense of humour, it's very good, very witty*".
Another strength was caring and empathy. This was described as: "*empathy he has got with people... his social skills are stunning for his age*". Another mentioned: "*He has such a lovely personality, very caring, he has buckets of empathy*".

And another parent described: "*his personality, his openness, his honesty, his total utter integrity and honesty.*" And one other: "*He is very, very understanding, very caring*".

In contrast to some students reporting organisation as a weakness, one parent described her child as having good organisational skills: "*well organised and hard working, focussed*". Another parent, also in contrast to some student reports that her son had positive social skills: "*he has 'come out the other end' a well educated, personable and articulate young man. He is now "excelling at work*" and "*He took the hardest classes at school and became an 'eagle boy scout' that is one in a million*".

However, there was a major difference in parent reporting compared to student reporting as described in Chapter 6, where parents considered that Executive Functioning (EF) skills such as organisational skills were clearly not seen as a strength in the majority of individuals. In contrast to 21% of the DCD student group reporting this as strength, between 70-87% of parents reported this as a concern. Similarities were seen between parents and students in the strength of empathy. These reported strengths of caring and empathy that may predict a better outcome. In contrast, having poor social skills will hamper the ability to mix effectively with peers.

9.2.4. Areas of reported current concerns.

Some parents reported continuing difficulties for their children during the stage of emerging adulthood. Additionally, some new difficulties emerged and some difficulties persisted. One area emerging or more formally identified were mental health difficulties described as: "*Moods, depression*" but one parent reflected whether this was associated or not: "*not quite sure whether that was going to happen anyway or it accelerated*". Other parents had seen a positive change at this time. One young man had been depressed in his younger years but in emerging adulthood his parents had seen a change: "*in the last nine months to a year he has been gradually mixing better and been brighter*".

The following describes six key areas of continuing concern that parents expressed:

9.2.4.1. Co-ordination skills

9.2.4.2. Independent living skills

9.2.4.3. Learning a new skill

9.2.4.4. Organisational skills

9.2.4.5. Social and communication skills

9.2.4.6. Emotional and Psychological state

9.2.4.1. Co-ordination skills.

Some parents reported improvements in co-ordination: *"co-ordination has come on a lot"*. Another described participation in sport without potentially the skills: *"He enjoys rugby, he's not that good at rugby ...but he does enjoy rugby and he does play it, he doesn't really like any other sports"*.

However, many parents described continuing difficulties in quality of movement and acquisition of skills. One parent described the quality of movement in their son: *"his movement is quite immature generally"* and another said *"Holds himself in an awkward position when running"*. Another parent commented on the persistence of problems but unwillingness on their child to acknowledge them: *"He still has a lot more problems than he is willing/able to recognise as almost all problems he had as a child remain. Still clumsy (but says he isn't)"*. Spatial awareness seemed also to be one of the problems cited: *"still has difficulty with crossing roads, dealing with change, new spaces"*. One parent postulated why some difficulties might persist. Their son *"will not try new methods in case he fails"*.

One persistent difficulty for many was continuing writing difficulties, with little improvement since childhood: *"handwriting remains very poor"* and *"Writing notes. It's difficult to make out what he has put down."* Another parent reported that: *"his handwriting is still appalling and he still has this problem of actually* *turning his thoughts into a concept"*, and another described the handwriting as *"Very poor, like a six year old"*. Some parents described some improvement: *"tidier, it's not as large as it used to be and he does follow the line"*.

One parent described a good rationale for adaptation over intervention: *"the issues were his handwriting however that has got better as he has got older simply because he can use technology to get around it but his handwriting - it is almost illegible"*. Parents described the benefits in learning to type: *"He got a lap top which he got in Year 5 of the senior school and he had a short hand typing course, touch typing I should say and he learnt to type and that's what he does now, he types everything"* and: *"He is quite good with the keyboard"*.

One parent described the issues of writing and using a laptop: *"He has never really been able to write, the biggest hurdle was when he was doing his GCSEs because I couldn't even read his writing, never mind an examiner. So he did have a lap top but that didn't help because it took him actually longer to type than it did to write so he had to really target which bits of text in the exams he would use the lap top for"*. One parent described starting early with typing but intimated that it was a slow process to acquire the skills: *"He began to use a computer at primary school and had a laptop for his secondary education. His typing has certainly speeded up over the years, but it is still slow"*. Another parent described how much input had been required and how long it took her son to become competent: *"I did make sure he* *learnt to touch type from 8 years on, his sister and he spent ten, twenty minutes every morning for three years doing this touch typing".*

However, one parent described how more advanced skills had been gained: *"he uses my management software tool to draw mind maps and that helps a lot".*
Another parent stated how the laptop becomes an important vehicle for expression [he] *"relies on laptop a great deal"*

Several parents described difficulties in the acquisition of a common skill, riding a bike, and the differences in experience, performance and outcome. One parent described how their son eventually learnt but was: *"wobbly for a very long time and I wouldn't like him to be out on a road where there were more than one or two cars but he did it, he learnt".*
One parent described their child gaining the skills and what was the motivating factor for finally learning: *"We couldn't get him to ride the bike at all and finally it was really interesting this, it must have been about nine or ten years ago his friends at the time in the street here got very frustrated by the fact that he couldn't ride a bike so they taught him how to ride it. So he can ride it but he doesn't get any enjoyment out of it at all. [he rides] poorly and in fact he has given up riding the bike".* Another described their child learning to ride a bike: *"He didn't ride a bike until he was eleven and that was only because we pushed him to. He still doesn't look comfortable on a bike now but you would never get him on a racing bike".* Another parent reported trying for some time but: *"he still can't ride a bicycle; he had many bikes as he kept on growing we bought him more".* However, one parent

described a successful outcome at a relatively young age but it was linked to seeing his sister competently cycling that appeared to be the driver: *"I think he was about six and what happened was his sister suddenly sailed down the drive, I think we had taken the stabilisers off her bike and she suddenly sailed down the drive, 'Look I can ride my bike' and he sort of gritted his teeth and said, 'I am going to learn' so he was probably about five and he did learn".*

Students interviewed also described their bike riding skills and demonstrated they remained less confident in their skills: *"I guess I am a bit wobblier than maybe others. I have been riding for a couple of years and I still don't feel totally comfortable with hand signals and so on".* And: *"My balance is pretty bad."* And another student: *"I wasn't able to ride a push bike until I was thirteen, fourteen. I couldn't work out the coordination to pick it up".*

These reports clearly demonstrate that in some children with DCD motor difficulties continue into emerging adulthood, especially in skills such as handwriting which have been practiced in school for many years. Even skills acquired, such as bike riding, remain less automated and for some avoided. It is interesting to note that one parent reporting their child did not admit to having co-ordination difficulties even though they remained and another avoided trying out new skills in case of failure. Poor outcomes in the past may lead to a spiral of loss of confidence and then avoidance, leading to further lowered competence.

9.2.4.2. Self care and independent skills.

Independent living skills are cited as an area of difficulty in childhood in the DSM-1V (APA, 1994). Parents expressed their continuing concerns of their childrens' lack of independent living skills and gave examples of a general lack of skills across a range of areas such as in *"cooking, washing clothes, shaving, cutting nails etc"*. Another parent stated: *"Finds basic things like peeling vegetables and drying dishes a slow and frustrating process"* and another *"can opening"*. Some of these skills could be considered as 'new' skills only starting to be gained or needed in adolescent years. However, some skills from childhood remained a problem such as: *"coordinating cutlery"*. One parent described the additional time required to complete a task such as: *"making a meal – he would be there all day"*.

One mother described in some detail where she thought her son was having difficulties: *"quite a lot"* of difficulties and then goes on to say: *"anything that involves sequencing, like making a cup of tea or a sandwich"*. She describes how success is achieved in contrast if there are fewer processes: *"He can make a very simple meal, taking something out of the fridge and putting it into the microwave, or toast or a sandwich"*. One parent gave an example of the difficulties their son had: *"Impulsive, lacks stability for daily living skills e.g. difficulty in pouring drink in a controlled way"*. One reason for this was alluded to that the environment needed to be right for the task to be done. Another parent also commented on this: *"needs to concentrate and have peace and quiet to carry out everyday tasks"*. Another described difficulties relating to a lack of self confidence: *"General lack of confidence in [being in] public (shopping, finding way about, filling out forms)"*.

Self care was an issue and descriptions included: "*Neglects his own health, dental care."* One mother of a 19 year old female reported that: *"personal hygiene was still poor*". Another mother stated that a basic grooming task remained difficult: *"combing his hair was difficult"*. Another parent described continuing need for giving a considerable high level of support: *"I've got to remind him still to bathe and look after his teeth and then I ask him if has been to the toilet, because he would go days and days and not tell me and feel quite unwell"*.

Money management issues were cited by several parents: "*Needs constant support particularly with money management"*; "*he cannot manage himself or money and is in major debt"*. And another parent reported *"In debt and seems to cause problems wherever he goes"*.

Self care and independent skills were evidently a persistent and unresolved area reported by some parents. This highlights that some of the signs of childhood clearly do not 'disappear' at this time, despite many years of practice. One parent reported continuing to clean the teeth of her 19 year old son. This could be seen as inappropriate behaviour and a potential co-dependent relationship and may highlight the need to specifically support parents and teenagers at this time, teaching skills of separation.

9.2.4.3. Learning a new skill.

A potential new skill is driving and parents described difficulties their children had learning to drive a car. This has been more fully explored in Chapter 8 from the detailed students' reports. Difficulties were echoed by parents: *"He actually took his test in April prior to his eighteenth birthday, he was seventeen when he took it and this is always what we've drilled into him, it was hard work getting him through this driving test, we never thought he would pass"*. Parents also reported concern over safety for their children on the road once they had passed the test itself and related this to road awareness rather than skill: *"The actual mechanical side of it – no problem at all but his self awareness on the road worried us terribly"*. They also reported that the individuals were less worried about this than the parents: *"It worries me but he's not frightened"*.

This again, as in the previous reports, demonstrates persisting motor skills as well as emerging difficulties when novel skills are presented, especially when there are dual tasks to be undertaken.

9.2.4.4. Organisational skills.

In order to progress to adulthood the individual needs to plan ahead for activities for both work and leisure. Parents were concerned over their children's ability to self organise as were the students themselves. Students with DCD (described in Chapter 6) clearly showed differences from TD students on a wide number of organisational skills, such as 89% reported difficulties packing a bag compared with 46% of the TD students.

Examples of parental concern over self organisation include: *"X cannot organise himself so needs help sorting things out-cannot sort clothing or live independently in any way which makes him very angry at home"* and *"organisational skills remain a challenge"* and another parent described her daughter: *"Organisation is abysmal, can't seem to get things together to sort herself out e.g. dental appointments, finances or workload"*. Another parent said: *"he lets himself down because he is so badly organised"*. Additional symptoms were also associated with poor ability to attend and concentrate, along with poor time management: *"Easily distracted"; "Starts another task before completing first"; "No concept of time, her perception of it is very poor"; "Forgetfulness, lapses in concentration"* and *"General absent mindedness"*.

Students themselves described the implications of poor organisation for themselves on university and college life. This may not be witnessed so easily by parents: *"my organisation was just shocking, my time keeping and I even turned up for my, on the wrong day for an exam at one point"*. And:[I] *"just have stacks of paper everywhere and actually have to find something to look at it. But even more than that is time related organisation when I should be where"*.

Poor organisational skills were not the rule for all young adults with motor difficulties. In contrast, some appeared to have some good organisational skills: *"He travels to school every day on train or bus"*. Another parent reported that her son was *"brilliant"* getting up in the morning but reflected on how she felt this was different from other teenagers: *"In fact I found this most odd because most teenagers you say they want to sleep all day and party all night"*. One parent responded by saying how good her child's organisational skills were *"I don't know whether he is organised in what he does but he does everything himself"*.

Another reported that her child does things *"He tends to do things routinely still"* but this individual may have some obsessional traits also driving this: *"he is very good at everything because he meticulous"*. However, this trait has also given him some advantages in his course in film studies: *"The tutor told us that the other students were giving him their editing to do because he was so good at it"*. It is interesting to note at 11 years his mother had reported him preferring *"sameness and routine"*.

Poor organisation and time management skills have major implications for the emerging adult who needs to be acquiring these skills, otherwise successful transition into college and university will clearly be difficult. It is clear from the questionnaires and interviews that executive functioning difficulties remain for some but not all students with DCD. It is unclear whether those that become well organised are as a result of input by parents or professionals or because they have obsessional traits that might drive a need for order.

9.2.4.5. Social and communication difficulties.

A key area of parental concern was relating to social and communication difficulties. Parents described the areas of difficulty such as describing how their son: "*finds it very difficult to hold family conversations*" and for one girl, despite being 21 years of age, her mother reported difficulties with social skills and described poor pragmatic functioning:

"Social skills with peers poor [and] they do not accept her. [she]Interrupts conversation, uses inappropriate topics at wrong times, over friendly at wrong times[and]-wants to be liked. [She is]Vulnerable at all times, cannot read appropriate behaviour from others". Another parent described their child as having *"A difficulty in reading people and social situations at times".* Another parent similarly described difficulties adequately, recognising social cues from others : *"Not reading signs and therefore walking into dangerous situations, or perhaps not walking away from them as he hasn't picked up the clues"*

One parent considered why he thought their child had not had many friends in childhood: *"he's never really had good friends because the awful thing is people think of him as being weird because he has still got a strange gait when he walks".* One parent described how they had been concerned about social skills when their child was younger but how there had been improvements: *"we were worried that his* *social skills would be very poor and that he would not be able to pick up social prompts such as when to speak, be quiet or interrupt...This could not have been more wrong thankfully. X's social and conversational skills are his best attributes exceeding those of his 'normal' peers. I actually think his experience of being 'behind' has provided him with vast stores of empathy for other people whatever their status or education".* The implications of this could be that for some individuals early difficulties could enable them to 'learn the lessons' as long as the lessons can be translated effectively. It is not clear what other resilience factors were at play here that could have modulated this positive outcome.

Loneliness was a term several parents mentioned and that their children had expressed a want to have more friends. One parent described the social difficulties as *"He really lacks friendship, he has been very lonely since this group from secondary school dropped him, he hasn't got a special friend".* Another parent reflected on the teen years as being *"...lonely. He eventually got a group of friends about third year of secondary and they found his sense of humour good and he was just so delighted to get friends and that lasted about two years, maybe two and a half years and then they dropped him which was difficult. He was made fun of a bit".* One mother described how her son went to a music festival alone: *"I said surely to goodness can't you find someone to go with you and he went on his own. We took him up there and he went on his own and he met loads of people there that he knew but I wasn't happy with him going on his own and he said on the way home, 'I think I'll go with somebody next time'".* This is a good example of 'normal' emerging adult behaviour of a child going off to leisure event without parents being present but not having the peer – peer interaction that would normally occur alongside this activity. Another mother reported that her child had always preferred younger children to socialise with and this even continues despite him being 18 years of age: *"I mean the nearest he's got to a special friend is the son of some friends of ours. He is much younger this boy, he's probably about twelve now but they don't live anywhere near each other, they do spend time together in the holiday and I think that has always been the pattern that X has tended to get on better with those younger than him, several years younger"*. This is evidence of delayed social maturity. This mother also reflected that: *"I think he would love to have more friends"*.

A retrospective analysis of notes from this mother was noted that she had reported at 15 years of age friendships were difficult for him. This reflects the continuing nature of social difficulties and the need to identify these individuals earlier and help to give them the skills they require.

Several parents reported that their child spends leisure time predominantly with their family as a consequence of social differences to peers: "*he probably spends a great deal more time with us and that's the time that his friends' contemporaries will be out with their friends*". One parent describes how her son "*still lacks a social life of his own constructing*". And how this had been a continuing pattern since primary school: *"[he], never arranged any social events for himself"*. She describes how her son remains reliant on her to plan activities and outings despite being 17 years of age: "*he still likes to be taken out frequently. If nothing is planned for at least some* *point of a day when he is at home, he can get very worked up and frustrated"*. Another mother said: *"my husband and I have been a friend for him and its making that step at the beginning of a day to say, 'I think you should do something, what are you going to do? I want to know what you are going to do"*. Another reported how they are very much a part of their child's social life *"we go out an awful lot to the theatre with him and he loves it"*. Several of the parents highlighted that some individuals want to be sociable but lack an infrastructure for this to happen. Parents also linked poor social skills with decision making in choosing educational pathways: *"[she] doesn't feel that she is able to go onto University because she wouldn't be able to cope socially"*.

The picture again was not uniform with some parents reporting that as their children were getting older, social interaction was finally improving. *"Socially she gets on with adults much better than she gets on with kids as she is getting older now and as the children are becoming more accommodating she is finding it easier to get on. She now has a couple of friends that she has literally in the last four months started to see occasionally and she is going away for weekend on a camping theme down to Paignton with them, that's like a major first"*.

A grandparent of one young adult did report how their grandson now had friends and described how he was: *"spend[ing] a day with his friends wandering around Reading [with] just a bunch of nice kids"*. Another parent reported improvement in social interaction : *"he did make an effort to speak to people and he's doing that* *more so"*. One parent reported excellent social skills: *"His social skills are phenomenal, probably the best out of all his peers and probably his sister who is extremely intelligent, probably better than hers"*.

One parent commented how her son's good social skills were used to mask his other difficulties: *"I know there are things he can't do but he covers them up, that's the main skill he has learnt is just to compensate by doing other things, is not to do them"*.

Opportunities for social interaction with peers are a crucial part of becoming a successful adult. Parent reporting mirrored some of the difficulties students themselves had reported, although the level reported by students was lower at only 18%. This may demonstrate a lack of insight that some of the parents described. As discussed in Chapter 6, social skills may also have been difficult but other concerns such as organisational and motor difficulties were more prominent for the students and causing greater concern. Parents may be more concerned for their children if they see them with few friends and little social life and still relying on them for leisure pursuits.

9.2.4.6. Emotional and psychological issues.

Several parents described how their children had been bullied at school and the implications for this: *"probably more physical than verbal"* and *"bullying and just not coping with school really"* and *"He was made fun of a bit. They saw him as different and he didn't have the same skills as the ones he was mixing with had"*.

Several parents also mentioned low confidence levels: *"Lacks confidence in his* *abilities and will not try new methods in case he fails"*. This was mirrored by another parent, who said her child often says; *"I'm just useless, I'm not very good, I'm not very bright"*.

Associated emotional and psychological issues were also described by several parents including comments such as: *"He is often depressed and withdrawn"* and *"OCD means he spends a lot of time checking/rechecking switches, doors, taps etc"*. Another reported that her 17year old son: *"Panics if a situation is not structured"*. Another described increased anxiety levels and how this affects her son: *"When he is under stress everything goes to pot. He can't concentrate; he can't remember what you have asked him to do five minutes ago"*. Another talked about the daughter as being: *"almost agoraphobic and obsessive"*. Another parent of a 17 year old talked about her son's moods: *"can still quickly change if things don't go the way he is expecting"*. One parent also talked about the emotional issues as emerging later: *"Moods, he does suffer from depression"*. His parent described how her son sees many situations as negative even when they are really positive for him: *"Every time he gets a compliment he puts himself down and he going through this counselling process at the moment, CBT"*. Another parent described how her daughter: *"has spates of the paranoia where she thinks that people are looking at her all the time and very often they are not, but as a consequence she will hold herself in such a way that she makes herself look like a victim and then people do look at her*" and another said he: *"is very depressed at the minute, on anti-depressants"*.

One parent described how her child was potentially vulnerable: [he] *"is led astray by others. [he] is used/taken for a ride by others/very gullible. [he] shows no remorse for actions. Is emotionally distant"*. Several other parents also discussed the emotional immaturity of their children: *"he's still very, very naïve at nineteen"*, and another commented that their child *"very immature, child like, goes from relationship to relationship"*. Another stated: *"he is almost eighteen; he really doesn't seem like an eighteen year old in many, many ways"*.

Other parents reflected that their children were not always insightful about their level of difficulties: *"He says 'I know where everything is', I say 'No you don't know where everything is which is why we have to look for your glasses at least once a week'. His books are a mess and he says 'its okay I know where everything is,' but when the teacher said he can't work like that I said, 'right, okay, come on', so we sat down for the weekend and he got it all sorted out"*. And another:*"now he has left school he denies being dyspraxic. He says he has grown out of it and doesn't want to be identified as different or lacking in any way and doesn't want to be identified as different or lacking in any way"*. A further parent: *"Although M has made huge progress and swam in the welsh disability team he still has huge difficulties and feels much happier surrounded by people with disabilities"* and another: *"...now he has left school he denies being dyspraxic"*.

Some parents described a lack of insight despite having persistent difficulties especially in the social domain: *"Cannot understand how he remains so confident when knocked back so much"*.

An additional concern described spontaneously by a number of parents was how their children got very tired and they described this: *"When tired [he] cannot function. It is as if all systems start closing down"* and: *"He's very tired, that was always a thing with him"*.One student was able to describe what it felt like being tired:*"For no apparent reason [I] cannot focus for very long, especially on bright screens, like TV or computer screens. Sometimes this is better but I then become exhausted for long time after and require sleep or cannot think straight"*.

Parents have described a number of different mental health difficulties including anxiety, depression, paranoia and obsessional and compulsive behaviours reflecting, as with ADHD, that DCD does not come alone and the need for longitudinal follow up and early identification and support is essential for these individuals. Some parents also reported a lack of insight in their children. This could also be denial rather than lack of awareness and this aspect would need to be sensitively teased apart in further work.

9.3. Reflections of school days by parents and students.

This final part of the chapter outlines the changing nature of motor difficulties as seen by parents and students from questionnaire and interview data. In order to see the child as an emerging adult it is useful to consider what helped them as children and the type of support they gained. Additional insight can be gained by listening to the reflections from parents about what they considered would have helped towards a successful outcome if they were able now to replay their child's time once again.

9.3.1.Key memories of difficulties in childhood.

Parents and students were asked to describe what they remembered were their first memories of difficulties for them and their children. This was an unprompted open question. These memories, as can be seen, do not purely relate to motor difficulties. Some parents noted that their child had difficulties from a young age: "*when he was in playgroup and they all did painting one day and you are talking three, four year olds and the paint was everywhere and they used an old clothes dryer with all their paintings on just to drip dry, they splashed the paint everywhere and water and all sorts but he came out with a big piece of paper with tiny little mark of paint in one corner*". Further parents described fine motor and hand – eye difficulties: "*when he was about six, he would paint himself with yoghurt, he couldn't get it into his mouth or he would manipulate the spoon and it was a particular problem*". Some parents described language difficulties: "*his speech did not mature normally*". Another parent described similar difficulties: "*He did not begin to talk until quite late*" along with motor difficulties "*He seemed to learn nothing by copying. Handwriting caused him particular problems, as did anything involving his fine and gross motor skills*". Another described memories of fine motor difficulties along with sensory issues:"*his fine motor skills, he couldn't pick things up and he was very sensitive about what sort of clothes he would wear*". Another parent described specific difficulties: "*In sporting activities and walking*" and described his gait as "*walking down the street* *beside me he was all over the place one side and then the other".* A parent described early social difficulties and memory difficulties: *"not being able to make friends very easily and.... Reading, writing, he could memorise anything for a very short time but would not remember it a week or two later".*

Students were also able to recall some early memories and one described how his mother had always known there had been a problem: *"I think my mum has always had the kind of idea that something was not quite right. She had me tested for everything, she had all kinds of people, she just kind of nagged the school to get this and that kind of talked to me".* Another student described memories of visits to different professionals and the impact these had: *"My mother knew that there was something wrong, not wrong, not quite right and I remember she took me, this was when I was in Primary School to the Doctor and I had to have a chat with the Speech and Language Therapist, and said 'there is nothing wrong with him, he's just slow' and I remember that".*

Some students also remembered their experiences in school, not being able to participate as well as others in sports, and the feelings this engendered :*[I was] "no good at PE" and "tennis was a bit of a problem".* The feelings of a waste of time: *"it just seemed to be an hour of just pointlessness",* and how it made them feel: *"I hated it, I was always one of the last to be picked"* and: *"I had a long running battle with my PE Teachers, because I actively refused to kick the ball and such and they got quite irritated with me".* Another recalled school days being isolated: *"Socially (at school) I tended to be isolated, but this was partly me trying to isolate myself* *from those who were not understanding. I ate my lunch inside classrooms, spent breaks in the library etc. anything I could to keep away from people. Throughout my entire secondary school experience I had about four friends, and they were all outcasts of one form or another, thus my group of friends were quite understanding and ignored my 'quirkiness'"*. This student also reflects the importance of gaining support from others: " *I think finding people who can empathise is very important and is possibly the only reason I survived school at all"*.

9.3.2. Making sense of the difficulties.

Some of the students described attributions for their difficulties in greater detail: "*So this whole learning difficulty and my leg and my balance is all linked, its either pre or post birth term trauma caused this birth defect or if you want to call it that and it also caused my right hemispheres not to be as developed as my left or whatever way it is, causing this severe disparity between my verbal and non verbal reasoning"*. Another student described: "*I have problems with my short term memory"* and a third: "*I always thought I had a lack of practical sense like I find things like cooking and cleaning and especially learning to drive really hard and my balance is not the best"*.

Disclosure of difficulties with or without a diagnosis may be potentially difficult. Unless the individual has a clear idea of their own strengths and difficulties it may be difficult for them to clearly conceptualise and voice to others their potential needs.

9.3.3. Resolution.

Parents positively reported some areas of improvement and these related not only to improved co-ordination and this has been reported in other chapters. Some descriptions of motor improvements included: "*co-ordination has come on a lot*". This was also associated with improved well being "*His self esteem is getting better*". This parent also reflected that improvement was a slow process "*it has taken a long, long time*". Another parent stated her son: "*has become far more adaptable as he has got older, and routines no longer need to be strictly adhered to*".

Reasons for improvement were attributed to consistent support gained at an early stage: "*Q has been very fortunate. He was diagnosed very early and has received superb support and advice all the way through*". Another parent said it was their own approach: " *it was the fact that we cared enough to organise something*". Another parent described specific individuals that had made a difference not only to their child but to the whole family:[the]"*Special Needs Co-ordinator and she was absolutely brilliant with him and he inspired her and there were just two teachers in the whole of that school really who understood where he was coming from.... the difference it meant not just to him but they made to the whole family because it is the impact on the family*". The parent described what he thought was the specific reason for success: "*they started off from where he was, where his interests were and worked at his pace and were totally on his side*". Another parent described help on a one to one basis as a reason for improvement along with learning typing: "*His* *school was fantastic. Had dedicated learning support unit providing one to one support in learning to touch type. Gave very good pastoral care ".* One parent attributed improvement to intervention from a behavioural optometrist: "*She was superb and she said that your eyes are better now but if you come under stress or what have you, you might need glasses again ".* Another parent described how her son had learnt a sport and gained success in it and this was an essential factor raising his self esteem: "*the two main things that have helped - it was suggested that he did something like judo or karate, so he has been doing karate since he was about seven or eight, he is now a black belt as his sister and that has helped tremendously I think with the balance and the control".* Similarly another parent focused on being able to partake in a physical activity: "*Swimming has greatly helped".* Another parent described their family strategy for coping with the difficulties and how they had sought out their son's strengths. It demonstrated the level of input they had put in, both time and effort to help their child: "*my husband and I split things into two. We tried to think about where X's strengths were despite his difficulties... I actually stopped working because I was in research myself, I was at Southampton at the time I used the medical library at Southampton to read and find out as much as I could".* She goes onto describe how she worked with her son and practiced a range of motor skills: "*I spent a lot of time at home doing exercises with him to try and build up his body awareness. I took him horse riding to help him get a sense of left and right. The exercises that I did at home helped him learn to catch a ball, and it took a long time to get him to rotate the skipping rope, he had trouble with that as well".* Another parent described how they had become involved in the school processes in order to help their child: *"Senior School was a great help. They had a very good Learning Resource Teacher at school that was also very good.... School was phenomenal, but again we've put a lot of input into School. My husband was the Governor there the whole time".*

A key theme here was focusing on the needs of the individual child and either seeking out strengths or finding ways of adapting or avoiding the difficulties. Some parents reported spending extensive amounts of time working with their child in order to see gains in their child's skills and also time spent liaising with other professionals.

9.3.4. Approaches and interventions tried.

Parents described trying a variety of ways to help their child, using both traditional and non-traditional approaches. Many parents reported paying for additional treatments. They also outlined the potential costs both financially and in time. One parent tried 'body brushing': *"I was driving him up to Rochdale once every six weeks, it cost a fortune. Was it a waste of money? No we don't think it was. Psychologically I think it actually did him a lot of good".* Another had tried a clinic that has now closed down and has a lack of sound research evidence for their intervention: *"been to DDAT as well for the balancing and co-ordination thing, we've done all kinds of things".* Another parent described how they had gained support for literacy difficulties by attending a parent support organisation: *"I paid BDA for help in English for four years as a substitute for school support and withdrawal from lessons".* Another parent had arranged for: *"Private sessions for 6* *weeks with occupational therapist for handwriting"*. One parent had: *"contacted someone from the British Dyslexia Association, got a private tutor for five years. Went up to the Institute of Optometry and used the colour over lays and the tutor really worked his handwriting as well as spelling"*. One parent stated that once their child had a Statement of Educational Need in place *"his primary school were very supportive and his teaching assistant was really committed to helping him develop his learning skills"*.

The parents reporting these different approaches may not be truly representative of a main stream population as they originated from parents who had attended the Dyscovery Centre, some of whom may have paid to come to the Centre for assessment and others who would have been funded from their health authority. It could have been that some of the parents may have been more likely to try out different types of intervention. However, a survey of parents from a wider grouping could clarify this and would be an interesting area of further work. Some, but not all, may have had greater financial means to 'shop' around for solutions for their child's difficulties.

9.3.4.1. The type of support that had been offered while their child was in school.

Parents were asked what specific help had been given in school to support their child. This widely varied and it was difficult to extract common themes. The help described was in terms of people support, additional time, and resources. Few parents discussed any specific intervention to assist with motor difficulties in the school setting. One parent described help given as a: "*Statement of SEN - X had support in class while at school, particularly with writing*". One parent highlighted the potential need for asylum: "*Help from head of year in comprehensive in giving safe place*". Another parent reported her child was only: "*Statemented in school from 2002*" and had been given "*use of laptop computer, learning support assistant in all lessons in school*". One parent said help had been limited and inconsistent and had been from: "*Only his teaching assistant at school and this has changed every year*". A number of parents described exam allowances and being given a laptop in class: "*The use of a laptop for his education and to sit his GCSEs*". A number of parents described additional time given in exams: "*B has benefitted from allowances in exams for his dyspraxia*". Specialist help seemed dependent on local provision and no pattern was seen. In one case: "*One to one support with Maths GCSE was a success*" and in another: "*X has spent time in the Asperger's unit of the local high school*" and in another: "*He has had a support teacher every other day for 90 minutes in a group of ten*".

No parents described any 'motor programmes' being used by their children in school. Some of these programmes being used today may not have been present when their children were in primary school where they are mainly used.

9.3.5. The key difficulties and barriers necessary to overcome in school.

A number of parents reported a lack of support and understanding and these were the key themes described and the need to fight for help for their child. One parent described this: *"the help he's had has been very, very poor"*. Another stated: *"'X' is bright and has always worked so hard and it seemed wrong that he shouldn't succeed because of inadequate support at school"*.

One parent described receiving empty promises: *"He was promised all sorts of help at school and when I went up about it they were saying, 'Well there are children much worse than him' but what I couldn't make them understand was with this little bit of help that 'A' could have had, he could have achieved his potential"*. Another parent described this also: *"He was offered help in the first year in the class but did not want it. The help he was offered at the interview was not forthcoming when he started the course"*. The impact for parents feeling their child did not get help was conveyed in terms of a sense of loss: *"X never educationally got what he needed"*. Several parents described how they had to *"fight"* and would recommend to others to do the same: *"I followed my instincts I've came to the conclusion that your instincts are quite good really and I've just fought for him with education. I've been very constructive in the discussions that I've had with teachers but walked away and collapsed into a pool of tears. I think I have done all the right things and I've tapped into the right people and I've always sought sound therapy"*. One parent commented that: *"it's always taught me that if you can't do one thing you can excel* *at something else. And really fight for them and getting lots of help and grabbing all the help that's on offer".* One parent described this and some continuing potential ignorance around the area of motor difficulties in education as: *"I had battles for years with the school and the authority. I was told by his Year six teacher when he was eleven that they had never had dyslexia in that school at all or dyspraxia and that was the biggest primary school in the whole of [the county]".*

Another parent described the difficulties trying to gain support from both health and educational professionals and that transition through to secondary school saw decreasing levels of support being given: *"Junior School were very supportive, things have not been quite so successful in Secondary School and I think in his Infant School his problems were not truly recognized" and "there has been very little help or support locally. The clinical psychologist at the hospital shrugged his shoulders and said that there was no treatment available, and X was not offered a place in occupational/physiotherapy sessions that were being held with children of a similar age because the therapist said his concentration skills weren't good enough".* It was important to try and capture the thoughts and feelings of parents about what had happened to their children and what they might have done differently if they could 'turn back time'. The need for parents to seek out their own solutions for their child was described. One parent reported that: *"everything we've done has been pretty much guesswork. Even when he was much younger I was told there was no therapy available for him".* A further parent described the emotional costs of lack of help and current frustrations: *"It is very distressing to find that there is no funding to help people of D's age. He desperately needs strategies to help him* *live his daily life"*. A parent gave one reason why their son may not be recognized as having learning needs and so did not gain specific help: *"main problem along the years have been that he looks 'normal' and therefore people do not know that there is a problem"*.

Some parents wished for a 'cure' for their children: *"There seems to be a cure, or help for most things these days I find it hard to believe that there is nothing for my children"* and: *"If someone could find a cure or something that could help children/young adults like this it would be wonderful"*.

Parents were asked what they thought was their recipe for success that they could tell other parents if they could. Ideas included the relationship with the teacher and the child, parent-teacher co-operation and listening to the voice of the child: *"the relationship with the teacher that dictates his success"* and: *"work with the school as far as you can, tap in to anybody in the school who is willing to listen to you and to work with you. Always be constructive and just keep the channels of communication open"* and *"Basically you know your own child and you know if there is something that isn't right within them and regardless how many times you are told you are over anxious keep at it until you can sort out because you do know there is something that is not right"*.

One student also reflected what he would have done differently: *"I would still avoid art and PE but what I would do is try and get some more/have support because it just seems to me that if you are disruptive, like when I was working in the schools,* *the disruptive ones would get diagnosed, but if they are like me and just get on with their work they don't seem to get a diagnosis and even like in the 6th form, if you have got the 5 A-C and you are assumed to be normal".*

Having a child with motor difficulties does not affect just the parent and the child themselves but other family members as well. DCD is not just an educational difficulty but affects the child at home as well. A specific question was also asked where there were siblings in the house, about the relationship between the individual and the sibling and how the difficulties had affected the whole family

9.3.6. Impact on the whole family.

Parents talked about how having a child with motor difficulties had an effect on more than just the parents but on siblings as well: *"his sister has had a bit of a rough ride with him. He just takes his aggression out on her. ... verbally. He has raised his hand to me a couple of times but he hasn't carried it through because I have stopped him with, 'I wouldn't if I were you, you know what will happen' and then he breaks down and he says, 'You are my best friends'."*Another parent described how the siblings had supported their brother or sister: "*When she was small she used to give wrong answers and then wait for 'X' to come up with the right answer*". Several parents compared the differences between the child with motor co-ordination difficulties and the other siblings without difficulties: "*She is very confident and* *obviously can make her own decisions".* Another compared the sister of their son as: *"She's a lot more independent. She has got loads of friends, she is popular".*

The students interviewed spontaneously reported feeling different from their family because of their co-ordination difficulties: *"In a way I felt like the odd one out"* and: *"I wasn't as good as my siblings"* Another student described: *"I had been very different to my family like they are much more science and maths orientated, like my dad is a doctor, my parents met in medical school. My grandparents are in the science and maths field and my sister is at University doing physio now. So I've always felt in a way like the black sheep but at the same time I have had people to fall back on and I've had a secure home and stuff".*

A few students related being different to their lack of sporting skills especially in the context of their families: *"I come from a sporty family"* and: *"Two of my siblings rock climb, they win the national finals and my sister did gymnastics, the other boys play cricket and my dad is really quite sporty and my mum runs".*

9.4. Discussion.

The parental perspective is an important one in considering the process of emerging adulthood in DCD. Listening to the voices of parents can be seen to give an additional dimension which may be missed if histories are only taken from the individuals' themselves. There is a challenge for further and higher education how to gather this additional information in order to be realistic about the support needs of students with DCD. As students arrive at university and college, especially if they are over eighteen years of age, there is an assumption of competence and the ability to appropriately seek help. It is clear from the interviews and questionnaires that there are a number of students where parents need to be actively involved in supporting their children. Allowing parents to be involved at this stage has to be carefully managed with respect to the young person.

Parents still reported needing to give a high level of support and described continuing to support their children in their everyday living skills. One parent reported: *"I need to prompt him with teeth cleaning, I still clean his teeth once a day if he will let me"*, and another described how he had the skills to do tasks around the house, such as hovering but: *"he doesn't do anything without being told"* and another: *"He desperately needs strategies to help him live his daily life"*. Another parent described how her teenager was capable of undertaking everyday tasks: *"he will feed himself"*. The parent also described that feeding meant a ready made meal: *"but he would never cook a meal as such, it would be something out of the freezer"* but implied this was not due to a lack of skills but rather being unwilling to do so: *"and yes he can do it, by all means he can do it"*. Another parent described some of the practical ways of supporting their child: *"needs our support with form filling etc."* One parent reported how difficulties had led to fears: *"Poor assessment of direction and speed of traffic. Fearful of crossing road and taking public transport"*.

There was also an additional continuing need to support their children emotionally and this accentuated fears for their child's future: *"Worry as to whether he will be able to lead a fully independent life-still very dependent on us"* and *"Always wants reassurance and goes almost everywhere with me"* and *"I have many concerns about Z's future. Will he ever be able to lead a fully independent life? He is still very dependent on us - far more so than his sister who is two years younger"*.

The need to still parent was evident: *"making decisions for himself almost non-existent"* ; *"Although he is very motivated with his schoolwork he has very little initiative and needs constant prompting"* and: *"Lack of initiative, can't occupy himself for very long, no social life outside home"* and *"easily manipulated by other people"*.

In order for children to emerge as an adult, as described in Chapter 2, there is a need for parental separation. Parents described the dilemma of wanting to let go but still needing to support their child. Examples of this were: *"I suppose it's difficult now for me to actually let go and let him try on his own which is what he is going to have to do now"*. And: *"he has been very dependent on myself and so obviously that stops the maturing process"* And: *"I've done a bit too much in the past and he said to me, 'You worry too much', which is probably very true"*.

One parent described the tensions of still needing to be a part of their child's life but this being harder to do once they moved through secondary school and beyond because it was assumed the child was old enough to mediate for themselves: *"Once* *he got to College that wasn't successful because they said he was sixteen and the parent was not allowed to speak up".* Another parent implied how the role weighed upon them: *"Burden of parenting a child with additional learning needs".* Another parent reported high levels of continuing concern: *"We, as parents, spend our lives constantly worrying about our son who is on our mind last thing at night, first thing in the morning and throughout our waking hours".*

The parent may have had a long term role as a carer and may find it hard to give up their role and see their child 'leave the nest'. They may be more wary of allowing their child to undertake normal risk taking and experimenting behaviours usually seen at a younger age. There is a need to work with parents in order to help the child have skills to become independent and so give the parent confidence to allow this to happen.

CHAPTER 10: CONCLUSIONS AND DISCUSSION

10.1. Introduction.

In my introduction I set out the questions and areas I hoped to address in order to understand the lives of individuals with motor difficulties at the stage of emerging adulthood, with particular respect to those in further and higher education.

One reason I focussed particularly on students in further and higher education was because there had been some discussion previously by some researchers whether poor outcomes were related to lower IQ in individuals with DCD (Losse *et al.*, 1991; Cantell, Smyth & Ahonen, 2003). For this reason I wanted to consider those in university or FE, especially those one would expect to be of at least average or higher cognitive ability, to examine their outcomes as I suspected that this would be a more resilient group.

A second reason for the focus of the research was because there had been little work examining the specific age group of 16-25 year olds in DCD. This period of time was named by Arnett (1994) as a time of emerging adulthood and is a crucial time for developing peer – peer interactions as well as slowly reducing the dependency on parents, before finally reaching the stage of adulthood.

Thirdly, there was a pragmatic rationale as increasing numbers of students are arriving at further and higher education presenting with a diagnosis of DCD or

Dyspraxia but there is little knowledge of their needs by those supposed to be supporting them.

Finally, on a personal and more selfish note, I had a son in this age group at university with DCD and so there were reasons for me to gain an understanding of others' experiences from both parent and student perspectives that would aid my son's progress through this stage in his life.

Since completing this work there has been increasing interest in learning more about this group and I have organised a conference with those working in FE and HE around assessment and support both in ADHD and DCD. This again reflects the growing need to understand this group of students and the specific focus of work at this time.

To recap the main questions as outlined in the introduction:

1. Are there differences between students in further and higher education with motor difficulties to students without reported or recognised learning difficulties in terms of their experiences and behaviours? How can these be distinguished?
    - **a.** How do students report their strengths and difficulties?
2. What are the social characteristics and behaviours of the motor difficulties group compared to the TD group including specifically:

- **a.** Leisure and hobbies.
- **b.** Smoking, alcohol consumption and drug usage.
- **c.** Driving behaviours.

3. How does the reported support given in further and higher education differ between those with motor difficulties given a diagnosis of DCD/Dyspraxia and other students with other diagnoses such as Dyslexia?
4. What are the lived experiences of emerging adults with motor difficulties as seen from the individual *and* parental perspectives?

These questions led me to use a mixed method approach, using both quantitative (using questionnaires) and qualitative approaches (using questionnaires, interviews, and case notes) to give both depth and variety/breadth to the understanding of the lives of emerging adults with motor difficulties.

Information was gathered on the DCD group through staged online questionnaires and also a subset of student interviewed. One of the groups of students came through disability officers in universities and colleges and a second group was selected from a clinical cohort that had been assessed in childhood. This allowed for a useful comparison as the former group would be typical of those seen in FE and HE and it was important to consider how these groups were similar or different. Parents came from the clinical cohort of students with DCD and subsets of these parents were also interviewed. The parents provided a valuable insight at the present time but also case notes were available to also reflect upon changes over time. The TD group came from FE and HE through placement of posters and direct recruitment.

Another group arose unexpectedly during the study. This was a group of students who thought they were poorly coordinated but had received a diagnosis of Dyslexia and not DCD. Where it was possible, they were compared to the DCD group as this gave an added advantage in being able to compare levels of support when differing diagnoses were given.

Four key questions were asked:

The first question explored whether, on their history of reported difficulties and support in childhood, the DCD group and TD group were distinguishable from one another. Following on from this, how, on a day to day level of current functioning, did students with movement difficulties differ from the TD group? The latter part of this question explored the reported strengths and difficulties of the DCD group.

The second question examined in greater detail the day to day social behaviours. It is useful when characterizing a group of individuals that their social behaviour is sought, as these represent potential markers to decide which stage towards adulthood they have reached. The behaviours examined included their smoking, alcohol, drug usage, and leisure choices. Driving skills were also compared between TD and DCD groups. This was especially relevant as there has been extensive evidence for overlap with ADHD and DCD (e.g. Rasmussen & Gillberg , 2001). Additionally, research on driving and other social behaviours in the ADHD literature was available which allowed some useful comparisons to take place.

The third question considered the current support being given to students with a diagnosis of DCD. A comparison was possible also with students with movement difficulties but with a diagnosis of Dyslexia. This was useful, in view of increasing numbers of students coming into FE and HE with a diagnosis of DCD requiring support but also because of meeting the requirements of SENDA (2001).

The final question compared and contrasted information gathered from both parents and their children with DCD. This was an important approach to take as some studies in the field of developmental disorders, specifically in the field of ADHD, have shown that a more complete picture is gained from multiple informants but at different ages there may be either over or under reporting of symptoms and signs. In one study, for example in ADHD, adolescents under reported their symptoms compared to parent reports (Cantwell *et al.*,1997) but in a college study of students in the same age band as this particular study there were higher reported symptoms from the students than their parents (Glutting ,Youngstrom & Watkins, 2005).

The rationale of having another informant (the parent in most cases) I believe strengthened the validity of the study and was an important factor in gaining a more complete picture of the lives of emerging adults with DCD and to compare and contrast the differing views. This was also a unique approach, as this had not been undertaken for this age group before in the field of DCD research.

This final chapter draws together the conclusions from each of the results chapters and reflects on these with regard to both current and past thinking of emerging adulthood. In order to conclude and discuss the results and consequences for each question, they are each outlined.

10.2. The differences between students in FE and HE with motor difficulties compared with TD students.

Differences were found between the DCD and TD students on a number of variables. There were intragroup as well as intergroup differences. Comparisons were made, where possible, between the DCD and TD groups on the variables and additionally with the 'dyslexia' group with motor difficulties. The evolving picture, led the research to explore some areas in greater depth.

10.2.1. Past childhood difficulties- comparison of DCD, Dyslexia and TD groups.

The DCD group represented both young people with DCD and those with DCD and other developmental disorders. DCD commonly overlaps so the rationale for placing them in one group was that this would be representative of students arriving at FE and HE. Some students would be known to have difficulties with a specific label given and others may have a wrong or different diagnosis.

There were significant differences between the TD and DCD group on their reported functioning in childhood, including skills such as self care, writing, bumping into objects and people, difficulties with team games, learning to ride a bike, and play a musical instrument. There were also significant differences between the DCD and Dyslexia group. The Dyslexia group appeared to form an intermediary group on these responses but still distinguished themselves from the TD group. This highlights that, while cut offs on standardised tests are given in order to define the disorders, there may be significant difficulties in other areas apart from the area leading to the primary diagnosis. For example, the student with a diagnosis of Dyslexia may present with reading and spelling difficulties that are impairing. However, they may not have had the motor aspect examined as the difficulties they have been acknowledged and diagnosed. The professional door the individual enters will also determine the likelihood of being given a particular diagnosis.

10.2.1.1. Current functioning.

There were distinct differences between the TD and DCD groups on current functioning on the majority of questions asked. The difficulties could be divided into those mainly related to motor tasks followed by those that had a planning and organisational element. The latter included questions relating to: organising things in your room, finding way around new buildings, packing a suitcase, folding clothes, dual tasking, and planning ahead. Motor difficulties remain a distinguishing feature between the groups, in particular self care tasks, writing and playing team sports, reflecting both persistent difficulties in both fine and gross motor aspects of functioning. The combination of motor and planning difficulties means that the difficulties remain pervasive and affecting the students in all areas of their lives both in school and at college/university. On average, 51% of the students with DCD reported some difficulties on all questions, showing the persistent nature of DCD in daily functioning. This is an important finding in light of the approaches currently taken to intervene in childhood. Historically, the approach to intervention was correcting the deficits but this has so far not be shown to be an effective approach (Mandich *et al.*, 2001) and the more recent approaches have been to consider a dynamic systems model and learning is seen as a "multistage process of interaction between the individual, the environment, and the task" (p229) (Mandich & Politajko, 2004). One approach developed from Canada (Politajko & Mandich, 2004) is the Cognitive Orientation to daily Occupational Performance (CO-OP). This is set in an ICF framework (WHO, 2001) and encourages problem solving skills through a process of guided discovery. Task analysis is undertaken. In view of these findings, it may be necessary to delineate where these difficulties are breaking down in terms different aspects of executive functioning in order to provide focussed intervention. As can be seen in Chapter 6, many individuals with DCD had great difficulties with tasks needing to be done under time pressure. A different sort of organisational task was also described linked to prioritisation and organisation, and not relating to time.

such as packing a case, organising a bag, completing jobs given to you. While around 50% of students with DCD had difficulties with both these aspects, not all students had difficulties in both areas. Differentiating where the learning is breaking down may be as important as recognising the child has a difficulty, as this seems to be one of the areas that persists into adulthood.

10.2.2. Reported strengths and difficulties.

Recognising strengths as well as difficulties has gained increased focus in recent years. Seligman (2004) in the introduction of the edited book on "Character Strengths and Virtues", describes strengths as the:

> "bedrock of the human condition and that strength-congruent activity represents an important route to the psychological good life"
> p4.

For this reason, strengths as well as difficulties were compared between the DCD and Dyslexia groups. The rationale for this was that much of the focus of research in DCD has only been related to deficits rather than seeking out strengths. Some literature has focussed on the particular strength of creativity in the field of Dyslexia, for example, Wolff & Lundberg (2002). The DfES website also states that "dyslexic learners may possess, or have developed, more positive talents such as: creativity, thinking laterally and making unexpected connections, being able to see the 'big picture', good visual spatial skills and being able to think easily in 3D, problem-solving skills, good verbal skills, good social skills" (DfES,). Other themes were chosen apart from motor skills were executive functioning skills, as DCD commonly co-occurs with ADHD (Kaplan *et al.*, 1998) and this has been described in this field of literature; social and communication skills, as this has been highlighted as a problem for children with DCD (Skinner & Piek, 2001; Dewey *et al.*, 2002).

Both the DCD and Dyslexia groups reported continuing motor weaknesses (50% and 45% respectively). However, there was one difference in executive functioning (EF) skills, where 50% of students with DCD reported this as a weakness compared with only 23% of those with a diagnosis of Dyslexia. In a comparison of reported strengths, the converse was seen with 38% reporting EF as strength, with only 21% of the DCD group doing so.

An interesting and surprising finding was that 51% of the DCD group reported social skills as a strength compared to 38% of the Dyslexia group as difficulties with social interaction had been described in Chapter 1 in the literature from children with DCD.

This is consistent with parent reporting where 50% of parents reported social skills difficulties. As seen in Chapter 9 (Figure 9A,p 294), when these parents are paired to their offspring and are compared only 38% of the corresponding children reported some social skills as a weakness. There could be four possible explanations for this.

Firstly, the level of insight the individual has; secondly, a parent may be the one picking up the pieces; and thirdly, the student does not want to report these difficulties, or finally, it could be that other problems could be seen as a greater difficulty at the time of reporting.

Many researchers have also examined self esteem in children with DCD (Cantell, Smyth, & Ahonen,1994; Cantell,Smyth and Ahonen, 2003;Piek *et al.*,2000; Skinner and Piek, 2001) . Children with DCD have been described as having significant differences in perceived competence in the athletic domain between them and control children without motor difficulties. However, this has not shown an effect on global self worth in childhood. It is not clear whether this has a longer term impact or again may remain domain specific. From this research we can see that avoidance of team sports was reported by 73% of the DCD group so it is likely that early difficulties continue to have an effect on sporting choices long term.

One determinant whether there is a long term impact of domain specific low self worth may be associated with external factors, such as the feedback that others give you in childhood and adolescence. If a positive approach is taken, seeking out strengths for example, then the individual may persist in trying out different sports for example rather than moving towards avoidance strategies. In Chapter 9, one parent describes her son's success in a martial art but this was directed by the parent to seek out a sport where he was likely to succeed.

The ability to recognise one's own strengths may also be related to the level of self awareness and self perception of that individual. The DCD group studied in this thesis may be different from other clinical cohorts, as they were successful in reaching further and higher education. For some students their social skills and intellectual capacity may act as a resilience factor and increase their ability to survive effectively, despite having other potential difficulties (Masten, 2004). However, the adult's perception of their self may not be a reality in all cases and the individual may have a 'false' sense of self. Two potential reasons for this could be that individuals either have had excellent parental support for example, and so their sense of self has been boosted and maintained (potentially unrealistically) or the individual may have a poor 'theory of mind' (Baron-Cohen, 2002). Both may have a truth, as AS has been associated with motor difficulties (Sahlander *et al.*, 2008) and, as described in Chapter 9, there is evidence that some parents continue to provide high levels of support to their offspring.

Two factors that previous researchers have associated with poor outcome were the degree of severity of motor symptoms (Cousins & Smyth, 2003) and the presence of other developmental disorders (Rasmussen & Gillberg, 2000). Poorer educational outcome has also been linked with IQ (Losse *et al.*, 1991). Certainly the group studied were not all 'pure' DCD, with 53 out of the 91 students with DCD having another diagnosis apart from DCD. In the field of research into emerging adulthood, differing models have been described to consider factors affecting a successful outcome, leading to independent adulthood. Self determination theory (Deci &

Ryan, 1985), Berzonsky and Kuk's identity theory (Berzonsky & Kuk, 2000) and the Selection, Optimization and Compensation Model (SOC) (Baltes *et al.*, 1999) are three examples of these.

The first model has three potential loci for outcomes. Firstly, that actions are based on the own personal standards and goals and, if this is the case, the individual develops high self esteem and self awareness. Secondly, the individual is controlled by external factors and behaves how he or she thinks he 'should' behave. Lastly, the individual has little influence over their own actions and have an 'external locus of control' (Rotter, 1966), being used to having decisions made by others rather than controlling actions and decisions themselves. If this model operates for the individual with DCD, if they have self awareness of their difficulties then this may have an effect on self esteem. Berzonsky and Kuk's 'Identity Theory' is a transactional model, in that, as experiences occur, individuals form their own personal constructs that then influences their behaviours. Their 'reality' may also be influenced by past events. This is interesting in the context of emerging adulthood in DCD. For example, where individuals grow up with a diagnosis of DCD, they may develop a view that they are disabled and need 'mending'. In addition, childhood events such as experiences of social isolation and bullying may have also altered their view of themselves. This may be also reinforced by the fact that some children may receive treatment for many years and see a range of different professionals. Sixty two percent of the students with DCD in this study had received help or therapy in childhood compared with only 32% of students with Dyslexia.

In contrast to this model, is Baltes *et al.'s* (1999) SOC model. A successful individual will select and optimise their strengths and learn to compensate for weaknesses. The fundamental basis of this model is the selection of appropriate goals where the individual is functional, in order to focus resources appropriately, and to compensates for difficulties provides an ideal model for development. In the context of DCD, the individual may have poor goal setting choices with the individual continuing to practise and maintain their weaknesses in order to try and reach perceived goals that have been set in childhood by others and not be able to narrow their energies into the areas where their strengths might lie and use compensatory approaches to 'get around' the weaknesses. By teaching children how to goal set when they are young, as has been described by Missiuna *et al.*, (2006) who have devised a goal setting system for children, and using similar approaches for adolescents and adults, this may result in individuals with DCD learning to prioritise and compensate and also choose appropriate goals. However how one learns to optimize skills may be dependent on the specific goals being set.

When each of these models are considered in the context of DCD and the results seen in this study, it is clear that outcomes for individuals must be related not only to internal systems but also to a variety of external factors. The resultant outcome is part of a complex dynamic system, as described by Thelen and Smith (1994) and later expanded on in the context of adolescence (Lerner *et al.*, 2001) as the endpoint for each individual is determined by innumerable variables. Emerging adults with motor difficulties may have travelled along many different pathways before arriving at this stage. Fischer and Daley (2007), when describing development in executive functioning, but can be used in this context, move away from a view that developmental processes are like a ladder where the individual climbs up each stage in synchrony but far more like a web.

> "that includes consistency and variability, consistent pathways in a domain and different pathways among the different domains."
> p60.

This analogy is a good one when considering the differences between students with motor difficulties and comparing themselves with the TD group. Exploring the differences between the groups has shown differences in a number of domains but also variability within these domains in terms of outcomes. There are meshes of influences that interact in a dynamic way to determine the ultimate outcome for each individual. As Cantell, Smyth and Ahonen (2003) stated, when they followed up a group of children with DCD at 17 years of age,

> "it is a challenge to disentangle the combination of personal dispositions, such as self-esteem and resilience, and environmental influences such as the impact of home and school"
> p 428.

However, as with other studies of adolescence and DCD, this study confirms that there are a number of emerging adults with DCD whose difficulties are pervasive, persistent and significant, as has been described in the previous chapters and despite variations within the group they are still distinguishable from the TD group.

One area that has emerged at a symptom level as being linked strongly is the area of EF difficulties. There may be several explanations for this. This harks back to the concepts of MBD or DAMP which are dimensional and that students with motor difficulties sit on a continuum and that attentional and motor difficulties overlap with one another. There has been some discussion and research about the area of the brain responsible for EF. The frontal cortex is known as the key area in the control of EF but considering a one-dimensional understanding of localisation may be an over simplification. The development of EF skills is not a static and uniform process but influenced bidirectionally, with transactions with the environment. As Bernstein and Waber (2007) state:

> "developmental abilities and disabilities, are likely to reflect processes associated with the construction, integration and establishment of functional networks, rather than the functions of specific brain regions"
> p45.

Control over learning is related also to achievement and self concept. Controlling for a familiar setting is very different from planning and controlling for a novel setting.

These aspects were particularly highlighted as difficulties within the DCD group (see Chapter 6). These findings are very important in supporting students with DCD in education, as it is likely that a controlled or static test for EF would have limited value, as it is necessary to find out how the individual manages the novel task situation which is key. The relevance to future practice is important, as task analysis in different settings and undertaking different tasks would be of more value and this is something that student support services needs to be aware of in assessment for support. This reinforces the earlier comments about the need for multiple informants and multiple setting information in order to give a truer picture of functioning and can aid the planning for support and guidance.

10.2.3. Gender differences.

One additional aspect of this study was the gender balance in presentation of students with motor difficulties, as compared with studies of children with DCD. Previous studies in DCD have reported greater numbers of boys to girls being diagnosed ranging from 3:1 (Miller *et al.*, 2001) to 7:1 (Kadejso & Gillberg, 1999). This will be dependent on the criteria used and the tests undertaken. In this study, there were 45% females and 55% males. There may be several explanations for this. A pattern of females presenting later has been noticed in other developmental disorders such as ADHD (Hinshaw *et al.*, 2006). The reason for females responding to the recruitment for this study may be because adult females may be more responsive to this type of research. Some gender differences have been shown in usage of the Internet. In one study comparing Chinese and UK groups, females were more likely to respond to e-mail and chat rooms and males more likely to play on computer games (Li & Kirkup, 2007). Adult females may also be more willing to seek help than males. This has been noted too in the area of mental health services (Green & Pope, 1999; Mackenzie, Gekoski & Knox, 2006). Girls may not have been identified so readily with DCD in their younger years because sporting skills may not have been seen as important socially. As girls grow up and academic demands increase, the difficulties may come to the fore such as handwriting difficulties and only then is the need for support identified, especially in those who are more academically able. Cousins (2003) in her PhD study of older adults, had higher proportions of females recruited than males. She attributed this to social factors and that the females were more willing to volunteer. The group she studied, interestingly, also had better fine than gross motor skills. University students may be a self-selected group that have a profile where their motor difficulties are worse for ball skills than their manual dexterity skills. Females may be able to avoid their weaknesses more easily than boys with excuses of 'periods' especially when there are more male PE teachers who may not be willing to contest this. Another reason for presentation in this and in Cousins' study, is that the boys may not do so well academically because of overlap with other developmental disorders and so may be underrepresented in a study in FE and HE. There may be also resilience factors at play in females, such as lower rates of externalising behaviours that may influence a better outcome.

One female student of 20 years of age alluded to why girls may be identified later than boys or have Dyslexia identified first.

"I had no diagnosis at all until I was 19. It wasn't until I had deferred from my first year at university and was in therapy that I was diagnosed. My parents had thought there was something wrong since I was first at school and didn't get on as well as anyone else, but they kept being told, for years, "she reads so well, she can't be dyslexic (no-one ever even mentioned Dyspraxia, even though I was so totally uncoordinated, I think most people who dealt with me hadn't heard of it). The reason I read so well is because I LOVE reading so I forced myself to do it".

10.3. The social characteristics and behaviours of the motor difficulties group compared to the TD group.

The DCD and TD group differed on a number of variables, in particular their social choices and use of drugs, as well as differences in driving a car. These are all important social markers that may influence the process of emerging adulthood. The DCD group were also more likely to be single than the TD group, reflecting potentially greater levels of social isolation.

10.3.1. Leisure and hobbies.

The results from this thesis have shown that team playing was reported to be avoided by the DCD group. The TD group were also more likely to choose sport as a favourite hobby than the DCD group. Other social differences included the DCD group being far less likely to choose clubs or dancing as a preferred activity. Several students mentioned lack of experience in going out to clubs, social isolation and the noise as reasons for not choosing clubs to go to. The emerging adult is likely to arrive in college or university less mature than his or her peers, as been described in the parental interviews and also by some students with DCD.

Choices in the type of sports and leisure pursuits in emerging adults may be related to the individual's general self efficacy. Poor motor skills may lead to reduced physical opportunities and this then leads to fewer opportunities for social practice. Poulsen, Ziviani and Cuskelly (2006) demonstrated that encouraging the child to be involved in choices for their leisure pursuits leads to higher rates of enjoyment, higher self concept scores and increased likelihood of persisting with them. This study of boys with DCD also demonstrated that those who did not participate in team sports had significantly lower general self-concept and life satisfaction than the boys who spent more time in team games. This is of interest with respect to this study where team participation is occurring less often by choice. Evidence from other studies about children with DCD have also shown this group to undertake less physical activity than typically developing children (Bouffard *et al.*, 1996; Cantell, Smyth & Ahonen ,1994; Schoemaker & Kalverboer, 1994).

Lack of social interaction and fewer extracurricular activities may be an important factor in the development of the emerging adult. Fredericks and Eccles (2006) have shown a direct association with extracurricular participation and the reduction in inappropriate usage of drugs and alcohol. Anderson *et al.* (2003) also confirmed the influence of parents in encouraging their children to participate in extracurricular activities.

It may be particularly important for the development of the male in teen years to seek out other peers and to have forms of appropriate social currency to be able to exchange to gain acceptance.

Cairney *et al.* (2005) highlight the limitations of concentrating purely on motor function and not recognising that coping strategies may be of greater importance for a positive outcome:

> "at the present time it seems unlikely that underlying motor proficiency problems can be corrected" and emphasises: "developing children's coping strategies to accommodate their motor difficulties can be accomplished". p855.

In emerging adults it may be necessary to focus on strengths, as early as possible, and to find ways of modifying or avoiding difficulties where possible, so that realistic and achievable goals can be set. This may require a refocusing of therapeutic services engaged in children by providing early goal setting skill training and a change in approach to therapy, in one that seeks out strengths rather than persisting 'sorting out' the difficulties.

Another factor that needs to be considered for individuals with DCD is the avoidance of sports in emerging adulthood, as this may have an effect on cardiovascular health as well as increasing the risk of obesity. These concerns have been highlighted in the study by Faught *et al.*, (2005).

The intertwining of social participation, physical health and mental well being is an important one to consider together, rather than each in isolation. Cairney *et al.* (2005) examined the relationship between physical participation and self efficacy in nine to 14 year olds and found physical activity was mediated by the level of generalized self-efficacy. Poulsen, Ziviani and Cuskelly (2006) also demonstrated in ten to 13 year old boys with DCD:

> "relationships between boys' physical coordination and their self-perceptions of life satisfaction and general self concept were significantly influenced by individual self-concept appraisals of physical ability and appearance, peer and parent relations"
>
> p839.

These results of this thesis have implications for considering sporting choices, especially for males with DCD early on in their school careers to ensure continuing participation.

10.3.2. Smoking, alcohol consumption and drug usage.

The main differences in the DCD and TD groups on these variables was that the TD group were more likely to have had experience of taking illicit drugs. This may be related to lack of social opportunity. Low levels of addictive behaviour could be attributed to lowered dopamine levels. This has been associated with Parkinson's disease where interestingly when L-Dopa is given there have been cases of gambling emerging. Animal studies have shown specific genes that affect novelty seeking behaviour and addiction related to Dopamine genes. Speculatively, there may be specific genes in DCD that differ with respect to the response to alcohol that differ for example to those individuals with a more typical ADHD presentation of impulsivity and the links to addictive behaviour (Merims & Giladi , 2008).It is interesting also to note the overall distinct gender differences between groups with males much more likely to have tried drugs than females, but this pattern not being replicated in the DCD group.

10.3.3. Driving behaviours.

Fewer students with DCD chose to drive a car than the controls, and some of the reasons given were fear of their potential driving skills, although finance was a common reason for both the DCD and TD groups. There were no differences between groups in taking either their practical or theoretical tests. One limitation of the study was that the number of lessons taken was not asked and this may have been a better indicator in terms of difficulties learning. Students with DCD drove fewer miles and some reported opting for an automatic car because of problems coping with gears. Difficulties in distance estimation were a reported difference between the TD and DCD groups, with half the students with DCD reporting difficulties with parking. Spatial awareness was cited as a reason for this by several students.

Three potential reasons for poor driving skills could be poor motor skills, poor executive functioning and visual perceptual difficulties. Wilson and McKenzie (1998) concluded that visual perceptual abilities were a specific area of deficiency in children with DCD. Difficulties in driving may be related to the number as well as the pattern of co-occurring disorders including visual perceptual deficits (Crawford & Dewey, 2008). EF deficits may make selection and prioritization difficult, especially in novel situations. Driving obviously presents a constantly changing situation for the individual and so this may be the key factor in poor outcomes for this group. The fewer miles driven may be only driving familiar routes rather than exploring new horizons. This is an area for further research.

Despite having executive functioning skills difficulties, the DCD group, did not show similar characteristics as those reported in driving studies of adults with ADHD (Barkley, Murphy & Fischer, 2008), such as speeding, driving, drinking or illicit drug usage. This is interesting in light of the incidence of the evidence of ADHD-DCD overlap in 35-40% of children (Rasmussen & Gillberg, 2000). This may be because those with DCD are a pre-selected cohort as they are from a student population. Those with conduct or impulsive behaviour may have been excluded from this group because of their associated difficulties leading them to be less likely to be in further education. Two specific students did show completely different profiles to the rest, as described in the conclusion section in Chapter 7, and displayed more of the characteristic patterns of individuals with ADHD.

10.4. How does the reported support given in FE and HE differ between those with motor difficulties given a diagnosis of DCD/Dyspraxia and other students with other diagnoses such as Dyslexia.

It remains difficult to know how many students with DCD are currently in FE and HE as there are no specific data for this. The current processes for assessment of students with motor difficulties are flawed in a number of ways. This starts even before the student arrives at college or university with little evidence of pro-activity.

Specific invitations for support on websites using key words such as DCD or Dyspraxia remains low as seen from the random sample of 20 out of 304 universities screened to find out whether they mention either term on any part of their website or provide any specific support. DCD, especially as a key word, is rarely being used which makes it harder potentially for children growing up with this label today to gain support.

Methods of testing recommended are not grounded in evidence base. Recognition of students in order to provide support for them appears also to be limited. Under SENDA (2001) Section 28; 108: Disabled students are not to be substantially disadvantaged even though it states that: "a duty on responsible bodies for further and higher education institutions to take reasonable steps to ensure that disabled students are not placed at a substantial disadvantage, in comparison to students who are not disabled, in their access to education and associated services to students."

In section 109, there is also an emphasis on pro-activity, stating that: "require educational institutions to consider the provision which they make for disabled students generally. The duty covers *all aspects of a student's life*, including academic activities and access to services which are available to him as a student."

This is especially of interest for the student with DCD as it means that support is not only about study skills but also about the 'softer' skills of supporting the student in their home life, especially if living on campus. As has been seen, students with DCD have difficulties with independent living skills and organisational/time management skills and if support is limited to study aspects the student will not have the appropriate provision in place.

Universities and colleges still clearly operate a medical model of disability. The student needs to declare a difficulty first to be assessed. They then need to find someone who can assess them. The allowance is directly linked to being 'disabled', by virtue of its name. The disability resides with the student and not the institution. This process can be stressful, costly and lengthy and is constructed to discriminate the student with DCD as they have to complete handwritten forms and negotiate new places to be assessed at specific times. Alternatively, using a WHO, ICF model as described in Chapter 2 would require a mindset shift and training but could result in millions of pounds being diverted away from lengthy assessment processes and more funnelled into creating a supportive environment and teaching generic skills such as organisational and independent skills to all. For example, providing inclusive approaches in universities in colleges where adaptive software is available on all computers reduces the need to be assessed for it. Secondly, providing study skills training over a period of time, even before starting at university, could prevent difficulties rather being reactive.

Students arriving at FE and HE may also not be neatly packaged with appropriate tags on them. In this study, students with motor difficulties had a diagnosis of DCD, Dyspraxia and a variety of overlapping diagnoses as well as Dyslexia. The label itself did not determine the severity of symptoms or how pervasive these were.

10.5. The lived experiences of emerging adults with motor difficulties as seen from the individual *and* parental perspectives.

Gathering views from multiple sources gives a unique view of the experiences of that young person and how it may affect not only the individual but the whole family. The concurrent transformative strategy taken in this study, where data were collected both quantitatively and qualitatively and was guided by the literature review of knowledge in emerging adulthood, in DCD and related developmental disorders. The approach of using information gathered from both parent and child , provides a method to examine both consistency and variability between given stories, but also to consider additional perspectives. Integration of this information has been enabled through the interpretation phase of the study (Cresswell, 2003).

In Chapter 9, both the unique characteristics of individuals with DCD are portrayed by parents and also their common views and experiences. Additionally, a comparison of the voice of the individual compared to the view from the parent was undertaken. Parents, in describing their children's difficulties, no longer focussed on the motor difficulties, but described the emotional impact that had resulted for their children. These difficulties included anxiety, OCD, panic attacks, anger, depression, being over sensitive and lacking in confidence. They also described personal hygiene issues, tidiness, as well as poor organisational skills. However, motor difficulties remained evident and many parents commented on poor writing skills, balance and gross motor difficulties. The picture while reporting difficulties for all domains in at least 50% of individuals , did also mean that 50% of individuals were functioning well on some domains. A few parents reflected upon change in their children and improvement as they moved into the phase of emerging adulthood. Successful outcomes were generally related to an understanding by others, early awareness, and listening to the needs of their child and effort on their behalves. No parent mentioned a motor programme or specific therapies apart from some alternative therapies.

Variability in presentation at the stage of emerging adulthood can be seen. Most individuals, even with an improved outlook were still in general, requiring parental support and were more likely to be living at home than their peers without difficulties. There was some evidence from parents and students that peer-peer interaction was slowly increasing when new opportunities arose, when individuals moved from school to college and university and were able to start afresh.

One student puts this so aptly:

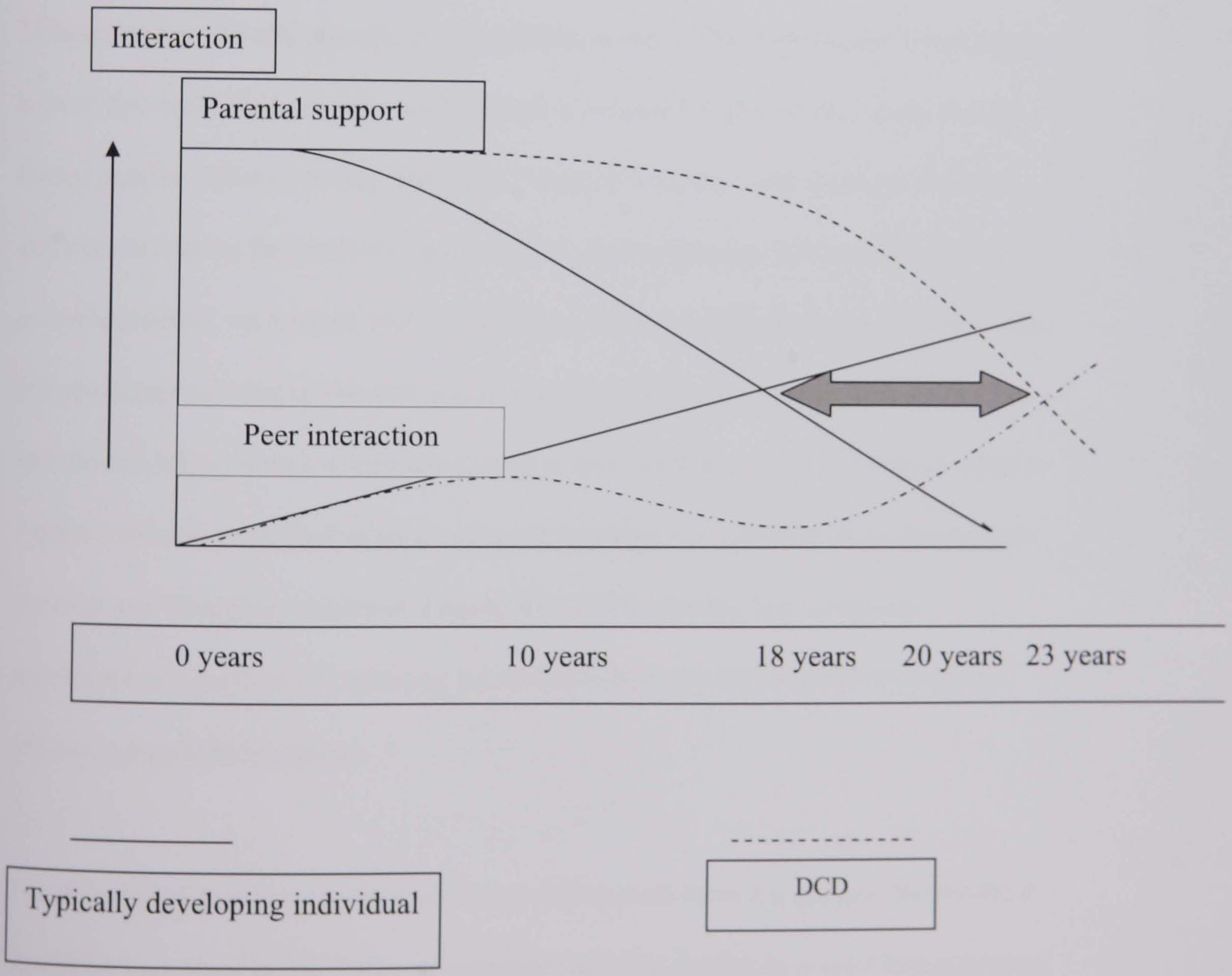
> *"Throughout my entire secondary school experience I had about four friends, and they were all outcasts of one form or another, thus my group of friends were quite understanding and ignored my 'quirkiness'. I think finding people who can empathise is very important, and is possibly the only reason I survived school at all. At university I could start all over again, no one*

> *knew who I was and therefore their opinion was not clouded by a view of me when I was at my most clumsy".*

Listening to the voices of the parents of children with DCD has recently been shown to be informative in gaining an understanding of some of the lived experiences (Missiuna *et al.*, 2006). This current study has highlighted that the parents' voice is important in also considering the needs of the emerging adult with DCD even when the individual is seen as an 'adult' in education, he or she may be very much a child at home requiring caring and support as described in Chapter 9. This has been echoed in work in the field of ADHD where one study showed low agreement between parent and student dyads about attention problems (Rohde *et al.*, 1999) and so multiple information can give a more complete picture. Some parents reported concern for their children's future and some also showed some evidence of difficulty letting go, still doing many of the tasks usually done for a child and not an adult. While children are living at home it may be harder for some parents to accept or see the changes that may be occurring. Another theme that emerged from parents' interviews was experiences of having to fight the system in order to gain help for their child. Evocative language was used, such as terms such as having 'battles'.

One potential model for traversing the stages of emerging adulthood and moving to independence is shown in Table 10A.There is an interaction between the continuing need of higher levels of parental support into late teens and early twenties and low levels of peer – peer interaction. The two processes of separation from parents and individuation (recognised by self perception, and peer-peer interaction) although happen independently, may have a dual effect in terms of timing and could be postulated to lead to the delay when the intersection occurs heralding a stage of independence. Living at home with your parents may not be a factor but the need for organisational support and the parent still providing the primary role for social interaction may be the crucial indicators.

Figure 10A: Stages of Emerging Adulthood.



10.6. Limitations of the study.

In any study there are numerous limitations with regard to time, resource, access to the cohorts to be studied, time for interview and the time to then transcribe materials and analyse the data. This study has been with students in the 16-25 age groups in further and higher education and may not reflect outcomes for all individuals growing up with movement difficulties. Socio economic status of the group was also not established and this in hindsight would have been useful additional information.

I did not undertake any specific motor testing on any of the individuals. However, I believe this is an ecologically valid approach because the aim of this study was to mirror practices that currently exist and I wanted to explore and focus on the lives and experiences as the students reported them and to gain an understanding of the possible parents' viewpoints rather than focus on motor functioning in isolation. One key challenge relating to this and supporting my reason not to test was a difficulty and tension know what I would have chosen, and secondly, would testing an adult in a quiet room have resulted in an assessment that may not correlate to performances in novel and changing situations. I chose the online surveys and telephone interviews as a method of capturing information from a wider number of students across a geographical spread.

The driving information showed some key differences between groups. However, it would be important in the future to consider real time testing as is now being done in the field of ADHD. Additional information also on who chose to drive an automatic car and how many lessons each individual took would also have been interesting. The interviews, while generating rich information, need to be used with caution in generalising these experiences across families.

10.7. End notes.

This study has shown that some individuals with DCD have persistent difficulties affecting home and university/college life and a variety of aspects of daily functioning. Some of the difficulties reported were seen in a number of areas of their lives. These included independent living skills. There were continuing difficulties for many with their handwriting. New motor skills also presented a challenge, such as driving for the young person with DCD.

Associated features reported by a number of students with DCD were related to executive functioning skills. These included difficulties prioritising work, time management, planning for the future, and organisation of self and tasks, especially when under time pressure. Secondary consequences of some of these difficulties were also portrayed by the continuing social and communication difficulties that have been demonstrated in previous childhood studies and differing social and leisure choices.

Differences were also demonstrated between those with a diagnosis of Dyslexia and those with DCD, in terms of their support given by others in FE and university settings with fewer students receiving DSA with a diagnosis of DCD than compared to those with a diagnosis of Dyslexia.

Finally, parental reporting showed similar patterns of difficulties to students but parents reported higher levels of difficulties than their children, particularly in social functioning and in organisational skills. Few parents reported that their children had no difficulties at all in emerging adulthood, although some commented on improvements in some skills and increased confidence in their children. The improvement was linked to both internal and external factors such as increased maturity as well as parents pinpointing key persons that had made a difference to their child's life. There is evidence from this that the process of emerging adulthood for some may be prolonged and the final stage of independence may be delayed.

The presentation in adulthood may be dependent on the changes in external demands and the multiple pathways taken by each individual in finally reaching further and higher education.

Masten (2004) points out that

> "Common endpoints and final pathways can emerge from diverse beginnings and individuals who start down the same path can end up going down many different roads over time"

p311.

There maybe some individuals who developmentally are 'early wilters', bowing to the demands as they move through the academic system, and others as also described by Denckla (2007) as 'late bloomers' and manage better as they grow older as they have automated some skills freeing them to cope more with new demands. The latter group may have undergone brain maturation in specific areas of the brain such as the prefrontal cortex (Giedd, 2004).

In order to be a competent adult there is a need to cope with competing demands. In childhood, activities and actions are usually structured and directed by adults at home and in school, whereas in adulthood there is a need to be self directed, be organised and have reasonable independent skills. This maybe the reason why, in Chapter 6, there are some of the key differences between groups with not only on differences in motor functioning but also on EF skills as self organisation becomes a necessity and not a choice.

It is interesting to consider whether there is a difference between syndromic persistence and symptomatic persistence in DCD. This study shows that some of the features described in childhood persist, where as others alter or are represented in a different manner. The presenting features in emerging adulthood have been tempered by years of practice, sometimes daily practice, with some motor skills finally accomplished such as being able to dress. In contrast, some young adults continue to have difficulties with basic self care skills such as cleaning teeth as was cases with two students still having their parent cleaning their teeth for them. It was not clear in these cases whether this was related to poor motor skills or, as parents commented, that their children lacked interest in doing self care tasks. Despite years of practice in handwriting, there were many students continuing to have some difficulties with skills such as handwriting. Handwriting presents a complex task and continuing difficulties may be greater where students have overlapping difficulties with other developmental disorders such as Dyslexia and also have visual perceptual difficulties. This was not able to be clarified within the confines of this study.

If criteria are to be set down defining DCD in adulthood, then this requires a menu of related signs and symptoms to be chosen rather than narrow criteria. Both avoidance and adaptation may make the presenting features different in emerging adults to children and with variability within the group.

There will be a number of students arriving at colleges and universities across the UK every year without a diagnosis, yet who have difficulties that are impairing. In this study, a small group of students reported motor difficulties in childhood but had not been given a diagnosis (n=7). They were not included in the main analysis. However, in comparing their reported difficulties in childhood they represented an intermediary group between the Dyslexia and DCD groups with mean number of reported childhood difficulties being 3.64, compared with the DCD group with 5.52 and the Dyslexia group with 3.22. These individuals may represent difficulties at a subsyndromal level but, nevertheless, may still not be operating optimally and may be a group particularly to consider emerging in Further and Higher education where there are going to be greater intellectual and executive functioning demands and they may only start to have difficulties when having to manage on their own.

10.7.1. Personal notes

As a parent of a 23 year old man with motor difficulties I have to provide a personal context which was one of the rationales for being involved in this field of work and undertaking this research. My son has now travelled independently across several continents, he can drive an automatic car, he can manage his own finances and he is completing a degree but he still needs help packing a case and planning an essay and his writing is no different from when he was 11 years old. Over the last 15 years of working professionally in this field of work, I have seen increased recognition and growing numbers of adults presenting for assessment and guidance. Daniel Radcliffe is one of the few celebrities that has recently come to the fore and this has stimulated newspaper interest (Mc Donald-Smith, 2008).

One woman came to see me recently, seeking a diagnosis. She was 66 years of age. She had two grandchildren with a diagnosis of 'dyspraxia' and wanted to know if she had the same diagnosis. She had been told as a child that she was 'scruffy' and her mum had hit her for being the 'only dark cloud in the house' because of her difficulties. She gave a classic history of DCD with late walking, poor writing, dressing skills and poor at games. She had lost her job at 15 years of age because she could not tie a parcel with string. On assessment she could still not walk backwards or forwards on a line, or catch and throw a ball. She made me sure that DCD, for some, does not just disappear when childhood ends.

10.8 Future.

This thesis has targeted deliberately one age group and in one specific area in further and higher education. The result of this work is the basis for several actions to occur in both health and education.

At a governmental level there is a need for the government to acknowledge the presence of students in further and higher education with specific motor difficulties and to continue to encourage parents as partners in policy making so that the needs of their children are considered. Organisations such as the Dyspraxia Foundation and DANDA lobby for change but there are some organisations that may have specific knowledge that could work with them further to ensure their voices are heard such as 'partners in policymaking'. If the government shifts its approach to individualisation, then this will fit more in with an ICF model rather than a DSA one. However, there remains work to develop this model to fit in with an educational setting. How to measure level of impairment remains a challenge. Aiming High (HM Treasury/DfES, 2007) is one of the first documents to lay out specifically about personalisation of services with support for individual budgets, and management of key transition points (Beresford, 2004).

There remains very limited and patchy provision and knowledge of adults with developmental disorders and the need to develop specific services for this age group that are appropriate. This is clearly an area that commissioners need to consider when planning service development (Marcer, Finlay & Baverstock, 2008).
At the stage of emerging adulthood, there is a need for an assessment framework that has an ecological basis and increases the focus of supporting the specific needs of individuals and away from supporting just the labels.

Future work is required dissecting the aspects of executive functioning deficits in this group and understanding further the variety of mechanisms and resilience factors that feed into the successful outcomes.

Finally, one area that may be harder to work on is attitude. In schools and in therapy in the future, there may need to be a mindset change where there is a drive to seek out strengths of the child. Adapting the learning environment to optimise success rather than persisting with failings, may need to be seen as the primary role. Handwriting for the age group studied was a key feature that students expressed as a difficulty for them. With increasing access to cheap computers it does seem to be one area that can be compensated for easily and one that, if tackled early on, could make a profound difference to the lives of the individuals concerned.

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Appendix A: Student Questionnaires.

Section A: Initial Questionnaire

Please complete the following questionnaire giving as much information as you can.
Tick or circle all responses where appropriate. It will take you about 10- 15 minutes to complete this.

Name:
Date of Birth:
Date completed:

Address:

Post Code:
Tel. Number or mobile phone number:
E-mail:
Name of School/College/University/workplace:

If undertaking study, please answer:

Course being studied
...

Year of study (e.g. first year etc)...
Are you a:
Part time student
Full time student

Status:

Single
Married
Divorced
In relationship

Current living arrangements:

At home with parents
At home with others
At home living alone
In halls of residence

In rented accommodation with others
In rented accommodation alone
Other, please state
……………………………………………………………………………………………

Are you in receipt of:

Disability Student Allowance
Disability Living Allowance

Do you have, or have you ever had…. If yes, please describe.

A serious illness

A serious injury, including head injury

Surgery

Convulsions/fits/epilepsy

Cerebral palsy

Muscular dystrophy

Polio

Stroke

Any other conditions/diagnosis (please state)

Mental illness including anxiety or depression

Have you been diagnosed with any of the following:

Dyspraxia, Developmental Co-ordination Disorder, Clumsy Child Syndrome

Dyslexia

Attention Deficit Hyperactivity Disorder, ADHD, or ADD

Asperger's Syndrome, Autistic Spectrum Disorder

Learning Difficulties Disabilities

Who diagnosed you?   Don't know

Did you receive any therapy/help/support from anyone as a child?
Yes No

As a child did you:

Please tick the box if the statement is true:

Have difficulties with self care tasks such as tying shoelaces, fastenings such As buttons and zips, cleaning teeth

Have difficulties learning to ride a bike compared to peers?

Have difficulties playing team games such as football, netball, catching or throwing balls accurately?

Have difficulties writing neatly (so others could read it) and/or as fast as your peers?

Bump into objects or people, trip over things more than others?

Have difficulty playing a musical instrument e.g. violin, recorder?

Were called clumsy, or had others comment about your lack of co-ordination?

Do you currently receive any help with your education, training or in employment or at home?
Yes No

If yes, who gives you help?
Parents
Friends
Student support services
Other, please state
....
....

If yes, what help do you receive?
Extra time in examinations
Use of a laptop
Note taker
Mentoring or coaching support

Other, please state
....

If no, please answer why

None required
Have not asked for help

None on offer to meet my needs

Other reasons, please state
....

What do you feel are your greatest strengths?

What do you feel are your weaknesses?

Thank you very much for completing this questionnaire

Please indicate whether you would be willing to complete further information:

Questionnaires (these should take no longer than 30-45 minutes)
Yes No

Telephone conversation (lasting around 30 minutes maximum)
Yes No

Face to face interview (lasting around 1- ½ hours)
Yes No

Which format do you prefer to complete questionnaires?
(You can choose more than one option)

Web based
Paper based
By Telephone
Through interview

Section B: Driving survey

Please answer the following questions to the best of your recollection:

Are you or have your learnt to drive	YES	NO
If no, why not?		
How long have you been driving? (In years)		
How many times have you taken your theory test?		
How many times have you taken your practical test?		
How many miles do you drive in an average week? (Approximately)		
Have you ever had your license revoked or suspended?	YES	NO
Have you driven without a valid license?	YES	NO
Have you been in an accident or crash while you were driving?(including knocks and bumps)	YES	NO
Please describe		
Have you struck a pedestrian or cyclist while driving?		
Have you received a speeding ticket? If yes, how many?		
Have you been cited for failing to stop at a stop signal or sign or been cited for reckless driving?		
Have you been cited for driving while intoxicated?		
Have you received a parking ticket? If yes, how many?		

Section C: Social and Leisure Questionnaire

Do you drink alcohol?	YES	NO
If yes, what age did you start to drink		
How much do you drink per week on average		
Do you or have you ever smoked?	YES	NO
If yes, at what age did you start?		
How much do you smoke per day?		
Have you or do you use drugs of any kind?	YES	NO
If yes, at what age did you start?		
What are your favourite ways of spending your leisure time?	Bar Reading Films/TV Club Sport Other, please state	
Do you do any physical sport regularly?	YES	NO
How often per week?		
If yes, what sport(s)?		

Appendix: B. ADDITIONAL QUESTIONNAIRE- for subsection of the DCD and TD cohorts.

Section1: Current functioning.

Currently:				
Do you have difficulties currently with the following 9 items:				
	Never	**Sometimes**	**Frequently**	**Always**
1. Self-care tasks, such as shaving or make-up?	☐	☐	☐	☐
2. Eating with knife and fork/spoon?	☐	☐	☐	☐
3. Writing neatly when having to write fast?	☐	☐	☐	☐
4. Writing as fast as your peers?	☐	☐	☐	☐
5. Reading your own writing?	☐	☐	☐	☐
6. Copying things down without mistakes?	☐	☐	☐	☐
7. Organising/finding your things in your room?	☐	☐	☐	☐
8. Finding your way around new buildings or places?	☐	☐	☐	☐
9. Have others called you disorganised?	☐	☐	☐	☐
10. Do you have difficulties with sitting still or appearing fidgety?	☐	☐	☐	☐
11. Do you lose or leave behind possessions?	☐	☐	☐	☐
12. Would you say that you bump into things, spill or break things?	☐	☐	☐	☐
13. Are you slower than others getting up in the morning and getting to work or college?	☐	☐	☐	☐
14. Did it take you longer than others to learn to drive? (If you do not drive, please indicate so on the attached paper and describe why you chose not to drive.)	☐	☐	☐	☐
15. Do others find it difficult to read your writing?	☐	☐	☐	☐
16. Do you avoid hobbies that	☐	☐	☐	☐

require good co-ordination?				
17. Do you choose to spend leisure time more on your own than with others?	☐	☐	☐	☐
18. Do you avoid team games/sports?	☐	☐	☐	☐
19. If you do a sport, is it more likely to be on your own, e.g. going to a gym, than with others?	☐	☐	☐	☐
20. Did you tend in your teens/twenties or currently to avoid going to clubs/dancing?	☐	☐	☐	☐
21. Do you have difficulty preparing a meal from scratch?	☐	☐	☐	☐
22. Do you have difficulty packing a suitcase to go away?	☐	☐	☐	☐
23. Do you have difficulty folding clothes to put them away neatly?	☐	☐	☐	☐
24. Do you have difficulty managing money?	☐	☐	☐	☐
25. Do you have difficulties with performing two things at the same time (e.g. driving and listening)?	☐	☐	☐	☐
26. Do you have difficulty planning ahead?	☐	☐	☐	☐
27. Do you feel you are losing attention in certain situations?	☐	☐	☐	☐
Total				

Appendix B
Section 2: Activity and Participation Questionnaire.

The purpose of this questionnaire is to learn about how you manage your time at home and with family, as well as in your leisure activities outside the home. Please answer for each of the following items:Do you feel that you perform the following activities at the **proper pace** which is expected from you by your surroundings?

The activity	Always 0	Usually 1	Sometimes 2	Seldom 3	Never 4	Irrelevant
. Getting up from bed in the orning	☐	☐	☐	☐	☐	☐
. Going to the bathroom	☐	☐	☐	☐	☐	☐
. Washing your face, brushing our teeth and hair	☐	☐	☐	☐	☐	☐
. Getting dressed	☐	☐	☐	☐	☐	☐
. Your meals	☐	☐	☐	☐	☐	☐
. Washing/showering	☐	☐	☐	☐	☐	☐
. Organising your bag	☐	☐	☐	☐	☐	☐
. Following instructions	☐	☐	☐	☐	☐	☐
. Getting ready to leave the house	☐	☐	☐	☐	☐	☐
0. Preparing different ssignments	☐	☐	☐	☐	☐	☐
1. Filling jobs you get	☐	☐	☐	☐	☐	☐
2. Completing jobs/tasks you take pon yourself	☐	☐	☐	☐	☐	☐
3. Arranging your room and your ork area	☐	☐	☐	☐	☐	☐
4. Finding objects in your room r around the house	☐	☐	☐	☐	☐	☐
5. Getting organised for an tivity which was planned in vance for a specific hour (a ride, meeting, an event)	☐	☐	☐	☐	☐	☐
5. Getting organised for	☐	☐	☐	☐	☐	☐

ocialising with friends or family nembers						
7. Planning leisure activities	☐	☐	☐	☐	☐	☐
8. Getting organised for a class or meeting	☐	☐	☐	☐	☐	☐
9. Getting ready for sleep	☐	☐	☐	☐	☐	☐
0. Performing activities which are equired from you at work or chool	☐	☐	☐	☐	☐	☐
Total						

Appendix B.
Section 3: Daily Living Questionnaire.

Please tick the choice which best describes how you would answer the question.

Question	**Satisfied**	**Somewhat satisfied**	**Neither satisfied nor dissatisfied**	**Somewhat dissatisfied**	**Dissatisfied**
1. How would you rate your overall ability to think?	☐	☐	☐	☐	☐
2. How would you rate your overall ability to function?	☐	☐	☐	☐	☐
3. How satisfied are you with your ability to do what you need to do in your daily life?	☐	☐	☐	☐	☐
4. How satisfied are you with your ability to do what you want to do in your daily life?	☐	☐	☐	☐	☐

Appendix C : Parent Questionnaire.

I would be extremely grateful if you could take a few minutes of your time to answer the questions below in relation to your son/daughter

Your name... Your child's name & date of birth...........................

Your contact details ....

....

Do you currently have any concerns in relation to your son/daughter's functioning at:

Home
Yes No If yes, please give further details

School/ college/University/work
Yes No If yes, please give further details

Has your son/daughter received any intervention/support in the last five years?
Yes No

If yes, please describe intervention/support & state whether you think it has helped.

What specific difficulties do you feel remain with regards to co-ordination and organisation?
Any further comments?

Appendix: D Interview (form of words)

Basic outline of interview conducted with parents of children with motor difficulties.

(The telephone interviews took an open and flexible approach and so the questions were used as a guide but parents were encouraged to respond freely and to elaborate on other areas they felt were important to them.)

When you were first concerned and what did you notice?

In the past what were your main memories of difficulties with your child?

What has changed over the years?

Who/what have most helped?

What are currently main concerns?

What skills are still difficult at home?

What skills are difficult at school/college?

What aspects still require support?
- When
- How
- Who with

Specific concern over transition e.g. applying, examinations, choice of courses

Specific concern over friendships:
- Same sex
- Opposite sex

What are the preferred hobbies undertaken and does tend to be with the family or on own?

What sporting activities does your child undertake?

What, to your knowledge is/has been her/his drinking and smoking behaviours

Is your child driving – have you taken him/her out? Has he or she had lessons?

If you have sought external help who has this been with and what for?

If you have any, what are your fears or concerns for future?

What compensatory strategies have you or your child used?

Family impact

What are relationships like with your child and the rest of the family?

What are relationships like with your child with siblings?

How is your child different /similar to other siblings?

What is the effect of difficulties on family and siblings- if any?

Do you avoid or do certain activities because of your child?

What specific Independent living skills difficulties remain- if any?
(If parents responded positively- additional questions were specifically asked around the following areas:)

- Self organisation
- Handwriting
- Keyboarding skills

What advice would you give to other parents of younger children if you had to start again?

If you knew then what you know now what would you have done differently?

What do you see are your child's plans for the future?

Appendix: E Semi structured student interview schedule (form of words)

Basic outline of interview conducted with parents of children with motor difficulties.

(The telephone interviews took an open and flexible approach and so the questions were used as a guide but parents were encouraged to respond freely and to elaborate on other areas they felt were important to them.)

Past history

Have you been given a diagnosis
When were you first diagnosed?
What do you remember about this, if anything?

As a child what was it like for you at :
School
Parties
Sports day
In class
Making friends

School

Teachers
- Change of teachers
- Subjects liked and disliked
- Break times/lunchtimes

Do you remember what it was like in school- what you liked/disliked
What did you find difficult?
What/who helped you most?

Teen years

Risk taking behaviour
Drink, drugs, bars and clubs
Going out
Going on holidays

Being diagnosed

Has it helped having a diagnosis

If you had a label do you think that would have been a help?

How do you think your difficulties impacted on your family/parents/siblings?

Present day

Were there any factors influencing your choice at college/university?

What was it like when arriving at university?
What were the hardest things for your?
What/who helped?
What else do you think might have helped?

New difficulties/strengths
Peers
Every day tasks
Driving a car
In lectures
Around campus
Going out
Types of hobbies
Going away with parents/friends
Drink/drugs/smoking
Participation in sporting activities – why choose and why avoid?

Do you have any continuing difficulties- is so please describe more

What has helped you most?

Do you still describe yourself as having DCD/Dyspraxia- and if so why/why not?

What do you think would help most of all now?

What have you experienced of others attitudes to you now and in the past?

What do you think are the main barriers for you in achieving your potential?

Appendix F- Sample of type of support from a randomized sample of universities and colleges collated from their websites.

University	Is support available?	What terms are used?	Mentioned agencies	Individual disorders information
South Devon College	-They 'support students with disabilities' and 'endeavour to meet your special needs' -No mention of specific support - Disability assist service available	'Disabilities including dyslexia'	DSA	None
The University of Nottingham	Offer academic support: study, dyslexia and disability support as well as an access centre Mindmanager available on University network Staff advise on dealing with dyslexic students Dyslexia screening available, no mention of other screening Extra exam time available for dyslexic and 'disabled' students Note taking available for disabled students	Disability Dyslexia	DSA BDA Local Dyslexia association	Information available on dyslexia and mental health difficulties with 'more to follow'

	'including those with dyslexia'.			
Harper Adams University College (Shropshire)	Support tutors available for: disability, maths, Dyslexia & study skills General study skills support available to all students regardless of diagnosis Allow extra time in exams for dyslexic students Only dyslexia screening assessments available Note takers, personal care workers, auxiliary aids and services, and special exam provisions are available to other students with disabilities	Dyslexia Disabilities	DSA	None
City of Bath College	Extra help with literacy, language and numeracy skills available, as well as learning	Learning difficulties including dyslexia	None	None

	difficulties support and mobility issues			
Sheffield Hallam University	Offers Dyslexia support: 25%extra time in exams, computer use, reader and scribe, peer mentoring, additional time for assignments and tutor leniency to mark for content not spelling/grammar, one-one tutor support Learning support worker available to ASD students from DSA funding Specialist ASD research centre on site	Autism and Aspergers syndrome, Dyslexia and specific learning difficulties (within this section it only mentions dyslexia support)	DSA	*'Dyslexia is a pattern of difficulties related to language and may affect reading, spelling, writing, organisation, memory, sequencing and automaticity of skills.'* Extensive document available detailing ASD and how to support
Highbury College (Portsmouth)	LSAs and support groups, specialist tutor advice and guidance, cassette recorders (other equipment can sometimes be provided). Extra exam time can be considered	Learning difficulties and disabilities	DDA	None
Northumberland College	Support in communication, numeracy and information technology is available. Provide contact	Physical difficulties/ disabilities, sensory difficulties/disabilities, emotional difficulties	Connexions	None

	details for further information about types of support available. Additional Learning Support assessment available. No details of available support online.	/disabilities,behavioural difficulties/disabilities		
University of Chichester	Currently support students with: dyslexia, dyspraxia, visual impairments, physical and mobility difficulties, social communication disorders, mental health issues and various medical conditions. Speicialist Dyslexia advisor also available – initial screening for Dyslexia and other SPLDs. Advise students to contact them in the application process to establish support availability.	dyslexia, dyspraxia, social communication disorders	DSA	None
Newman University College, Birmingham (was	Information on the assessment process focuses on Dyslexia. Offer meetings	Disabilities specific learning difficulties (dyslexia, Dyspraxia,	DSA	None

Newman College of Higher Education)	with an inclusion officer for prospective students. General adjustments (dyslexia): exam help (scribe, extra time/breaks), audio recording, sympathetic marking scheme, minmapping software, extended library loans & support workers. Support for students with mobility/dexterity impairments: notetaker, library help, locker use, voice recognition software and scanner, adapted keyboards. ASD/ADHD support: mentor, buddy, dictaphone	dysphasia, dyscalculia) Aspergers, ADD/ADHD		
London School of Economics and Political Science (University of London)	LSE Circles Network, the peer/staff system provides mutual support, note-takers, extra exam time/rest breaks, readers, proof-readers. Students are advised to contact the disability office	Disabilities Dyslexia Dyspraxia	DDA, DSA	*'Dyslexia is a specific learning difficulty, a complex neurological condition, which is constitutional in origin and is indicated by a*

	asap with requirements. Dyslexia/Dyspraxia section only advises only on what Dyslexic students can do for support (DSA, LEA etc)			*discrepancy between IQ and literacy, specific cognitive deficits eg - short term memory, slow speed of information processing, or inability to structure text and inefficient organisational skills Dyspraxia, often linked to dyslexia is indicated by difficulties in co-ordination of physical activities, particularly handwriting and associated skills. Both conditions vary in severity and range.'*
Napier University, Edinburgh	Drop in service offered to current and prospective students. There is a focus on Dyslexia under special needs section but also state that	Special need disability specific learning disability (dyslexia)	DSA	Online access to a leaflet: 'Understanding dyslexia in higher education'

	they can advise on a disability or special need other than dyslexia. P odcast available discussing difficulties Dyslexic students face. 5 step Dyslexia support checklist available online. Assessment available for Dyslexic students only. Other special needs and disabilities section was under construction (07/08/08)			
Somerset College of Arts and Technology	Learning support offered to prospective and current students. For prospective students, they will work with the school in order to fulfil learning needs. Will then draw up learning support plan. Learning support tutors available. Case studies of two dyslexic students available. Integrated learning centres available:	Learning difficulty	DSA mentioned in one of the case studies	None

	working space, software etc. Student support officers are available for the differing areas of study (technology, construction etc) but no mention of their specialities.			
Bangor University	Dyslexia Unit available offering assessments (for general public and students), support groups, 1-1 tuition, research, and an outreach teaching service to local schools. Statement in the disability services section: *'Not everyone who uses our Service will perceive themselves as being disabled or as having a 'disability', the University uses this term however to cover the barriers faced by people with a wide range of physical and sensory impairments, including*	Disability, specific learning difficulties, dyslexia	DSA	Extensive manual available online 'Dyslexic students at bangor'

	specific learning difficulties, chronic health conditions and mental health difficulties.' This section details availability of disability support and personal learning plans.			
The University of Huddersfield	Strong support team available inc: dyslexia tutors, mentors, library assistants, note takers and interpreters. Supports enrolment and holds an induction day for all disabled students. Has outreach assessment centres. Options to change colour scheme and font.	Disability specific learning difficulties	None	None
University of Cumbria	*'The University defines disability broadly, including: mobility impairments, sensory impairments, medical conditions, specific learning difficulties (e.g. Dyslexia),*	Disability learning difficulties, specific learning difficulties (e.g. Dyslexia)	DSA	None

	mental health conditions'. Support is available for current and prospective students. Assist with funding, exams, software and arrangements. Ask that students inform of a disability at the earliest possible stage.			
The University of Salford	Details disability as: Specific learning difficulties, sensory impairment, physical disabilities, mental health issues, ASD, unseen disabilities. They note that the list will alter as they support new disabilities. Offer technological aids, support workers, special study/exam arrangements. In the case of Dyslexia they offer assessment. Most support seems to be offered in respect to	SPLDs: Dyslexia, Dyspraxia, Dyscalculia, ADD/ADHD, Irlen Syndrome, ASDs	DSA	Details difficulties relating to each of the mentioned disorders (difficulties) – Dyslexia is the most extensively discussed

	Dyslexia: counselling, local support groups, assessment etc. Such information isn't available for the other SPLDS			
Edge Hill University	Detail disability as: Dyslexia, physical and sensory impairments, mental health needs and visual or hearing impairments. Recommend that students contact them for further information. Informal assessments offered but there is no information as to whether for Dyslexia only. Offer downloadable note taking guides and grammar guides for essay writing. Offer i-1 skills sessions.	Disability specific learning difficulty (e.g. Dyslexia)	DSA	None
The College of Agriculture, Food and Rural Enterprise (various locations	Encourage students to disclose any disability or medical condition to ensure appropriate	Disability Dyslexia Dyspraxia Other conditions that may affect your academic study	None	None

through N Ireland)	support and guidance is offered. One student support officer covering all aspects of support.			
University of Aberdeen	Option to change font size on website. Offers assistive technology. Page containing disability information for staff. Accessible teaching policy for staff (accessible: lectures, presentations, e-learning, tape recorded lectures). Services for current and prospective students. Each academic school has a disability co-ordinator. University computer programme available that assesses for Dyslexia, if test shows a positive result referral to an educational psychologist occurs. *'Non-medical help, such as*	Dyslexia Dysgraphia Physical impairment Specific learning difficulties	DDA, DSA	None

	note-takers, tutors, scribes or readers for written examinations can be arranged, if your assessment indicates this would be of benefit.' Dyslexia support advisers can provide 1-1 support for students with dyslexia and other splds.			
University of Sunderland	Offers support to prospective and current students. The prospective students page states that: '*the disability support team advises on a range of issues such as assistive technology and extra time in exams*'. They request a copy of a recent assessment in order to access services. Comment that the number of students with Dyspraxia is increasing though the majority of students registering with	Disability Specific learning disability such as Dyslexia. There is a policy and code of practice for students with a spld (Dyslexia, dysgraphia, Dyspraxia, Dyscalculia)	DSA	No information on specific diagnoses. Downloadable leaflets for disabled students and students with splds on all aspects of University life (finding your way around campus, exams, personal support)

the disability
support team are
dyslexic.