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# **Portfolio for Professional Doctorate in Counselling Psychology (Dpsych)**

## **The Art of being Different: Journeys from Shame to Self-Acceptance**

**A portfolio of work including an interpretative  
phenomenological analysis of the experience of adolescents  
with a diagnosis of developmental coordination disorder  
(DCD)**

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**May 2018**

## Table of Contents

LIST OF TABLES	5
LIST OF ABBREVIATIONS	5
ACKNOWLEDGEMENTS	6
CITY, UNIVERSITY OF LONDON DECLARATION	7
<b>PREFACE</b>	<b>8</b>
SECTION A: DOCTORAL RESEARCH	9
SECTION B: PUBLISHABLE PAPER	11
SECTION C: CLIENT STUDY	13
REFERENCES	15
<b>SECTION A: DOCTORAL RESEARCH</b>	<b>17</b>
ABSTRACT	18
<b>1 INTRODUCTION</b>	<b>19</b>
1.1 BACKGROUND	19
1.2 LITERATURE REVIEW	21
1.2.1 <i>Description, Definition and History</i>	22
1.2.2 <i>Lack of research and prominence</i>	24
1.2.3 <i>Issues regarding Definition and Diagnosis</i>	25
1.2.4 <i>Cognitive Deficits and Executive Function</i>	27
1.2.5 <i>Diagnosis and Stigma</i>	32
1.2.6 <i>Children</i>	35
1.2.6.1 Social relationships and participation	36
1.2.6.2 Psychological implications	38
1.2.7 <i>Adolescents</i>	40
1.2.7.1 Psychological Implications	41
1.2.7.2 Self-esteem / self-concept	42
1.2.7.3 Physical well-being	43
1.2.8 <i>Adults</i>	45
1.2.8.1 Psychological implications	46
1.2.8.2 Participation and Quality of Life	46
1.2 SUMMARY	48
<b>2. METHODOLOGY</b>	<b>50</b>
2.1 OVERVIEW	50
2.2 QUALITATIVE APPROACH	50
2.3 EPISTEMOLOGICAL FRAMEWORK	51
2.4. INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)	54
2.5 PROCEDURES	59
2.6 SAMPLING AND PARTICIPANTS	59
2.6.1 <i>Participant List</i>	62
2.6.2 <i>Key to abbreviations</i>	63
2.7 THE INTERVIEW	63
2.8 THE PROCESS OF ANALYSIS	66
2.8.1 <i>Step 1 - Reflexive Notes</i>	67
2.8.2 <i>Step 2 - Transcription</i>	67
2.8.3 <i>Step 3 - Reading, re-reading, and re-listening</i>	68
2.8.4 <i>Step 4 - Initial noting of themes</i>	69
2.8.5 <i>Step 5 - Developing emergent themes</i>	70
2.8.6 <i>Step 6 - Connecting across emergent themes (by case)</i>	71
2.8.7 <i>Step 7 - Moving on to the next case</i>	72
2.8.8 <i>Step 8 - Master themes and subthemes (comparing across cases)</i>	72

2.9 EVALUATION	73
2.9.1 Sensitivity to context	74
2.9.2 Commitment and rigour	74
2.9.3 Coherence and transparency	75
2.9.4 Impact and Importance	75
2.10 ETHICAL CONSIDERATIONS	75
2.11 REFLEXIVITY	77
2.11.1 Methodological	78
2.11.2 Personal	80
<b>3. ANALYSIS</b>	<b>83</b>
3.1 INTRODUCTION	83
3.2 DESCRIPTIVE PARTICIPANT LIST	84
3.3. MASTER THEMES	88
<u>3.3.1 Table of Master Themes and Sub Themes</u>	88
3.4 THEME 1 - SENSE OF OTHERNESS	88
3.4.1 Recognising and Re-framing Difference	89
3.4.2 Social Acceptance	94
3.5 THEME 2: COMPLEXITY OF RESPONSE	100
3.5.1 Relief	100
3.5.2 Shame	102
3.5.3 Ambivalence	104
3.5.4 Need for acceptance, understanding, and support	106
3.6 THEME 3 - RECOGNISING AND COPING WITH LIMITATIONS	109
3.6.1 Not being 'good' at things	109
3.6.2 - Unseen Struggle	111
3.6.3 - Emotional Impact	112
3.6.4. Coping Strategies	114
3.6.4.1 Stay positive, don't give up!	114
3.6.4.2 Minimising and rationalising	117
3.6.3.4 Accessing Support	121
<b>4. DISCUSSION</b>	<b>123</b>
4.1 INTRODUCTION	123
4.2 SENSE OF OTHERNESS	123
4.2.1 Reframing Difference	124
4.2.2 Social acceptance	130
4.2.2.1 Identity	130
4.2.2.2 Self-Esteem	136
4.2.2.3 Stigma - the role of shame	137
4.2.2.4 Status	139
4.3 COMPLEXITY OF RESPONSE	139
4.3.1 Response to diagnosis	140
4.3.2 Need for acceptance, understanding and support	140
4.4 RECOGNISING AND COPING WITH LIMITATIONS	143
4.4.1 Unseen Struggle	143
4.4.2 Not being good at things	143
4.4.3 Emotional Overload	145
4.4.4 Coping strategies	145
4.4.4.1 Staying positive	146
4.4.4.2 Minimising	147
4.4.4.3 Escape	147
4.4.4.4 Accessing Support	148
4.5 PSYCHOLOGICAL IMPACT - COMPARISON TO PREVIOUS RESEARCH	148
4.5.1 ANXIETY AND DEPRESSION	150
4.6 STRENGTHS AND IMPLICATIONS	151
4.7 GENERAL IMPLICATIONS	152

4.8 COUNSELLING PSYCHOLOGY IMPLICATIONS	153
4.8.1 <i>Interventions to improve resilience</i>	154
4.8.2 <i>Interventions to manage stress</i>	154
4.8.3 <i>Online CBT Interventions for anxiety</i>	155
4.9 LIMITATIONS	155
4.9.1 <i>Methodological Limitations</i>	155
4.9.2 <i>Procedural Limitations</i>	156
4.10 PERSONAL REFLEXIVITY	158
4.11 CONCLUDING COMMENTS	159
<b>REFERENCES</b>	<b>162</b>
<b>APPENDICES</b>	<b>185</b>
APPENDIX A: JOURNAL INFORMATION AND AUTHOR GUIDELINES	185
APPENDIX B: LETTER TO HEAD TEACHER	189
APPENDIX C: RECRUITMENT POSTER	191
APPENDIX D: ETHICAL PERMISSION FROM DYSPRAXIA FOUNDATION	192
APPENDIX E: PARENTAL INFORMATION SHEET	193
APPENDIX F: PARTICIPANT INFORMATION SHEET	195
APPENDIX G: PARENTAL CONSENT FORM	197
APPENDIX H: PARTICIPANT CONSENT FORM	198
APPENDIX I: INTERVIEW SCHEDULE	199
APPENDIX J: DEBRIEF	202
APPENDIX K: EXAMPLE OF WORKING TRANSCRIPT (INDIVIDUAL)	203
APPENDIX L: VISUAL OF GROUPING THEMES (INDIVIDUAL)	205
APPENDIX M: THEMES FOR INDIVIDUAL PARTICIPANT	206
APPENDIX N: SAMPLE OF MAJOR THEME WITH QUOTES	211
APPENDIX O: MASTER AND SUBTHEME OVERVIEW	213
APPENDIX P: PSYCHOLOGY ETHICS FORM	214
<b>PART B: PUBLISHABLE PAPER</b>	<b>225</b>
ABSTRACT	226
<i>What This Paper Adds</i>	227
1. INTRODUCTION	227
2. METHODS	228
2.1 <i>Approach</i>	228
2.2 <i>Participants</i>	228
2.3 <i>Table 1. Participant List</i>	229
Key:	229
<i>SPD – Sensory Processing Disorder</i>	229
2.4 <i>Ethics</i>	229
2.5 <i>Data Collection</i>	229
2.6 <i>Data Analysis</i>	231
3. RESULTS	232
3.1 <i>Table 2: Master Themes and Subthemes</i>	232
3.2 <i>Theme 1 - Sense of Otherness</i>	233
3.2.1 <i>Recognising and Re-framing Difference</i>	233
3.2.2 <i>Social Acceptance</i>	235
3.3 <i>Theme 2: Complexity of response</i>	236
3.3.1 <i>Relief</i>	236
3.3.2 <i>Shame</i>	237
3.3.3 <i>Ambivalence</i>	239
3.3.4 <i>Need for acceptance, understanding and support</i>	239
4. DISCUSSION	241
5. CONCLUSION	247
6. FUNDING	248

<i>References</i>	249
<b>SECTION C: CLIENT STUDY / PROCESS REPORT</b>	<b>255</b>
INTRODUCTION	256
<i>Referral</i>	259
<i>Assessment</i>	260
FORMULATION	261
TREATMENT PLAN	263
OUTCOME AND ENDING	266
<b>PROCESS REPORT</b>	<b>268</b>
OVERVIEW	268
TRANSCRIPT	269
ENDING AND EVALUATION	279
REFLECTIVE DISCUSSION	280
REFERENCES	284

<b>List of Tables</b>	<b>page</b>
1. Participant List (Research)	92
2. Key (Research)	93
2. Table of Master Themes (Research)	118
3. Participant List (Article)	256
3. Table of Master Themes (Article)	259

### List of Abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autistic Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
CBT	Cognitive Behavioural Therapy
DCD	Developmental Coordination Disorder
DSM	Diagnostic and Statistical Manual of Mental Disorders
EF	Executive Function
GT	Grounded Theory
IPA	Interpretative Phenomenological Analysis
MBD	Minimal Brain Dysfunction
MPD	Motor Perceptual Disorder
OT	Occupational Therapist
RCT	Randomised Controlled Trial
SEN	Special Educational Needs
SENCO	Special Educational Needs Coordinator
SLI	Specific Language Impairment
SPD	Sensory Processing Disorder
TA	Teaching Assistant
TD	Typically Developing/Developed

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### **City, University of London Declaration**

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## PREFACE

*The experience of shame is inseparable from man's search for himself. The search for true relatedness with others and for answers to the question "Who am I?" is central to our experience as human beings. The need for a secure, self-affirming identity that provides both continuity and meaning to the paths we travel lies at the core of each of us. Identity is a sense of self, of one who is and who one is not, and of where one belongs. It is a sense of inner centeredness and valuing. (pg. 568)*

(Kaufman, 1974)

This portfolio is a product of my journey towards becoming a counselling psychologist. It is composed of three individual pieces, which express the duality of being a scientist-practitioner: a thesis, a publishable paper and a client study. All three pieces are connected by the theme of shame. During my training, I have had the opportunity to work in a variety of settings, including charities, IAPT services and specialist NHS secondary-care teams. Although the clients I have worked with have reported very different symptoms and come from very different backgrounds - shame was a near constant backdrop to our work together.

The word shame has its root in the Indo-European root 'skem', meaning to cover or hide (H. Lewis, 1974), as in Judeo-Christian mythology Adam and Eve concealed their nakedness once they gained knowledge, so we all attempt to hide our shame. Shame is relational - it is rooted in our need to be accepted and attractive to others. But due to the unpleasant and paralysing experience of shame, those affected often shirk from social contact and hide themselves (Lindsay-Hartz, De Rivera, & Mascolo, 1995). In conditions of secrecy, silence and judgement shame can flourish; when met with openness, empathy and acceptance, shame recedes (Brown, Rondero-Hernandez, & Villareal, 2011; Brown, 2007).

Working with my client Jared<sup>1</sup>, whilst also embarking on my interviews with participants with DCD created a special type of serendipity. As the therapy progressed, it became clear how deeply his shame was rooted in not being what other people wanted or expected. On interviewing my participants with DCD, it also became clear that many had grown up grappling with shame, due to being different and not fitting what society deems the 'norm'.

Looking at my own relationship to shame has been necessary for this work: the shame of not being a good enough therapist or student or mother, the shame of finding my vocation so late in life, studying with those young enough to be my children, and a myriad of other shames from not meeting people's expectations or daring to take my own path. The courage of my participants and my clients have often been an inspiration to me.

### **Section A: Doctoral Research**

This section of my portfolio represents an original piece of qualitative research into the experience of adolescents with Developmental Coordination Disorder (DCD), known more commonly in the UK as dyspraxia. Taking on this research had specific significance for me, as my own son has a diagnosis of DCD and at the time of writing was also an adolescent. My interest in the effect of this was therefore both professional and personal. My own experience was that DCD is little known and even less well understood by the general public and a literature review confirmed a general relative lack of research into this population. Of the research that had been carried out, most had been conducted with children or parents and/or had taken a

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<sup>1</sup> *Jared is a pseudonym - any potentially identifying details have been changed or omitted*

positivist, quantitative stance. I felt that more qualitative research into the experience of adolescents was needed.

Eleven participants, aged between 11-18, were recruited from the Dyspraxia Foundation. Data was collected by semi-structured interviews and was analysed by Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009). The aim of the study was to explore the experiences of these adolescents with DCD. Psychologically, adolescence is a critical period of development; a time for reassessing and developing identity (Erikson, 1968) and a time of critical neurodevelopment as our attention directs away from parental to social relationships (Blakemore, 2012).

Three major themes emerged from the data: A Sense of Otherness; Complexity of Response; Recognising and Coping with Limitations. Participants recognised a sense of being 'other' or different - sometimes this was as a result of bullying, but it was also due to noticing the difference in abilities between themselves and peers. Social acceptance and status were important, with most participants having experienced exclusion or victimisation on account of being 'different'. However, the ability of some participants to re-frame this difference as a positive rather than a negative was an important new finding in this group. Reframing 'odd' or 'weird' to 'quirky' or 'unique' or the defiant 'nerd', showed a developing sense of acceptance and resilience.

The nature of the study - the qualitative and phenomenological stance - allowed the participants to express complex emotions, which was seen in their response to diagnosis. Relief was expressed. A diagnosis meant they were not to blame for their difficulties and provided a relief from the shame of not being good at things, not being able to keep up with their peers. At the same time shame was indirectly expressed,

as many kept DCD secret and limited information about it to the minimum. All participants highlighted the lack of knowledge and information about DCD and the inconsistent support they received, especially in comparison to other neurodevelopmental disorders such as dyslexia. Most of the participants complained of difficulties with Executive Functions in areas of memory and attention, which are not diagnostically defined as DCD. This further increased confusion. There was frustration and a feeling of neglect, that they were inconsequential; the poor relation among neurodevelopmental disorders.

Participants recognised limitations and often struggled with day-to-day activities. The feeling of 'not being good at things' could be difficult to manage and damaging to self-esteem. The lack of understanding from others also contributed to this, and many felt their struggles were unseen. However, in coping with these difficulties most remained positive, encouraging others not to give up, focussing on things they enjoyed, and accessing support from friends and family.

One of the aims of diversity movements is to remove the sting of shame from difference. Acceptance of difference, and importantly, society's accommodation (rather than lip-service) to that difference is needed. Within my thesis I look at how some of the participants manage to re-frame their difference from a position of shame to one of acceptance and sometimes pride. The results, limitations and implications of this research are discussed.

## **Section B: Publishable Paper**

I thought carefully about the type of journal in which to publish this paper. From a counselling psychology stance, I was concerned to discover a lack of research into the psychological wellbeing of those with neurodevelopmental disorders - from either

a counselling or clinical perspective. I believe that counselling psychologists have an in-depth understanding of mental health issues and that we can make a valuable and important contribution to research in this area - drawing on experience as well as data. For this reason, I first considered counselling psychology journals. I also considered journals on adolescence or development, as this research is grounded in understanding the emotional and social impact during adolescent development. Ultimately, I decided on writing for a journal that specialises in understanding developmental disorders and therefore have chosen 'Research in Developmental Disabilities', which is an international journal aimed at publishing interdisciplinary and original research that has a bearing on understanding neurodevelopmental disorders. I have presented the paper in accordance with the guidelines for authors (see Appendix A) and the style is in keeping with other published papers. In researching my thesis, I found that this journal had the most recent articles on DCD - particularly those challenging the definition as a purely motor disorder - but that qualitative research was presented less often. I believe publishing in this journal would reach the largest audience of practitioners from a diverse range of disciplinary fields who are interested in DCD. However, in future, I would like to write a paper aimed specifically at counselling psychologists, considering why there is such limited research regarding 'non-typical' populations. I believe that we need to consider our motives in only wanting to work with people 'like us'.

I presented findings from my first two themes only, due to limitations in word count, but also, as I felt these represented important findings for adolescents with DCD such as 're-framing' and response to the diagnosis that had not previously been given precedence in academic literature. This paper reflected themes of social status, self-esteem, and self-concept that I felt were the most relevant to the experiences of adolescents. Shame was discussed in relation to social acceptance and stigma. Previous literature has shown that adolescents with DCD typically suffer

from poorer self-esteem and a more negative self-concept than their peers (Eggleston, Hanger, Frampton, & Watkins, 2012; Ferro & Boyle, 2013; Piek, Baynam, & Barrett, 2006). I focussed on understanding social status in relationship to peers - also a critical aspect of adolescence (Fuhrmann, Knoll, & Blakemore, 2015).

### **Section C: Client Study**

The client study aims to show the integration and development of clinical skills with theory. In the context of this portfolio, it highlights the pervasive and damaging impact of shame, if left unchallenged. It describes a session with a young man who attended therapy for a year at a low-cost counselling charity. The session is mid-way through our work together. Jared was struggling with shame, anxiety and depression. Psychodynamically considered, shame occurs in response to perceived rejection from primary carers (M. Lewis, 1995) and Jared's upbringing was often shaming and confusing. It was interesting for me to contrast Jared's pathological relationship to shame to the more accepting and adaptive responses of many of my participants with DCD, and to consider the possible implications of attachment style in the differing response.

Jared had a sense that he was 'different' to other people and muted that he may have Attention Deficit Disorder, which he considered a 'non-shaming' reason for his behaviour and responses. He considered his behaviour and emotional responses 'not normal' and therefore invalid. Working psychodynamically and taking a relational therapeutic stance allowed us to explore this shame together and validate his emotions. Shame was a constant presence in our therapy and working with this shame, resolving it and moving towards self-acceptance was the goal of our sessions.

As counselling psychologists, we aim to create a space for our clients where shame can be alleviated through the therapeutic relationship. Carl Rogers understood that our clients need a space to be cared for with 'unconditional positive regard', a space without judgement and free from shame, where the client is fully accepted, and their feelings are valid (Rogers, 1961).

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## **Section A: Doctoral Research**

**'Nerds', 'Space-Cadets' and those 'a bit on the odd side':**

**An Interpretative Phenomenological Analysis of the  
experience of adolescents with a diagnosis of Developmental  
Coordination Disorder (DCD)**

**Pamela Kane  
City, University of London**

**Supervised by Dr Jacqui Farrants**

## Abstract

- Introduction** Adolescents with Developmental Coordination Disorder (DCD) are known to be at increased risk of psychosocial problems. There has been limited qualitative research into the impact of DCD from an adolescent perspective.
- Aim** The purpose of this study was to gain a deeper understanding of the lived experience of participants with DCD as they negotiate adolescence.
- Method** Eleven participants between the age of 11-18 (8F:3M) with a diagnosis of DCD were recruited through the Dyspraxia Foundation UK. Semi-structured interviews were carried out, audio-recorded and transcribed. The data was analysed by means of Interpretative Phenomenological Analysis (IPA).
- Findings** Three main themes emerged from the data: **'Sense of Otherness'** **'Complexity of Response'** **'Recognising and Coping with Limitations'**. Most participants related a sense of 'otherness' and had previously experienced social and/or emotional difficulties. However, adolescence emerged as a time where self-concept could be re-assessed, often positively. Feelings regarding DCD were expressed as complex - including relief at diagnosis, shame at limitations, general ambivalence and a need for acceptance and support. Participants felt their difficulties were often unrecognised and misunderstood in comparison to other developmental disorders. Limitations were described regarding coordination, executive functions (EF) and emotional response. Participants employed a diverse range of coping strategies to function academically and socially.
- Conclusion** This work has implications for professionals and policymakers regarding the continued lack of recognition and understanding perceived by young people with DCD. It highlights that many participants struggle with EF and emotional regulation, as well as coordination, but feel that this struggle is mostly unseen. Support, when offered, can often be inconsistent. The re-framing of 'difference' as 'individuality' during mid to late adolescence, indicates an alternative pathway regarding self-concept that is potentially inclusive of DCD. As adults with DCD continue to report lower self-esteem, poorer mental health outcomes and reduced participation, this research indicates that adolescence may present a window of opportunity for interventions to improve resilience and self-esteem in this population. Ongoing active collaboration between adolescents and researchers is essential.

# 1 Introduction

## 1.1 Background

Developmental Coordination Disorder (DCD), also known as dyspraxia, has a low profile; this is reflected not just by the lack of knowledge within the general public, but also by the lack of interest from and resources allocated by academic researchers and healthcare professionals. Due to this lack of attention, Novak, Lingam, Coad, and Emond (2012) refer to DCD as the 'hidden disability'. This lack of interest is not without repercussions; it can have a detrimental impact on the amount of support received. Parents complain about poor responses from educational and health professionals, who are often perceived as unknowledgeable and unhelpful, and this in turn affects the level and quality of resources made available to them (Novak et al., 2012).

A diagnosis of DCD reflects dysfunction in the physical (motor and visual) and cognitive spheres, and by its nature also affects emotional and social functioning (Dewey, Kaplan, Crawford, & Wilson, 2002). What this means to the individual concerned and how they understand the impact on their life is the focus of this study. Although DCD is mostly diagnosed in childhood, it is in adolescence that the impact of 'difference' becomes even more pertinent, as the adolescent begins to evaluate his or her own individual experience and his/her status among peers. How do individuals diagnosed with a neurodevelopmental disorder incorporate (or not) this into their understanding of themselves? Adolescence introduces additional changes to biological and behavioural realms, as well as to the spheres of family and peer relationships and the development of self-concept (Steinberg & Morris, 2001).

Adolescence is the key developmental stage and is crucial to identity formation (Erikson, 1968) and yet little is known about the impact of DCD on individuals as they negotiate this challenging period, because researchers have rarely asked those who

are primarily affected. In the main, current psychological research on DCD has been carried out from neuro-scientific, clinical and educational perspectives, mostly looking at positivist outcomes rather than phenomenological experience. Indeed, it is rare for DCD to be the focus of qualitative research, and even rarer for those with DCD to be given an active role in such research, with many studies focusing on parental reports (Eggleston et al., 2012; Kirby, Edwards, & Hughes, 2008; Miyahara & Baxter, 2011; Summers, Larkin, & Dewey, 2008). Magalhães, Cardoso, and Missiuna (2011) found that even though children with DCD were 'cognitively competent' they were rarely asked about their own limitations and abilities with researchers preferring external observations from parents or other professionals.

Counselling psychology traditionally takes a humanistic approach to research. It is concerned with the subjectivity, context, and diversity of experience (Orlans & Van Scoyoc, 2008), but until recently, this has been largely absent in studies of DCD. This may be due to the nature of developmental disorders, which may imply an assessment or medical intervention that, as counselling psychologists, is either not in our remit or could even be seen to be against our ethos. However, behind the diagnosis is an individual experiencing a life with this condition. Looking at DCD from the point of view of a counselling psychologist meant questioning many 'givens'. Does the label of DCD have utility and meaning for the individual concerned, and if so, in what way? Do they value it, or reject it? How do they see themselves in regard to their peers? Do they recognise or even celebrate 'difference' or do they reject it? Giving a child a label is a highly emotive subject that has repercussions for the individual concerned, as well as the family and the system (here most specifically schools) within which the child lives. It informs decisions on the ability of the child and the role of the parent/teachers in supporting that child. It also highlights difference beyond that which is 'normally' expected, and so places the child into a category. How the adolescents who are thus categorised experience this was the

most important question for me, and one that to date had rarely been posed. This study aims to gain a better understanding of how DCD affects individuals as they negotiate the challenges to identity and self-concept that accompany the transition from childhood to adulthood. It is an attempt to gain insight into the lived experience of an under-researched group at a crucial time in their lives. It places weight on their own experience, allowing for complexity and confusion and not demanding simple answers that conform to what it is expected from them or to what can be measured. It aims to allow the participants to have a voice in explaining the possible impact of DCD as they develop and navigate their way through adolescence. The phenomenological stance will allow those most affected to inform scientific inquiry as well as be informed by it.

## **1.2 Literature Review**

The aim of this study is to gain further insight into the experience of adolescents with DCD. The following literature review summarises the academic research into DCD from the past twenty years from a psychological perspective. All studies referred to are from peer-reviewed journals accessed through the City University London library; most are quantitative cross-sectional studies, some are meta-analyses, and a few are qualitative or longitudinal. Most of these studies indicate issues and concerns regarding the physical and mental well-being and poorer quality of life for those with DCD. For this reason, the scope of the review is wide and includes studies detailing cognitive, physical, and emotional measures, as well as discussing the implications of categorisation and diagnoses for this population. Studies which were specifically concerned with motor dysfunction or interventions to improve motor abilities, but which did not reference the impact or potential impact on the lives of the participant were excluded.

I begin by considering the history of definitions for DCD and discuss the dilemmas concerning categorisation, the possible impact of stigma on the individual, and the way the lack of attention/recognition may affect research in this area. I highlight the newer research that is emerging regarding the importance of Executive Function (EF) impairment within DCD and discuss what the implications are for those affected. I then proceed to summarise the published research concerning the impact of DCD on physical and mental health, quality of life outcomes, social participation, and self-concept/self-worth. Research has often been conducted at specific developmental stages, with most studies concentrated on childhood, and fewer studies investigating adolescent and adult outcomes. This is reflected in my review.

### **1.2.1 Description, Definition and History**

Defining DCD is not a simple process. Developmental coordination disorder (DCD) is defined in DSM-5 as one of several neurodevelopmental disorders. These are grouped into intellectual disabilities (such as global developmental delay), communication disorders (such as child-onset fluency disorder - more commonly known as 'stuttering'), autistic spectrum disorder, attention deficit/hyperactivity disorders, specific learning disorders (e.g. dyslexia) and motor disorders, which along with DCD, also include tic disorders (e.g. Tourettes's disorder). According to the DSM-5, DCD can be diagnosed when the following occur:

- A. Performance in daily activities that require motor coordination is substantially below that expected given the person's chronological age and measured intelligence. The disorder may be manifested by marked delays in motor milestones (e.g. walking, crawling, sitting), dropping things, by 'clumsiness' and by poor performance in sports or poor handwriting.*
- B. The disturbance described 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) and does not meet criteria for a pervasive developmental disorder.*

*D. If mental retardation is present, motor difficulties are in excess of those usually associated with mental retardation.*

*(American Psychiatric Association, 2014)*

Whilst DCD is the term preferred by clinicians and researchers, the term most often used by lay people and by front-line medical staff in the UK is 'dyspraxia'. The word 'dyspraxia' comes from the Greek and means literally bad (dys) action (praxis) referring to the difficulty that those diagnosed with DCD can have in performing day-to-day actions, such as tying shoelaces. The history of the terms/labels for DCD is complex and includes, amongst others, clumsy child syndrome, minimal brain dysfunction (MBD), developmental apraxia, perceptuo-motor dysfunction, motor learning difficulty, and sensory integration disorder (Gibbs, Appleton, & Appleton, 2007). This has further complicated research into the issue. Magalhães, Missiuna, and Wong (2006) found a range of terminology had been used in research, e.g., 'deficits in motor control' or 'coordination problems', making comparison of studies difficult. In the past 10-15 years, the term 'developmental coordination disorder' (DCD) has become the term most widely accepted internationally by health professionals. However, in the UK (unlike in the USA and Europe), 'dyspraxia' and 'DCD' are often used synonymously (Baxter, 2012; Gibbs et al., 2007; Henderson, Peters, Barnett, & Henderson, 2001). The Dyspraxia Foundation UK, which has been supportive of this research, has stood by use of the term 'dyspraxia'. In this paper, in accordance with academic preference, the term 'DCD' will be used. However, in conversation with the participants, I referred to their preference, which for all but one of them was the use of the word 'dyspraxia', as this was the most familiar.

Estimates of the population affected range from 19% (Tsiotra et al., 2006) to 1.5% (Lingam, Hunt, Golding, Jongmans, & Emond, 2009) depending on the stringency of the criteria applied; however, a commonly accepted number seems to be between 5-6% of the population, with 2% severely affected (Blank, Smits-Englesman, Platajko, & Wilson, 2012; Lingam et al., 2009). This equates to roughly one child in every school class.

### **1.2.2 Lack of research and prominence**

Despite this relative prevalence, the public profile of DCD is much lower than that of autistic spectrum disorders (ASD) and/or attention deficit disorders (ADD), which are estimated at 1.7% and 1.2% in the UK respectively (Russell, Rodgers, Ukoumunne, & Ford, 2014). DCD is found more often in males than in females; however, again, there is a discrepancy in the research, with estimates ranging from 2:1 to 7:1 (Blank et al., 2012). This lack of profile has been reflected in the limited research carried out so far. As an illustration of the research gap between DCD and other developmental disorders, a cursory search on PsycINFO database for articles from peer-reviewed academic journals between 2012 and 2017, resulted in 10,917 results when the search term was for titles with '*ASD or autism or Aspergers*'; 6,429 for '*ADHD or ADD or attention deficit*'; 838 for '*dyslexia*'; and only 521 for '*DCD or dyspraxia*'.

In a paper exploring which neurodevelopmental disorders get researched and why, Bishop (2010) identified three separate factors that determine the level of research. Firstly, she concluded that rarer conditions are researched to a far greater degree than common ones. She suggests that this is because rarer conditions (e.g., Lesch-Nyhan Syndrome, which is associated with self-mutilation and death from renal failure) often have more severe consequences than common conditions (e.g., dyslexia). However, Bishop notes that research for dyslexia, dyscalculia, and DCD remain far below the predicted levels. The reason for this may be due to the

assumed lower disruptive impact of DCD on society in comparison to that of ADHD or ASD; the majority of those diagnosed continue in mainstream education and ultimately live independently. However, the impact of DCD on the individual continues into adulthood. The motor difficulties experienced by those with DCD do not necessarily reduce with age, and in a longitudinal study of young adults with DCD, it was found that they are less satisfied with life in general compared to a control of typically developing (TD) participants and are less likely to participate in daily-life activities, including social relationships (Tal-Saban, Ornoy, & Parush, 2014). Although the disruption to the system may well be considerably less, the social, psychological, and emotional cost borne by individuals with DCD is only just beginning to be understood.

Because of the relatively small number of studies on DCD, especially regarding the experience of those affected directly, some of the papers in this literature review concern topics that are relevant but have been researched on different populations, e.g. those with ADHD.

### **1.2.3 Issues regarding Definition and Diagnosis**

As can be expected, defining exactly what is considered to lie within the bounds of 'normality' and therefore to be designated as 'typically developing' (TD) and what is to be classified as abnormal and therefore a 'disorder' is not without controversy and this is also the case with DCD. The DSM published by the American Psychiatric Association, is typically used as a benchmark for diagnosis of DCD (amongst other mental health and neurological disorders). It attempts to present classifications with the goal of enabling shared and reliable diagnosis and treatment, as well as facilitating valid and quantifiable research.

*DSM contains descriptions, symptoms, and other criteria for diagnosing mental disorders. It provides a common language for clinicians to communicate about their patients and establishes consistent and reliable diagnoses that can be used in the research of mental disorders. It also provides a common language for researchers to study the criteria for potential future revisions and to aid in the development of medications and other interventions. (American Psychiatric Association, 2018)*

There are many reasons why a diagnosis may be desirable for the individual, but one very important reason that cannot be overlooked is its social impact and currency; the ability of the diagnosis to make available hitherto out-of-reach resources, as well as moderating the responses/expectations of others. However, classifications are not themselves 'real' or 'true' they are, as Hyman (2010) states, '*Cognitive structures imposed on data to achieve particular goals*' (p.160). He argues that the danger in the reification of these classifications can be an '*epistemic prison*'. This is particularly pertinent to DCD as there is often overlap (comorbidity) between DCD and other neurodevelopmental disorders - in particular ADHD, where the overlap is estimated to be approx. 50% - there are also, to a lesser degree, further overlaps with dyslexia, SLI and ASD (Blank et al., 2012; Dewey & Bernier, 2016; Visser, 2003). Perhaps this is one reason why researchers often overlook DCD, as it is typically seen as comorbidity to other more visible or socially demanding disorders. This issue of comorbidity and the reification of classifications have particular impact on children who are reliant on a diagnosis to attain support and resources. Gillian Baird, Professor of Children's Neurodisability at Guy's and St Thomas' has noted that the classification used to determine neurodevelopmental disorders often did not meet the reality; in that those referred either did not quite meet the criteria for a specific disorder, or they might change from one disorder to another as they grew older and that often there was an unclear mix of disorders that the nosology did not allow to be

taken into account (Baird, 2013).

The discrete entity of diagnostic categorisation was further questioned in a study into the aetiology of neurodevelopmental disorders in Sweden. Structural equation modelling based on interviews with 6,595 parents of twins (aged 9-12) concluded that there is one general genetic factor that influenced all 53 neurodevelopmental symptoms (Pettersson, Anckarsäter, Gillberg, & Lichtenstein, 2013), with further specific genetic and environmental factors playing less impactful roles. In Scandinavia, as a reflection of the recognised overlap between DCD and ADHD a further developmental disorder of 'deficits in attention, motor control and perception' (DAMP) is recognised (Pereira, Landgren, Gillberg, & Forssberg, 2001). Children with ADHD often demonstrate lower motor control than TD peers and likewise children with DCD often report problems with attention and with the processing of information. This serves to further highlight the fluidity and overlap among neurodevelopmental disorders and the limits of diagnostic orthodoxy. In Scandinavia, it was felt that the overlap between these disorders was so prominent that a conclusion could be drawn of a common aetiological pathway between ADHD and DCD, so that the lines of the map, so to speak, needed to be re-drawn to create a separate category (Sonuga-Barke, 2003). However, in the rest of the world the evidence has not been considered strong enough to determine a further category of disorder and therefore 'DAMP' does not exist, and DCD/ADHD are treated as two separate conditions which often overlap.

#### **1.2.4 Cognitive Deficits and Executive Function**

The DSM definition is very specific in that it refers only to the impairment of motor function when defining DCD; however, research has highlighted the problems that many children and adults diagnosed with DCD also report regarding self-perceived deficits in attention, memory, self-organisation, and planning (Kirby, Edwards, &

Sugden, 2011). Furthermore, cognitive research has begun to highlight the fundamental interrelation between cognitive and motor development, both of which co-evolve over an extended period of time (Diamond, 2000; Luz, Rodrigues, & Cordovil, 2015). On examining the cognitive profile of children with DCD, Sumner, Pratt and Hill (2016) found that these children attained poorer results on processing speed and working memory than did their TD peers. Leonard, Bernardi, Hill, and Henry (2015) also found that individuals with DCD had several limitations in 'executive function' (EF). EF is a term for high-level cognitive functions. Three core EFs have been identified: cognitive flexibility (switching from one task to another), working memory, and response inhibition. There are also understood to be complex relationships between these three core EFs and higher-level functions, such as planning and fluency (Miyake et al., 2000). EFs become apparent in infancy and continue to develop until early adulthood; they direct our cognition and actions towards the completion of goals. These functions play an important role in how we navigate and manage day-to-day life (Best, Miller, & Naglieri, 2011). In their 2-year follow-up assessing EF in children with poor motor abilities, Bernardi, Leonard, Hill, Botting, and Henry (2018) identified five areas where EF was impaired in children with DCD: these were working memory, response inhibition, cognitive flexibility, fluency, and planning.

Working memory is the ability to maintain, update, and manipulate information in an active state, over delays in the range of seconds rather than minutes (Kaufman, DeYoung, Gray, Brown, & Mackintosh, 2009) and has been shown to be impaired in children with DCD, who also demonstrate slower processing speeds (Piek, Dyck, Francis, & Conwell, 2007; Wilson & McKenzie, 1998). This has a real-life social impact for the children, as others often misinterpret this deficit. In research with children with poor working memory, teachers often described them as not paying attention and being easily distracted rather than having a memory issue (Alloway,

Gathercole, Kirkwood, & Elliott, 2009b), and therefore, their behaviour was more likely to be attributed to a lack of focus or to a personality trait rather than to a cognitive impairment. Poor working memory is known to affect performance at school for reading, mathematics, and science (Alloway & Temple, 2007; Alloway, Gathercole, Kirkwood, & Elliott, 2009a), so for these children, the information they need to complete structured learning can easily become 'lost' if they are overloaded or distracted. There is also a link between poor working memory and slower processing speeds, meaning the time it takes for an individual to respond to and process information (L. Leonard et al., 2007). Further research has also indicated that poor working memory may be related to social impairment in children, in particular, rejection by their peers, and to a general lower level of social competence as well as an increase in physical and relational aggression (McQuade, Murray-Close, Shoulberg, & Hoza, 2013).

The impact of deficits in working memory may well be pervasive in terms of social functioning and long-term achievement. Hofmann, Schmeichel, and Baddeley (2012) made five connections from working memory to self-regulation. Self-regulation is defined as the extent to which an individual can prioritise long-term goal-directed behaviour, e.g., eating healthily over short-term gratification / immediate distraction. Firstly, working memory serves as a means of enacting the active mental representation of long-term goals. If these goals are not held in working memory, self-regulation is unlikely to be successful, unless behaviour has been habitualised (Fishbach & Shah, 2006). Secondly, cognitive research indicates that working memory is understood to have a primary role in how well individuals can resist temptation by directing their attention towards the goals (Kane, Bleckley, Conway, & Engle, 2001). Thirdly, working memory may act as a means of 'goal shielding' - that means protecting important long-term goals from less important but possibly more demanding distractions. Working memory allows individuals to concentrate more

easily and sustain activity on the tasks in hand. Studies have shown that when working memory is impaired or limited, automatic (impulsive) behaviour is more likely to occur (Friese, Hofmann, & Wänke, 2008; Grenard et al., 2008; Hofmann, Gschwendner, Friese, Wiers, & Schmitt, 2008). Fourthly, studies have shown a relationship between working memory and thought control - those designated as high on working memory were less likely to experience mind-wandering (Kane et al., 2007). And finally, more recent research indicates that working memory supports the regulation of emotional experience, e.g., anger suppression (Schmeichel & Demaree, 2010). In simple terms, those with high-functioning working memory find it easier to concentrate on the task in hand, regulate their emotions, and resist temptation.

Response inhibition is a concept that relates to the suppression of actions that are no longer appropriate or desired. Response inhibition is necessary to direct behaviour flexibly towards goals (Verbruggen & Logan, 2008). A simple example of response inhibition would be stopping walking across the road on hearing the sound of a fast-approaching car. However, response inhibition refers not just to motor behaviour (i.e., walking, stopping, reaching), but also to attention - diverting our attention from one subject to another. Several studies have linked participants with DCD to poor response inhibition in comparison to TD control groups (Mandich, Buckolz, & Polatajko, 2003; Piek et al., 2007; Verbruggen & Logan, 2008). Response inhibition, like working memory, is also linked to self-regulation. Those low in response inhibition have been shown to have a tendency to react more impulsively in social situations; poor response inhibition may increase the likelihood of adverse outcomes, such as long-term weight gain (Nederkoorn, Houben, Hofmann, Roefs, & Jansen, 2010), increased drug misuse (Berkman, Falk, & Lieberman, 2011; Verbruggen & Logan, 2008), and inappropriate social behaviour (von Hippel & Gonsalkorale, 2005).

Cognitive flexibility concerns the ability to switch from one course of action to another. Previous studies have shown impaired ability in children with DCD in this realm (Piek et al., 2007; Wuang, Su, & Su, 2011).

Planning is a complex EF concerned with strategically organising actions sequentially, and impairment in planning has also been linked to motor deficits. Studies have found that children with DCD typically perform less well in tests of planning than do TD children (Sumner et al., 2016; van Swieten et al., 2010).

Fluency is a measure of how well reactions can be generated in response to instructions, and it is a very under-researched area of EF in regard to DCD. However, Bernardi et al. (2018) and H. Leonard et al. (2015) found poorer fluency ability in studies comparing children with DCD to TD children.

It is hard to overstate the importance of executive functions in our day-to-day living; however, the current DSM-5 definition of DCD does not refer to this or to the significant impact a deficit must have on the individual. In a study of performance skills and emotion in young children with DCD, Liberman, Ratzon, and Bart (2013) found that the impairment of processing skills was far more concerning to the parents than the impairment of motor skills, and revealed that processing skills are seen by parents to have the most impact on participation in activities. Studies have found levels of EF to be a predictive link to further academic success in childhood (Moffitt et al., 2011). The severity of these impairments within DCD is hard to ascertain due to the lack of research, although some functions (particularly working memory) have been studied in much greater depth with DCD participants than with others (e.g., fluency). In a study of 141 adolescents (16-19) with DCD, O'Dea and Connell (2016) found that in adolescence, EF and social skills were the main concern rather than motor performance, which was commonly cited as most problematic during childhood. Of the 141 participants, 93 were either accessing or awaiting

psychological services. H. Leonard et al. (2015) question whether there are different 'constellations' of EF impairment within DCD and if / how these constellations affect overall functioning; however, at present, no research has been conducted in this area.

### **1.2.5 Diagnosis and Stigma**

Segal, Mandich, Polatajko, and Cook (2002) conducted a pilot study into the impact of stigma on six children aged 9-11 with DCD. The study was qualitative - and the analysis (grounded theory) was based on the interviews with the parents of the children and their perception of when/how the children experienced stigma and was understood with reference to Goffman's (1963) conceptual model of stigma.

Goffman's concept refers to 'stigma' as possessing an attribute that makes a person not only different to what other people expect, but in addition, the attribute is seen to be discrediting of the person, in that the difference is negatively valued. The stigma can be based on physical characteristics, beliefs, race, or any other perceived difference. However, the attribute is not necessarily stigmatising of itself, but rather it is dependent on the social context, e.g., being academic and conscientious may be highly prized in some school peer groups, but stigmatising in others. What is important is the social stereotype for the group in question. If a particular attribute does not fit the stereotype it is seen as a 'disqualifying' attribute. Having a 'disqualifying' attribute can lead to being a 'discredited person' that is, someone who is rejected by the group. However, if the 'disqualifying attribute' is not evident or not yet known (e.g., being homosexual in a homophobic environment), the person is a 'discreditable person', i.e., they stand the risk of being 'discredited' if the attribute becomes known. Where the disqualifying attribute (potential stigma) is not visible, individuals carefully manage their activities and their participation so as to limit the group knowledge of this and limit the risk of becoming a 'discredited person'.

Managing a non-visible stigma takes effort, as situations need to be carefully

monitored to gauge whether or not participation will reveal the stigma. Segal et al. (2002) identified various ways in which children restricted participation with peers in order to manage potentially stigmatizing situations where their poor motor skills may become further apparent in order to gain / retain acceptance with their peers. An interesting finding of this admittedly small report was the positive impact of specific task-based OT, as it gave the children a chance to practise and improve relevant motor skills e.g., learning to ride a bike, in a non-stigmatising environment. Once they were able to master these motor skills, the children were then able to participate more with their peer group. Participation is a crucial element of friendship-building. In his longitudinal study of British children at school, Blatchford (1998) found that friendships are formed and stabilised through the medium of physical play/games during break time - crucially around the age of seven. If children with DCD are either being excluded or are managing the threat of stigma by excluding themselves from physical play, this may have a long-term impact on their friendship groups and social support from a young age.

Diagnosis can be a double-edged sword, for whilst it allows the individual greater understanding of their difficulties and, theoretically, access to further help, it can also be seen as stigmatising in itself. Medicalising and labelling difference is convenient in terms of diagnosis and categorisation, but what of the impact on the child/individual that is being labelled? Whether behaviours are seen as laziness, social ineptitude or part of an 'illness' or 'disorder' by others affects the individual, in terms of how they see themselves and how they are regarded within society. Whilst there has been little research into the impact of stigma on children with DCD, research into other conditions illustrates some of the difficulties that can occur.

As Klasen (2000) points out in reference to chronic fatigue syndrome (CFS), when an illness is not recognised the individuals suffer more, as they feel delegitimised - their

perception of their own experience is denied them. However, critics of 'medicalisation' cite the lack of agency that can come about through this, leading to an acceptance of and passive stance towards difficulties. In their work with CFS, Broom and Woodward (1996) found that medicalisation was both helpful and unhelpful with patients worried about the potential 'self-fulfilling' prophecy in being labelled. However, when in a relationship with a collaborative doctor, patients reported a greater sense of coherence and a legitimisation, which helped in a variety of social relationships and importantly they had access to greater support and assistance.

The importance of giving a name to a condition/experience is the first step in recognising its existence and acknowledging the lived experience of the individual affected. However, the medical 'diagnosis' and the phenomenological experience of the individual do not always tally completely. Klasen (2000) found that with so-called 'new' diseases such as CFS or ADHD there was often a discrepancy between the lived experience of the individual and the social construction of a 'disease' or 'disorder'. For example, children with ADHD may construct certain experiences as medical in nature even though these experiences are not easily determined through diagnostic testing: this makes the medical profession unsure about the medical status of the condition.

In his work with parents of hyperactive children, Klasen (2000) found that being able to name their child's problem gave parents a sense of agency and social legitimacy. His work with parents also found that the diagnosis alleviated guilt and feelings of inadequacy and increased a sense of control. It also allowed them to seek and demand help, and they could become less defensive regarding interventions. The only time that labels were found to be unhelpful was when they did not increase the sense of coherence as they were not linked to any further explanations. Klasen did

not research how the children themselves saw this, but the greater sense of control and reduction in feelings of guilt/inadequacy for the parents may have a profound impact on the life of a child. Prior to diagnosis, parents were more likely to label the child as 'naughty' or 'lazy' the implication being that their behaviour was an active choice. Through the medical label of ADHD, this responsibility is removed from the child, and the problem is externalised.

However, receiving a diagnosis does not necessarily ensure further support. Parents of children with DCD have complained that attaining a diagnosis and then subsequently attaining further support was difficult, citing very long waiting times for assessment and follow-ups. Although parents became aware at an early age (often from three years old) that their child was not developing normally, they felt that they were dismissed by health professionals and were disappointed in the lack of knowledge shown by them. They reported difficulty accessing support or information on how to proceed and often had to push repeatedly for their child to be assessed. After diagnosis they were disappointed with the lack of on-going support (Alonso Soriano, Hill, & Crane, 2015; Maciver et al., 2011).

### **1.2.6 Children**

The vast majority of research into DCD has so far concentrated on children rather than adolescents or adults and has highlighted many issues regarding decreased social acceptance, reduced physical fitness, lower self-esteem and poorer outcomes for mental health (Campbell, Missiuna, & Vaillancourt, 2012; Cermak et al., 2015; Jarus, Lourie-Gelberg, Engel-Yeger, & Bart, 2011; Lingam et al., 2012; Missiuna et al., 2014; Pratt & Hill, 2011; Raz-Silbiger et al., 2015; Rivilis et al., 2011; Sugden, Kirby, & Dunford, 2008; Watson & Knott, 2006; Wuang, Wang, & Huang, 2012; Zwicker, Harris, & Klassen, 2013). In a recent qualitative study on children (8-12 years), responses indicated the importance of non-motor-related issues, specifically

the social and emotional impact of DCD, the impact of exclusion, and the need to develop resilience at a young age in response to daily difficulties (Zwicker, Suto, Harris, Vlasakova, & Missiuna, 2018).

#### **1.2.6.1 Social relationships and participation**

In a large study, which matched 159 children (aged 10-11) with suspected DCD with 159 TD peers, a significant increase was found in reported depressive symptoms, as well as reports of victimisation through verbal insults and social exclusion (Campbell et al., 2012). Bullying and victimisation can have long-term consequences. In a meta-analysis of bullying studies, van Dam et al. (2012) found a relationship between being bullied at school and later non-clinical psychotic symptoms; and that the frequency, severity and duration of the bullying predicted the severity of the symptoms.

Why children with DCD are more prone to victimisation/bullying may be due in part to their poorer social skills. Peer acceptance and the development of social skills are crucial issues within DCD; one observation study found that even very young children (aged 4-6) with suspected DCD showed a pattern of both increased aggression and victimization behaviours in comparison to TD children (Kennedy-Behr, Rodger, & Mickan, 2013). Another recent study found that young pre-school children who were designated as 'at risk' for motor problems showed more aggressive and withdrawn behaviours, and their parents reported higher scores for negative behaviours, such as not getting on with peers and being afraid to try to new things (King-Dowling, Missiuna, Rodriguez, Greenway, & Cairney, 2015)

Cummins, Piek and Dyck (2005) found that children with motor difficulties were less able to recognise emotion in others, which might be related to the impaired visuo-spatial processing ability that is often found in children with DCD, and claimed that

motor ability was a significant predictor of social behaviour. Furthermore, impairments in EF have also been linked to poorer social skills (Hofmann et al., 2012; McQuade et al., 2013; Schmeichel & Demaree, 2010; von Hippel & Gonsalkorale, 2005).

A further reason for social difficulties may be the frequently reported issues with participation for children with DCD. Participation refers to the level of engagement and inclusion in activities and situations. In a study of participation of children (aged 5-7) outside of school time, Jarus et al. (2011) found children with DCD chose less diverse and more socially isolated activities, and generally reported less frequent participation. In a longitudinal study over 3 years, Cairney, Hay, and Veldhuizen (2010) showed that this deficit between levels of participation and activity between children with DCD and TD children remained over time. Liberman et al. (2013) identified both motor and processing issues as important in reduced participation. Parents of children with DCD related widespread restrictions on participation for their children due to motor impairment/lack of skills, e.g., not being able to ride a bike with friends, and understood these as having a negative impact on the child's self-efficacy and sense of competence (Mandich, Polatajko, & Rodger, 2003).

For many children with DCD, school is an area where self-esteem is particularly vulnerable. Due to motor coordination difficulties, children with DCD can encounter numerous problems regarding participation, particularly with physical education, in regard to catching, throwing and balance. They typically report less enjoyment than control groups (Cairney et al., 2007; Cairney & Veldhuizen, 2013). Physically, those with DCD are more likely to be overweight or obese (Hendrix, Prins, & Dekkers, 2014) and are more likely to have an 'unhealthy' level of physical fitness (Nascimento et al., 2013). In fact, health-related quality of life is lower in both children with DCD and their parents (Wuang et al., 2012). Children with DCD also face difficulties in

other areas of education, such as mathematics, where problems with number fact retrieval and procedural calculation can lead to a developmental delay of up to two years (Pieters, Desoete, Van Waelvelde, Vanderswalmen, & Roeyers, 2012). They may also have problems in art education as reduced spatial processing abilities make drawing from observation difficult and can lead to feelings of exclusion and failure for children with dyspraxia (Penketh, 2007).

#### **1.2.6.2 Psychological implications**

Parents of children with DCD have reported significant emotional and behavioural problems in their children, which are considered to put them at risk of developing psychopathology (Green, Baird, & Sugden, 2006). The researchers conclude that children with impairment in one area of development (in this case, motor) should also be assessed on emotional and behavioural indicators, and that interventions should consider the psychological health of the child as well as the physical health. The psychological well-being and mental health of children and adolescents with DCD has often been cited as a concern in the research. Farmer, Echenne, and Bentourkia (2016) assessed the psychological health of 129 children (aged 4-18) diagnosed with DCD and found that 83% were designated as anxious and 64% were considered to have low self-esteem. In contrast, Watson and Knot (2006) did not find any significant differences between global self-esteem between the DCD group and their TD peers. However, they suggest that this may be due to the younger cohort and smaller sample (15 children aged between 8-12 years), which may indicate that issues with self-esteem develop more significantly during adolescence. Piek, Baynam, and Barrett (2006) considered the impact of the type of motor impairment and gender on self-worth and highlighted that for all males in their study (those with and without DCD), scholastic competence as well as gross motor ability were significant determinants of self-worth. For all females, scholastic competence and fine motor skills were considered important for self-worth, and for females with DCD,

athletic competence and gross motor skills were additionally linked. This implies that for females, self-worth can be compromised regardless of the type of motor impairment (i.e., fine or gross motor) whereas for boys, it is specifically impairment to gross motor skills that may damage their self-concept.

Although not specifically controlled for DCD, a study of the relationship between manual coordination and psychological functioning in children found that they were dimensionally related (L. Hill et al., 2016). Teachers rated children with poorer coordination lower on the Strengths and Difficulties Questionnaire (SDQ), which aims to assess core symptoms that are associated with childhood psychiatric disorders. Manual coordination explained 15% of the variance. Crane, Sumner, and Hill (2017) administered the SDQ for 30 children with DCD to teachers and parents and compared them to control groups. The teachers reported higher rates of emotional, conduct, hyperactivity, and peer problems, and lower rates of prosocial behaviour for the DCD group compared to TD controls. The parents likewise rated emotional and conduct problems, but rated hyperactivity as more problematic and prosocial behaviour as higher (i.e., less problematic).

Various studies have shown an increase in symptoms of depression and/or anxiety (Missiuna et al., 2014; Piek et al., 2007; Piek, Barrett, Smith, Rigoli, & Gasson, 2010; Pratt & Hill, 2011). Cairney, Rigoli, and Piek (2013) explore this in terms of a stress process model, which incorporates environmental stressors with the impact of reduced physical activity and increased obesity. They use this framework to explore the factors that increase the risk of psychopathology (e.g., peer rejection) and tendency towards internalising issues and those that are protective factors (e.g., family support). Although they recognise that the research is complex when dealing with this population, it is hoped that a deeper understanding of these factors will allow better-targeted interventions for children with DCD.

### **1.2.7 Adolescents**

Adolescence is normally defined as starting at puberty, and in Western cultures, as ending at the end of the teenage years (Steinberg & Morris, 2001). More and more research into adolescence is highlighting the significance of this period in the development of self-concept and self-esteem. In comparison to children, adolescents are more sociable; they develop peer relationships that are more complex and have a greater hierarchy; and they develop an increased sensitivity to the acceptance/rejection of their peers (Blakemore, 2012). Studies referring specifically to DCD in adolescents are less common than studies with children; however, some studies cover an age range from childhood to adolescence and these studies have been included here.

Adolescence is also a crucial period for susceptibility to mental health issues; many mental illnesses have their onset in adolescence, with almost half of all long-term mental health disorders having started by the mid-teens (Kessler et al., 2005; Kessler et al., 2007). One of the main triggers is social stress, which can have a disproportionate impact during adolescence and can lead to internalising disorders such as anxiety and depression. Looking at brain development during adolescence, researchers posit that there are 'windows of vulnerability' when the brain is rapidly developing and most susceptible to negative environmental influences (Andersen & Teicher, 2008). Rejection by peers is a major source of stress during adolescence and has been linked bi-directionally with depressive symptoms; peer rejection has been found to prospectively predict the onset of depression in adolescents, and this was found to be particularly evident in early teenage years (Nolan, Flynn, & Garber, 2003; Platt, Kadosh, & Lau, 2013). Jaspers (2012) found that having motor impairment as a child was a predictor of later neglect or rejection by peers in

adolescence. In terms of gender, female adolescents have been found to be particularly sensitive to social exclusion/rejection (Sebastian et al., 2011).

A qualitative study of the experience of six 13-year-old adolescents (5 male: 1 female) with DCD highlighted the importance of relationships at this crucial stage in life (Payne, Ward, Turner, & Bark, 2013). Participants talked about the importance of social support from family and friends and reiterated the greater significance of peer relationships. Sibling relationships were complicated in that younger siblings without motor impairments could reinforce a sense of inadequacy as they seemingly effortlessly reach milestones that the participant with DCD had struggled to attain. However, in this study older siblings were generally considered to be supportive and to act as role models.

Cantell, Smyth and Ahonen (2003) found that those with more severe symptoms of DCD had persistent and long-term cognitive difficulties in comparison to TD peers, scoring lower for IQ and having lower academic achievement. They were also found to be functioning at a younger developmental age than their peers.

#### ***1.2.7.1 Psychological Implications***

Children and adolescents (9-15, mean age 11.6) with DCD reported higher depression (Missiuna et al., 2014) and anxiety scores, which included panic, social anxiety, phobias and OCD (Pratt & Hill, 2011). In a study of adolescents (aged 11-16), Sigurdsson, van Os, and Fombonne (2002) identified motor impairment with a more than threefold increase in maternally rated anxiety in boys, but this effect was not found for girls.

In a paper examining physical and emotional coherence in DCD, Green and Payne (2018) recommend that researchers and clinicians consider the impact of non-motor factors in order to increase the efficacy of interventions. Harrowell, Hollén, Lingam, and Emon (2017) found that teenagers with DCD had a higher risk of mental health difficulties - being much more likely to report difficulties in peer relationships and also depressive symptoms. They also found that female participants were more likely to report depressive symptoms, and male participants more likely to report peer problems. An important mediating factor in poor mental health was found to be social communication skills. Although this study did not find evidence of lower self-esteem in participants with DCD, it did find that high self-esteem was a protective factor in DCD regarding mental health. The researchers argue that clinicians need to take more regard of psychological well-being in young people with DCD, looking not simply at motor deficits, but also at the possible role of interventions that encourage healthy peer relationships through social communication and that address issues with self-esteem.

#### **1.2.7.2 Self-esteem / self-concept**

Self-concept and self-esteem are two factors that are often discussed in terms of adolescent health. Self-concept is considered to be the image or idea that one has of oneself, including the view of one's own limitations and capabilities - it has also been termed self-perception, self-image, or identity among others. Self-concept does not immediately involve comparison to others (Hattie, 1992). However, a positive self-concept has been linked with superior psychological health, and a negative self-concept has been viewed as a risk factor for anxiety and/or depression (Harter, 1993). In addition, self-esteem, which may also be termed self-regard or self-worth, does imply comparison and judgement, and refers to confidence in one's self (Leary & Baumeister, 2000).

Eggleston et al. (2012) measured self-concept in children and adolescents with DCD and found that they scored significantly lower than their TD peers. A similar result was found by Ferro and Boyle (2013), who compared adolescents with physical illness or developmental disability to TD controls and also reported low self-concept in the developmental disability group.

In a meta-analysis looking at the self-esteem of children and adolescents with minor (e.g., DCD) and major (e.g., spina bifida) disabilities, Miyahara and Piek (2006) found that the severity of the physical disability did not determine the level of self-esteem, and the researchers concluded that major disabilities affect self-esteem to a lesser degree than minor ones. They give three hypotheses why this may be the case. One may be that minor disabilities are less visible and therefore receive less empathy and understanding from others - with poor performance often being attributed to lack of effort rather than to the disability itself, which in turn, leads to increased criticism and judgment. Secondly, it may be that those young people with major physical disabilities are able to develop superior coping skills. They are aware from an early age of their own limitations and the support they need and may therefore be able to better come to terms with this and adapt accordingly. Finally, the different comorbid conditions often reported with minor and major disabilities may affect self-esteem. Participants, specifically those with DCD, reported lower self-worth and higher levels of state and trait anxiety at 8-10 and 12-14 years old in comparison to other matched TD participants, and the difference in reported self-worth between the two groups increased from childhood to adolescence (Piek et al., 2006).

### ***1.2.7.3 Physical well-being***

Looking at comparisons in general and physical health between 16-18 year olds diagnosed with DAMP, ADD, or motor perception dysfunction (MPD) compared to their TD peers, Hellgren, Gillberg, Gillberg, and Enerskog (1993) found that those

with DAMP continued to show more health issues, including a higher rate of hospital admissions, than the general population. There was also a higher reported incidence of substance misuse. This alternative classification of DAMP makes it difficult to draw conclusions regarding DCD, as the increase could be due to attention deficit issues solely. However, the study found that the MPD group was more similar to the DAMP group than to the TD control; and that the ADD group was more similar to the TD control than to the DAMP group. This may indicate that the poorer outcomes are related to motor impairment, rather than solely to attention deficits. However, due to the small number of cases, the researchers urge caution in interpreting these results. Barnett, van Beurden, Morgan, Brooks, and Beard (2009) found a link between motor skills regarding object control (i.e., catching, kicking) and physical activity in adolescence, with proficiency in object control predicting participation in vigorous activity.

General health was found to be lower in adolescents (13-14 years old) with DCD. Coverdale et al. (2012) found that reduced baroreflex sensitivity, which is predictive of future cardiovascular disease and death, was reported as a greater risk in the DCD group; however, further analysis found that the percentage of body fat was the predictive factor rather than DCD in itself. This highlights the issues and implications of weight / fitness in adolescents with DCD. Adolescents (12-13 years old) with DCD had lower cardiorespiratory fitness compared to TD peers, which may indicate poorer health issues in the future (Silman, Cairney, Hay, Klentrou, & Faught, 2011). The research also highlighted the contribution of lower physical activity and perceived lack of adequacy in physical activities as significant contributors towards this difference. In late childhood and early adolescence, those with DCD are much less likely to be physically active: low self-efficacy rather than limited motor skills accounted for a sizeable proportion of this relationship. Children with DCD are also

more likely to be obese or overweight, although this applied exclusively to boys (Cairney, Hay, Faught, & Hawes, 2005; Cairney et al., 2005)

### **1.2.8 Adults**

The long-term impact of DCD is also poorly researched, although the past 5 years have shown an increase in the number of papers published. Many of the studies look at 'emerging adulthood'. This is considered to be the significant bridge between adolescence and adulthood; in Western societies, it is marked by an increasing independence from parents, although a level of dependence remains, e.g., students who are reliant on parents for support, but live mostly away from home. However, it also refers to a time when the 'emerging adult' can experiment in work and social situations with relative safety. It is a critical time for developing individual value systems and adjusting to societal norms (Kirby et al., 2011). Young people with DCD are more likely than other students in Further Education to be living at home with their parents (Kirby, Williams, Thomas, & Hill, 2013). Hill, Brown, and Sorgardt (2011) found that the quality of life reported by adults with DCD was significantly lower across all domains (e.g., physical health, leisure, social, emotions). A study investigating the environmental stress model in relation to DCD with young adults (18-30) found continued difficulties regarding social acceptance. When social support was perceived to be low, this negatively affected mental health, which highlights the importance of social support in mental health outcomes and interventions to improve them (Rigoli et al., 2016).

A phenomenological study into the lived experience of young adults with DCD found that the negative consequences of DCD were still apparent and recognised in adulthood; however, the participants felt more able to create positive situations. The greater control and freedom that adult life permits meant that participants felt less pressure to fit in with others (Missiuna, Moll, King, Stewart, & Macdonald, 2008).

However, many young adults were still struggling with aspects of academic functioning and activities of daily living. They reported more negative emotions and lower self-esteem than TD peers; this was more significant for the males in the group (Tal-Saban, Zarka, Grotto, Ornoy, & Parush, 2012). In view of the ongoing impact of DCD on young adults, Tal-Saban, Omy and Parush (2018) argue that a biopsychosocial model should be used to understand the complex causes and factors involved and to help design appropriate and effective interventions. Such an approach highlights the need for awareness of each factor (biological, psychological and social) and calls for a holistic approach. Psychological distress for the individual with DCD may be high and dealing with depression and anxiety and improving participation and self-esteem are important elements within the structure.

#### ***1.2.8.1 Psychological implications***

Kirby et al. (2013) compared adults with DCD both in and out of work and found that both groups reported dissatisfaction with life and higher levels of depressive symptoms and anxiety compared to the general population. They highlighted the need for mental health professionals to take account of DCD when delivering interventions. Furthermore, higher rates of anxiety and depression were found to continue into adulthood (E. Hill & Brown, 2013). The researchers also question whether these symptoms are a core or secondary part of DCD - i.e., are they caused through cognitive dysfunction / brain structure deviations or environmental stress - and call for more research into motor difficulties and mood impairment. Schiffman et al. (2015) looked at a cohort study and found childhood DCD as a possible indicator for vulnerability to adult-onset non-affective-psychosis spectrum disorder.

#### ***1.2.8.2 Participation and Quality of Life***

Participation continues to be an issue for teenagers and young adults with DCD. In a scoping review of 28 articles regarding social participation challenges for young

adults (15-25), Gagnon-Roy, Jasmin, and Camden (2016) concluded that those with DCD face challenges in all 12 key areas of life, typically showing deficits in comparison to their TD peers. The challenges were categorised as education (planning, memory, organisation), communication (written, verbal and non-verbal), interpersonal (bullying, exclusion, lack of confidence), community life (less participation), recreation (less sport or group activities, more sedentary), fitness (easily tired and less fit than peers), employment (EF difficulties were reported, higher percentage un- or underemployed), mobility (fewer adolescents with DCD are able to drive), personal care (difficulty with novel task e.g., packing for holiday and some fine-motor task e.g., shaving or make-up), nutrition (meal preparation was seen as challenging), housing (more likely to stay with parents for longer, difficulty with some chores), and responsibilities (difficulties with financial management/planning etc.). This highlights the continuity of challenges faced by people with DCD after education finishes and structured support drops away. Quality of life remained an issue; it was also found that young people continued to score low on self-esteem and self-worth and demonstrated higher symptoms of anxiety and depression.

However, it is also important to note that some improvements were found in adolescence/adulthood - some participants felt they could 'function' better and that the discrepancy between their ability and that of their peers was no longer so marked. This could be due to increased practice and / or to the reduction in compulsory participation in sports or other activities that they found difficult. Many participants highlighted the use of coping strategies, such as humour, or the choice of an appropriate activity. In conclusion, Gagnon-Roy et al. (2016) highlight the lack of evidence-based interventions for this population and the need to improve social participation and quality of life into adulthood.

## 1.2 Summary

Unfortunately, until recently, there has been little consistency among the studies as to how to determine DCD among participants. In some studies, the term used is 'suspected' or 'probable' DCD, which was normally assessed by parental completion of the DCDQ (B. Wilson et al., 2009) - a parental report form which is commonly used to diagnose DCD and has been found to have high internal consistency (Civetta & Hillier, 2008). However, in some research (Campbell et al., 2012), this put 20% of participants into the DCD category, which is far higher than the 5-6% accepted prevalence rate. Other studies recruited from the local dyspraxia foundation and asked for no formal diagnosis while others required either a prior clinical diagnosis or both DCDQ and occupational health assessments; likewise, some studies allowed for comorbidities, whereas others did not. Many studies relied on parental report for findings on behavioural and emotional responses, such as anxiety, whereas some asked for self-report.

However, despite these variations in definitions and methodologies, it is apparent from the number and consistency of the findings of the research across age-groups that those diagnosed with DCD or motor coordination problems are responding differently and more negatively than other children/adolescents with regard to self-esteem, quality of life, participation, physical and mental health. It is vital that these studies are followed up with valid and reliable qualitative investigations into the experiences of those who are considered to have DCD.

In a study to determine best practice for the delivery of service to children with DCD lack of awareness regarding the condition and lack of collaborative working (i.e., actually asking those with DCD how best to help) was found to be a major stumbling block to effective support (Camden et al., 2015). As counselling psychology is

primarily interested in the experience of the client, understanding the system within which the client exists and promoting positive health over pathological determination (Altmaier & Ali, 2011), the lack of research from a counselling or clinical psychology perspective indicates that those with DCD have so far been ill-served by our profession. Perhaps because of the nature of developmental disorders, DCD has been seen as the responsibility of educational psychologists, occupational therapists, or paediatricians. However, as Kasket (2012) states, a counselling psychologist is not just a psychologist who happens to do some counselling; rather, counselling psychology refers to '*professional practice with diverse populations across a wide variety of settings*' (p. 65). The lack of research interest into this vulnerable group by either counselling or clinical psychologists may be one of the reasons that psychological well-being has been relatively neglected thus far. This research hopes to begin to redress the imbalance by taking into account the views of those with DCD and to allow a better understanding of the phenomenological experience.

## **2. Methodology**

### **2.1 Overview**

The study has a qualitative design as it is primarily interested in the lived experience of individuals with DCD. It is exploratory and aims to complement the body of mostly quantitative research already available. Data were collected by means of a semi-structured interview and was analysed using interpretative phenomenological analysis (IPA) (Smith et al., 2009).

### **2.2 Qualitative Approach**

Current psychological research on DCD has mainly been carried out from neuro-scientific, developmental and educational perspectives, mostly looking at positivist outcomes rather than interpretivist ones. Indeed, it is comparatively rare for those with DCD to be given an active role in research, with qualitative studies often focusing on parental experience.

Even though positivist research is equated with a belief in a fixed external reality, as discussed in the literature review, the definition of DCD is not straightforward and has evolved over time. An acceptance of the definition of DCD leads the researcher into a realist stance; however, the purpose of this study is not to determine the nature of DCD or the validity of the diagnosis, but to examine how those who are diagnosed experience the world as they navigate their way through adolescence.

The quantitative / positivist approach, whilst useful in identifying potential causes or correlations and clarifying degrees of impact etc., does not tell us about the lived experience of those with DCD, and therefore excludes their own personalised involvement and viewpoint from the body of research. In a study to determine best practice for the delivery of service to children with DCD, Camden et al.(2015)

identified the lack of awareness regarding the condition and the lack of collaborative working (i.e., asking those with DCD how best to help) as major stumbling blocks to effective support and involvement. The overwhelming preponderance of quantitative research seems to indicate that this lack of collaboration is mirrored in the academic world. Furthermore, as a counselling psychologist, my interest and role lies in understanding the world of the client and in how the client experiences and makes sense of life; as well as understanding and paying attention to the role of the system in which the client exists and in promoting positive health over pathological determination (Altmaier & Ali, 2011). The methodology of this research recognises the imbalance of the research so far and aims to prioritise the experience of those with DCD and allow a better understanding of their phenomenological/lived experience as a way of informing research.

### **2.3 Epistemological Framework**

In the vast majority of research on DCD, the ontological stance, that is the theory of what exists, has been strongly realist, i.e., there is an external reality and it can be observed and measured, normally by means of self-report questionnaires, or observation. Such a stance is common among medical and clinical professionals and is typified by DSM definitions, which by their nature, define a disorder/syndrome as an external reality. This has led to quantitative, positivist methodologies being employed, that is, methodologies that aim to measure a quantifiable reality.

However, living with DCD is a personal, social, and nuanced experience, which can also be seen as socially constructed, especially in terms of diagnosis, education and physical expectations. Within the social sciences an interpretivist or post-positivist position is more common than in natural or medical science, and often this entails a relativist viewpoint; that there is no external reality or 'truth' out there and everything is understood in its own context.

The ontological stance (what exists) must inform the epistemology, which is the philosophy of knowledge or how we can know what we know (Outhwaite, 1987). A realist stance, which dictates that there is a fixed, external reality or truth, will necessitate a different epistemology and methodology (normally positive and hypothetico-deductive methods which aim to eliminate bias) compared to, for example, a constructivist approach, which claims that it is impossible to eliminate bias and that our individual 'reality' is shaped by context such as language, society and culture. Whereas a realist stance will hope to develop universally applicable rules, a constructivist stance aims to develop insight (Marks & Yardley, 2004), Constructivist positions aim to understand how others make meaning in their own world (Punch, 2005). However, despite this difference, there is not a rigid protocol defining a route from ontology/epistemology to methodology; rather, the researcher must clarify and explain their chosen rationale.

A valid methodology in respect of the epistemological stance of the researcher is crucial. For this research I have taken a critical realist stance. This means the acceptance of the possibility of an independent reality, but it is tied to an appreciation that each person must have a different understanding of that reality and that any measurement of 'reality' is fallible. For critical realists, theories must be open to revision. This allows an open or flexible approach to epistemology and methodology (Outhwaite, 1987). Critical realism rejects the absolute truth of one measurable reality and understands that everything is filtered by individual subjectivities; however, unlike radical constructivist paradigms, it allows research to be grounded in the accounts of the participants.

According to critical realist theories, the world (i.e., reality) exists as different layers or domains of reality. The 'empirical domain' can be directly observed and this is

where quantitative studies (such as the vast majority of the present research into DCD) are mostly directed. However, if we wish to examine how patterns of behaviour are produced and this is not directly observable, we need to explore the 'real domain' in an open system (Bhaskar, 2008). This is the approach most commonly taken in qualitative studies, where society and culture (or the lived world of the participant) form an 'open system' rather than an experimental 'closed' environment where interactions and unpredictability of outcomes/effects are assumed (Roberts, 2014). The use of semi-structured interviews (which took place in each participant's home) aimed to reinforce the social world and context by giving the participants greater power / direction of the process.

Within critical realism there is an emphasis on the fallibility of knowledge. It assumes that the world is complex and difficult to understand and that researchers need to keep searching in different contexts (Benton & Craib, 2001). Furthermore, it recognises that positivist measures alone cannot explain meaning within social phenomena, which is necessarily interpretive (hermeneutic). Because of the fallibility of measurement, a critical realist is open to different methodologies and aims to triangulate the knowledge that comes from them, rather than promote one type of knowledge as 'authentic' and of greater value (Clark, 2008).

By taking a critical realist stance, the knowledge already attained from quantitative studies can be built upon. Marks and Yardley (2004) make the analogy of quantitative studies being like a map that tells you where you are, whereas qualitative studies aim to explore and explain what it is like to be there. Both give information on the place, but the knowledge has a different quality and purpose. Whilst knowledge of the participants' lived experience has been lacking within much of the research so far, this does not invalidate that research. This study aims to add to the body of research and give greater insight into the issues involved.

The critical realist stance also allows the researcher flexibility in approach so that DSM-5 definitions and medical diagnoses can be accepted as a 'reality' experienced by the participants, even though there is ongoing debate regarding the utility of such labels or their 'validity'.

#### **2.4. Interpretative Phenomenological Analysis (IPA)**

As the lived experience of the participant has been a major omission in much of the research conducted to date, IPA (Smith, Flowers, & Larkin, 2009) was selected as the most appropriate approach for the methodology, as the focus of the research is to provide an in-depth study of the participants' own experiences. The main aim of IPA is to gain insight into the experiences of the participants and to gain an understanding of the quality of those experiences, rather than to develop theories, as would be the case with grounded theory (GT) (Bryant & Charmaz, 2012). IPA is particularly interested in the subtle distinctions of an individual's experiences that are hard to capture using positivist methodologies (Willig, 2013).

IPA has three central theoretical pillars: phenomenology, hermeneutics, and idiography (Smith & Shinebourne, 2012).

Phenomenology refers to the attempt to gain an intimate understanding of the participant's world and 'lived experience', it is associated with the early 20<sup>th</sup> century philosophy of Husserl and Heidegger (Heidegger, 1962; Husserl, 1989). It is not interested in 'objective truth', that is, in rules for the world in general or the abstract, but purely in how we experience the world. Thus, the critical question for Husserl was: What do we know as individuals? His phenomenology aimed at describing everyday conscious experiences while setting aside or bracketing preconceived opinions. For this reason, Husserl's approach is sometimes called descriptive

phenomenology. Phenomenology for Heidegger was interpretive, not descriptive. For Heidegger, every form of human awareness is interpretation. It is based on a rejection of the presupposition that something is behind or underlying experience: the hidden reality. What appears, what is experienced is what matters. As Crowell (2013) states, for Husserl, phenomenology was a science of consciousness, while for Heidegger, it was an approach to being. The experience of my participants is not merely being described, but also, there is a layer of interpretation on my part as to the meaning and context of their comments. Sometimes this interpretation may be based on linguistic emphasis or an apparent contradiction. Although I am attempting to get inside the world of the participant, I am aware always that I am separate from them, and my experience of their experiences is not the same thing.

It is acknowledged in IPA that the researcher is restricted both by their own paradigm/sense of understanding and the ability of the participant to adequately explain or acknowledge their own reality. This is known as a double hermeneutic, as the researcher tries to make sense of the participants trying to make sense of their world (Smith & Osborn, 2008). In this research, reflexive diaries were made use of both after the interviews and during the analysis to make note of personal thoughts / ideas. Whilst 'bracketing' off our own perspective is not always possible, it is important to acknowledge that we do have a distinct perspective and that this affects the study. As a parent of a teenager with DCD, I was aware that my perspective was heavily weighted towards the parental perspective. This was something I had to consider often in my analysis, as I was attempting to get the adolescent perspective/experience and therefore needed to be highly cautious of imposing overtly 'parental' viewpoints or interpretations.

An idiographic stance refers to the attempt to understand the complexity and unique experience of the individual (Smith, 2015). This is at the forefront of my study. The

impact of DCD, especially during adolescence, a time of additional life stress and change in self-perception, cannot be described in uniform, simplistic terms. Each participant has their own background and perspective, and giving them space to explore this, without the constraints of a rating scale or of marking 'strongly agree' was important to me. The freedom of this approach allows the participant a greater say in the research and in what is analysed.

However, there have been several criticisms of IPA. Giorgi (2011), for instance, has been particularly vocal in his opposition to IPA on the grounds that it is not truly based on phenomenology and that the methodological procedures are so vague that they cannot be counted as a scientific method. He sees IPA as a pragmatic approach to qualitative studies based on empiricism, but which has little to do with phenomenology or hermeneutics. His further argument is that the lack of guidelines on how to apply the IPA method renders it impossible to replicate/check the research, and so it does not meet the criteria of good scientific practice. Certainly, the vagaries of the procedure in IPA make the replicability of studies problematic, and if IPA is idiographic, as Smith claims, what can this tell us about phenomena of DCD in society rather than its meaning concerning one specific individual? Is the data generalizable in any way? I would argue that each study contributes to our knowledge and understanding of the experience of adolescents and that taking a critical realist stance towards this means that we can build on the knowledge, not just of what is happening, but how that feels, how that is experienced. IPA offers a valuable contribution to the existing body of research, particularly in view of its strong emphasis on the lived experience of the participant and the weight given to the participant's own perspective.

Grounded Theory (GT) could also provide a methodological route to explore the experiences of those with DCD. GT, as developed by Glaser and Strauss (1967), has

a realist orientation; it aims to discover external 'processes', however the aim is not to solely explore the experiences of the participants, but also to build an explanatory framework from which to understand the phenomenon. During GT, the researcher moves from data collection to data analysis. A typical GT research question, e.g., *'How do those with DCD experience adolescence?'*, is not dissimilar to an IPA question; it is open-ended and does not make assumptions. Again, semi-structured interviews or focus groups could be used as part of the method. However, the methodology here aims to build a theory. The focus is removed from the experiences of the participant to the theory building of the researcher and to processes rather than experiences. Further criticisms of GT state that it sidesteps the question of reflexivity, which is crucial to IPA. GT has also been criticised for being more descriptive than explanatory - a process of categorisation, which does not capture the essence (Willig, 2013).

There have been further developments in GT, including a constructivist perspective (Charmaz, 2006), which places much greater emphasis on the participant's own definition of terms and his/her assumptions or implicit meanings. A constructivist stance could also be applied to this research using either GT (Charmaz, 2006) or a form of discourse analysis as a methodology. In taking a relativist ontological position regarding DCD, implicit meanings take a greater priority and much attention is focussed on the language of the participant. Likewise, the presumptions that society makes as to 'typical' or 'normal' development and the construction of labels that segregate neurological differences and define them as impairment or problematic would be a relevant avenue of research. Why are children labelled with DCD? How does this come about, and who benefits from the diagnosis? Madill, Jordan and Shirley (2000) refer to this viewpoint as radical constructionist. These are valid questions in regard to education, where children with developmental disorders are seen to have 'a problem', rather than the school or education system not delivering

an appropriate education, and a diagnosis is the first step to gaining extra help and resources for a child who is struggling. Molloy and Vasil (2002) name this the 'pathologising of difference' in their post-structural analysis of Asperger's syndrome. Furthermore, the divergence over exact definitions and terms for DCD, percentage of population affected, as well as the comparatively low rates of research and public knowledge also raises questions of social construction. The method for such research could still be based on semi-structured interviews; however, a wider range of participants, including medical and educational professionals, as well as parents, would be helpful. The methodology would more likely involve a discourse analysis (e.g., Foucauldian), which could examine the power positioning of the one who is diagnosed as 'having the problem' (Willig, 2013). An examination into the construction of DCD as a 'development disorder' and an exploration of the power positioning inherent in the system is a valid aim of academic research. However, I felt that the body of evidence indicating consistent levels of negative outcomes for those diagnosed with DCD was better explored using an interpretivist epidemiology, that is, an attempt to understand how others make meaning in their own world (Punch, 2005) and that this would be more in line with the philosophy of counselling psychology and, most importantly, would be of greater present value for the population being researched.

Counselling psychology traditionally takes a humanistic approach to research. It is concerned with the subjectivity, context, and diversity of experience (Orlans & Van Scoyoc, 2008) and has historically been largely absent in studies of DCD to date. The quantitative, positivist data gathered so far has indicated that those diagnosed with DCD suffer greater distress and difficulty than those who are not. However, research has not clarified in detail how this feels to the individual, e.g., what the experience is like, and what is crucial to the experience. Taking a critical realist stance means that an interpretivist paradigm will add to this research, not diminish it.

Thus, IPA will allow those most affected to inform scientific inquiry as well as to be informed by it.

## **2.5 Procedures**

The method chosen for this research was semi-structured interviews with adolescents (aged 11-18) with a diagnosis of DCD. Using semi-structured interviews minimised the restrictions imposed by questionnaires or rigid protocols. Furthermore, it allowed the participants scope to explore their own feelings/meanings whilst also allowing me to keep the responses close to the research topic. It is extremely important that participants feel able to speak freely within this method, and therefore a large responsibility lies with the researcher to communicate openly and foster a relationship of acceptance and respect (Willig, 2013).

## **2.6 Sampling and participants**

Originally, I had hoped to recruit from my local area and so emailed letters detailing the research method, the aims of the study, and the participant criteria (see Appendix B) and a recruitment poster to be displayed/distributed to parents detailing the nature of the study and the criteria for participation (see Appendix C) to head teachers / special educational needs coordinators (SENCO) and local occupational therapy (OT) clinics, as well as to the Dyspraxia Foundation. The Dyspraxia Foundation agreed to put the research to its own ethics committee.

The initial response from schools was poor. It was difficult to speak to those responsible, and they were often very busy and reluctant to be involved in any further way. The timing of my request (June) was not optimal, as focus was on the long summer break. Furthermore, DCD did not seem to be a high concern, with one SENCO at a school of 700 boys informing me that she had only one student who

would qualify. The OT clinics were happy to display the recruitment poster but mostly did not deal with children over the age of 10 or 11. The original inclusion criteria were for participants with a diagnosis of DCD (e.g., from an educational psychologist, paediatrician or occupational therapist) between the ages of 11-18.

Originally, other developmental disorders, such as ADHD or dyslexia, were to be excluded; however, on the advice of the Dyspraxia Foundation and the OTs I had contacted, who felt that adolescents with DCD would be a hard to reach population and that excluding co-morbidities would create an even greater challenge, I removed this exclusion. This posed certain challenges, as I felt that restricting the participants only to those with DCD allowed for a 'purer' result. Obviously, in terms of quantitative studies with a positivist/realist stance, these criteria are often strictly applied.

However, one criticism of quantitative studies is that in their attempt to apply rigorous controls they do not actually reflect reality. This can be seen in randomised controlled trials (RCT) of, for example, depression, where additional comorbidities are normally excluded. Whilst this is of benefit for drawing specific conclusions, it may not reflect the clinical reality that we experience as counselling psychologists (Fonagy et al., 2015). My aim in this study was to explore the experience of those diagnosed, and disregarding those with further diagnoses could be seen as imposing a false boundary - taking the stance of the medical profession rather than regarding the lives of the participants. As the recruitment poster was specifically directed towards those with DCD, or their parents, and ultimately only those who saw the advert on the Dyspraxia Foundation website were recruited, it can be assumed that they all identified strongly with this diagnosis, and it was their perspective and experiences that were a priority for me. I felt further justified on meeting the participants on discovering that two of them were awaiting further assessment for other possible developmental disorders - any participant diagnosed with only DCD could later be diagnosed with a further comorbidity. As discussed in the literature review

boundaries between developmental disorders are often fluid (Baird, 2013) and I felt taking a phenomenological approach justified allowing the participants to decide if the impact of DCD on their lives was such that they wished to participate in a study and contribute their experience.

After two months the Dyspraxia Foundation processed my application through their own ethics committee (see Appendix D), and advertised the recruitment poster, which I had updated to remove reference to no further diagnoses, on their website. I also contacted an organisation called 'Dyspraxic Me' which is a London-based peer support group for those aged between 16-25. Although one potential participant contacted me through this site, we were unable to arrange an interview due to his schedule and upcoming A-Levels.

In total, twelve participants were recruited solely through the Dyspraxia Foundation - however one was excluded, as he was too young (a few weeks shy of 11) at the time of the interview, and it was felt that his experience was more reflective of childhood than adolescence. This left eleven participants in total. Qualitative research typically has a smaller number of participants than quantitative research, and as IPA is concerned with a detailed individual account of experiences and a smaller number of cases allows for deeper and more focussed work. Smith et al. (2009) state that for professional doctorates numbers between four and ten participants is considered appropriate. Eleven is therefore at the high end of interviews for IPA, but I felt that it was appropriate for several reasons. Contrary to my expectations, the majority of the participants were female, with a ratio of 8:3. Some of the last participants to accept were male, and I felt it was important to include their experience. As I was interviewing adolescents, I was concerned that some of them may drop out or decide on the day not to take part. I was not sure how far the parents had influenced them in taking part, and my role as a researcher was to assure them that their participation

was totally voluntary. As it happened, all of the participants were happy to participate. Furthermore, I was not sure if the data from all the participants would be suitable for IPA, which demands 'rich data', meaning the participants need to be able to 'to tell their stories, to speak freely and reflectively and to develop their ideas and express their concerns at some length' (Smith et al., 2009). Geographically, the participants' homes were dispersed throughout the British Isles including Wales, the North East, Midlands, London and the Home Counties. Having been contacted by the parent or guardian of the adolescent (and in one case by the adolescent themselves), I emailed further details of the study - the parent information form (see Appendix E), and the adolescent information form (see Appendix F) which was worded in a simpler way. These forms clearly explained the purpose of the study and detailed what was to be expected in terms of the interview. I also included the consent form for the parent/guardian (see Appendix G) and participant (see Appendix H). These forms made explicit the extent of confidentiality and the right to withdraw from the process. Once the parent/participant had read through the information and indicated that they were happy to take part a date for the interview was arranged.

### 2.6.1 Participant List

<b>Participant</b>	<b>Age</b>	<b>Comorbidity</b>
Rory	11	no
Skye	11	SPD / Awaiting assessment of dyslexia
Megan	12	SPD
Sophie	14	no
Florence	15	no
Kara	14	Awaiting assessment of dyslexia/ASD
Zac	13	no
April	12	no
Eliza	18	ASD

Ruth	17	Dyslexia
Ted	13	No

### 2.6.2 Key to abbreviations

ASD	Autistic Spectrum Disorder
SPD	Sensory Processing Disorder

Sensory Processing Disorder (SPD) is not recognised in the DSM-5 and there is some controversy regarding its validity as a diagnosis. However, two of the participants were given this diagnosis by professionals and therefore I have included it here, as it is representative of their understanding of themselves and diagnosis. Sensory processing disorders (SPD) are stated to affect 5–16% of children and refer to disrupted processing and integration of sensory information (Owen et al., 2013). Clinical descriptions of children with SPD indicate that they have an atypical response to sensory information in that they may misinterpret or feel overwhelmed by it, seek out intense sensory experiences or simply fail to recognise/respond to it. They may therefore show difficulty paying attention and are more likely to display behavioural difficulties, especially if distressed by sensations such as loud noises normally considered within a normal range (e.g. toilet flushing) or certain textures (e.g. seams on socks) (Schaaf et al., 2010).

### 2.7 The Interview

The data were collected by means of semi-structured interviews. An interview schedule was prepared taking into account previous research findings and also with the aim of giving a framework to the interview and making it easier for the participants to contribute (see Appendix I). The interview schedule had six separate general areas of questions and a closing section regarding how the participant had experienced taking part. The sections were devised based on previous research and

covered: the meaning of DCD for the participant, the impact on self-esteem/ self-concept, peer relationships, physical wellbeing, other people's reactions, and future expectations. Prompts were available for each section, e.g., when asking about the meaning of DCD, prompts such as

- 'Can you remember how you felt when you were told you had DCD?'
- 'How would your life be different if you didn't have DCD?'

could be used to help the participant explore the subject further. However, the use of prompts depended on how easily each individual participant was able to explore independently. The interview schedule was piloted on two adolescent volunteers (my son, who has DCD, and a further acquaintance). Compared to some IPA studies with adult participants, the questions could be considered more directive, e.g., specific questions were asked regarding what type of support the participants received at school, rather than relying solely on very general open question and more gentle probing. However, Smith (2004) highlights the importance of adapting techniques for different populations, e.g., children or those who do not have English as a first language. The alternative would be to limit IPA to only those who are fluent and are able to readily recognise, express and explore their own emotions without prompting. In my therapeutic experience with adolescents, I have also found that they can sometimes react negatively to the persistent use of open questions, which they can find 'weird' and often need more prompting to explore difficult issues. Most of the participants had never been interviewed in such a way before and certainly not about their feelings regarding DCD (or indeed adolescence), and it was my intention to make the experience as safe and containing as possible.

In order to do this, the interviews took place in the participants' own home. Before the interview took place, I had a quick informal chat with the parent and adolescent regarding when and how DCD was diagnosed, and if there were any further diagnoses. I also introduced myself as the mother of an adolescent with DCD, as I

felt this would make the interview feel less formal and would put the participant and guardian at ease.

Due to age constraints (all but one of the participants being under 18), a parent or guardian needed to be present in the house at all times, though not in the same room. This ensured that the participant had privacy to discuss difficult issues (such as guilt concerning the effort/role of parents in supporting them) while benefiting from the safety of their home environment and the nearby presence of a loved one.

Care was taken to make the interview as easy and comfortable for the participant as possible. Before starting the interview, I made sure both the parents and adolescent were aware of the limitations of consent. I assured the participant that whilst the information they gave me was confidential, if I felt what they told me indicated that they or anybody else was in danger of harm, or if I felt their distress was so great that they needed external support, I would need to break this confidentiality. I explained this in terms of serious bullying or self-harming scenarios. The participant and parent/guardian signed the consent form before continuing.

When alone with the participant, I confirmed once again that they were happy to take part in the study, and I reiterated that they did not have to talk about anything they felt uncomfortable with and that they could stop the interview or withdraw from the study if they wished. Only one participant asked for a short pause when she became distressed; however, she quickly recovered and wished to continue. At the end of the interview, I checked with all the participants how they had experienced the process and asked if there were any key elements about living with DCD that I had not asked them about or if there was anything else they wanted to tell me.

I recorded the study on two separate voice recorders to ensure that I had an

acceptable recording. These recordings were then transferred to my home computer, password protected, and deleted from the recording devices. After each interview, I debriefed the participant (see Appendix J) and if appropriate, I spoke to the parents. This occurred once when a participant told me she had self-harmed. She had told me that her parents were aware of this and that she was waiting for a referral from CAMHS. With her permission, we discussed this together with her parents at the end of the interview. The participant assured me that she was not currently self-harming and the parents confirmed that they were aware of the situation and seeking help. After each interview, when on my own (normally in my car) I noted down my feelings / thoughts about the interview as part of my own reflexive diary.

## **2.8 The Process of Analysis**

Although Smith et al. (2009) state there is no clear right or wrong way to conduct IPA, they define the following six stages:

Step 1: Reading and re-reading

Step 2: Initial noting

Step 3: Developing emergent themes

Step 4: Searching for connections across emergent themes

Step 5: Moving to the next case

Step 6: Looking for patterns across cases

However, I consider two preceding steps to be integral to the analysis, namely reflective notes taken immediately after the interview; and the actual transcribing process. Therefore, the stages I will detail are as follows:

Step 1: Reflexive notes/diaries

Step 2: Transcription

Step 3: Reading and re-reading and re-listening

Step 4: Initial noting of themes

Step 5: Developing emergent themes

Step 6: Searching for connection across emergent themes (by case)

Step 7: Moving to the next case

Step 8: Clustering themes into sub themes and master themes (comparing across cases)

Analysing one case at a time is typical for IPA as the approach taken is idiographic which means that the researcher works intensively with one participant, attempting to gain a phenomenological understanding of their experience through the text and only integrates the data at a later stage, once all the individual material has been analysed (Willig, 2013).

### **2.8.1 Step 1 - Reflexive Notes**

After each interview, I recorded my initial thoughts as recommended by Smith et al. (2009). These included descriptions of the setting, how the participant appeared and any thoughts and feelings that arose. For example, with Sophie, I noted her optimism for the future. I was struck by the feeling of someone grappling to make sense of the world. Although Sophie described many difficulties and was open and frank about her struggles with the emotional impact, I did not come away feeling sad or worried about her - rather I had a sense of a very determined person with a warm and supportive family. I noted that I thought she was 'a fighter'. However, with Megan, I felt a real sense of sadness that this young woman was really struggling to gain acceptance and had a keen sense of alienation and struggle.

### **2.8.2 Step 2 - Transcription**

Transcription for IPA is not as detailed as that used in conversational analysis, which makes note of the length of pauses and other prosodic details (Atkinson & Heritage, 1999); for IPA the emphasis is on meaning not on detail. Therefore, if the participant sighed loudly or hesitated this was indicated in the transcript - whereas the exact length of pauses (a pause was indicated by '...') was not regularly noted unless they

were felt to be unusually long and therefore to affect the meaning in some way, e.g., showing a sense of unease. The important guideline for me was to represent the interview as faithfully as possible, allowing the participant's own character and voice to be reflected rather than focussing on detail. Therefore, a sudden nervous laugh or the voice suddenly going quieter would be recorded, as this reflects a sense of meaning, a change in how the participant is explaining or describing events.

Transcription is a time-consuming process and it is estimated that one hour of recording can take up to 10 hours to transcribe (Willig, 2013). I typically spent one weekend per interview (interviews varied from 30 to 90 minutes) on transcription. Whilst not formally indicated by Smith et al. (2009) as part of the analysis, and whilst no notes were taken during the process of transcription, the renewed contact with the source material brings attention to individual elements of the interview and the participant, particularly the tone and quality of the voice, times of hesitancy and mummings, as well as re-connecting the researcher with feelings evoked during the interview. I feel that the conversion of the interview to text is an integral part of the process of analysis that is not given sufficient weight in literature.

### **2.8.3 Step 3 - Reading, re-reading, and re-listening**

Smith et al. (2009) recommend noting down any first impressions or recollections of the interview, so as to bracket them off before the actual analysis begins. I found it useful to go back to my original diary notes and add and update thoughts and feelings on re-encountering the data. Bracketing off our original feelings or thoughts is an integral element of Husserl's descriptive phenomenology (Smith et al., 2009), which states that putting aside that which we take for granted will allow us to concentrate on the phenomenological experience of the participant rather than pre-conceptions of the researcher. However, many would argue that this is not possible, and IPA itself demands a more interpretative rather than purely descriptive stance.

Writing down my impressions did help focus on my own responses and increase my awareness of how I was reacting to the participant, which helped me recognise and separate my own responses from those of the participants.

Although Smith et al. (2009) only recommend as 'helpful' that the researcher should listen to the interview again, I found this to be extremely important, and it sometimes led to the re-editing of the transcript if I felt that a further notation was needed to clarify the meaning (e.g., if the participant's voice became very quiet or s/he sighed loudly). The aim of immersion in the material is to keep the analysis and interpretation grounded in the experience of the participant and listening to the recording helped to embed the participant's voice in a way that simple reading cannot do. However, later reading without the recording drew more attention to specific linguistic elements rather than to tone or emphasis.

#### **2.8.4 Step 4 - Initial noting of themes**

After re-listening and re-reading the interview, I began making comments in the right-hand margin. These comments were relatively unstructured and could be summaries of what was being said, associations and connections or some early interpretations, keeping in mind the aim of the note-making, which is to make sense of the participant's experience (Smith, 2015). Whilst Smith et al. (2009) break down initial comments into descriptive, linguistic, and conceptual comments, this process felt too distracting from the work of connecting with the text - it is not a prescriptive recommendation. However, I sometimes found it useful to deconstruct more complex sections of text, e.g., taking a paragraph and reading it backwards sentence by sentence, and often found that linguistic comments became more apparent during this process. In one example, I noticed that a participant used the third person in one paragraph with 'it started' 'it came back' and 'they would say' when talking about her

diagnosis, which gave me the impression of something being done to her and her lack of control of the process.

Interviewing teenagers proved a challenge in that it was sometimes difficult to get them to talk, or they could veer off into different areas of life that, whilst very important to them, had little to do with their experience with DCD - such as wanting a new phone. Whilst some of this may be due to my relative inexperience as an interviewer, Smith and Dunworth (2005) point out that when interviewing children it can be necessary to encourage the participant to talk about different areas of their lives that may not necessarily have a direct relevance to the main topic, such as their hobbies or friendships, so that their confidence can be gained, and they can feel at ease. For one or two participants, occasionally, larger sections of text would have little comment. For example, one participant would go into great detail regarding exam/revision technique. Although the length and depth of her discussion indicated the importance and relevance of organising and structuring her mind and of succeeding academically (and this was noted). I considered the actual details of how she revised as less relevant to the aims of the study and the research question. Although there were other sections of the text where the data were rich, detailed and pertinent to the research questions, this could be disconcerting. Deconstructing the text reassured me that I was not omitting relevant information.

#### **2.8.5 Step 5 - Developing emergent themes**

Whereas the noting of initial themes is staying close to the phenomenological experience of the participant, developing emergent themes can be seen as moving a little further away and bringing in a stronger interpretative element. Larkins, Watts, and Clifton (2006) emphasise the importance of this interpretation within IPA and caution against taking a wholly phenomenological stance. IPA must be interpretative - it is not just a representation of an individual's experience, but also an interpretation

of that experience. In this research, that is in the context of adolescence and DCD and informed by prior research, which highlighted the risk to self-esteem, mental and physical health. Smith et al. (2009) consider this 'one manifestation of the hermeneutic circle' (p. 91). Emergent themes were noted in different colour ink, as can be seen in my example of a working transcript (see Appendix K). These tended to be more psychologically defined, i.e., terms such as 'normalising' or 'impact of labelling' were used, which were removed from the language of the participant.

#### **2.8.6 Step 6 - Connecting across emergent themes (by case)**

At this point, I attempted to refine the themes noted on each of the transcripts, whilst still focussing on each individual participant. Often themes were repeated or were very close in meaning and could be easily consolidated. Whereas until this point, themes had been logged in an Excel spreadsheet, here I felt I needed a better visual overview of the process. Thus, each emergent theme was written on a post-it note and placed on a whiteboard. This allowed me to group and re-group the post-it notes into subthemes. Sometimes this process was intuitive, particularly for the more common themes, such as feeling relieved on diagnosis or getting over-emotional or stressed. However, for other themes, considerably more thought and care was needed and different configurations / clusters were explored. At this point, some themes were discarded, if it was felt that they had little relevance. This is not simply due to the frequency of occurrence, but also to the impact and context. For example, if a participant complained that they had once fallen out with a friend, this may have been noted as a theme where social relationships were strained; however, in the context of a generally happy social life, it may not have been considered relevant.

Smith et al. (2009) identified six different ways of clustering emergent themes.

Abstraction - which is grouping like themes together and forming a new cluster - was the most intuitive and straightforward method. Using post-it notes on a whiteboard

again allowed experimentation with different names and groupings (see Appendix L). Polarisation would have meant finding opposite themes and grouping them together: for example, disempowerment versus sense of achievement could have been a theme. Contextualisation often refers to grouping themes around narrative events. As this research concentrates on the current experience of the adolescent, I felt temporal themes were limited in scope. While, it would have been possible to group the themes into the contexts of school, home and friends, as I asked specific questions regarding school and social life, I would have felt uncomfortable using these as sub or master themes, as it may have felt as if the themes emerged from the structuring of the questions rather than from the participants view. Grouping by function, e.g., positioning self as victim or as survivor was also an option, but I felt such a strategy would be veering towards discourse analysis, and I was clear that I wanted this research to be firmly rooted in the phenomenological experience of the participant. See Appendix M for an example of a table of themes for an individual participant.

#### **2.8.7 Step 7 - Moving on to the next case**

The process was repeated with each participant. In total, 60 themes were identified across the participants. These were listed in a table grouped by participant (see Appendix N) and illustrated with full with quotations.

#### **2.8.8 Step 8 - Master themes and subthemes (comparing across cases)**

Finally, the emergent themes for each participant were clustered together to form subthemes and master themes, following the process described in step 6. Even though IPA is an idiographic process where each participant is considered individually in their own right, there were some themes, e.g., the sense of 'otherness', which were found to be predominant across participants. These themes were relatively simple to cluster. Sometimes the title of an emergent theme felt like a natural title for a subtheme, e.g., 'minimising' or 'not being good at things'; however,

at other times, a different label was needed. Once again, all 60 emergent themes were written on post-it notes and placed on a whiteboard in order to group them into clusters (here termed subthemes). This allowed me to move the themes around and test out the different strategies as detailed above. Some emergent themes were discarded immediately or merged into another emergent theme, e.g., I felt that what I had termed as being 'bad' and being 'labelled' were both referring to the same concept.

This process felt like a continual sifting of data, distilling the themes into the most relevant and intrinsic form. The importance of a close relationship with the data became even more apparent; the aim of the research is to reflect the lives of the participants using their description and my interpretation, holding closely to their experience. This was not a simple process of moving words around, but of understanding and hearing the voices of those who took part. Eventually, thirteen subthemes emerged from the data and these, in turn, were clustered into three final themes (see Appendix O). For subthemes to be included, I felt that they needed to be recurrent for the majority of participants. For this reason, some emergent themes (e.g. being kind which was found for only two participants) were not included. This process was long and circular, and sometimes involved re-reading sections of transcript or even re-listening to recordings to maintain a connection with participant data.

## **2.9 Evaluation**

Evaluating qualitative research poses different issues than with quantitative research. As Willig (2013) points out, terms such as 'reliability', 'validity', and 'objectivity', which are used to evaluate the quality of such research, have little meaning for phenomenological studies. There is a sense of craft to qualitative research that is not so easy to define or evaluate. In my research, I aimed to follow the guidelines set out

by Yardley (2015), which define four criteria for effective qualitative research.

### **2.9.1 Sensitivity to context**

Allowing the participant to expand upon and describe their experience was an essential element. Whilst, as discussed, adolescents and children may often need more guidance in interview structure than adult participants, by conducting the interviews in the participants' own home, allowing them time to reflect and encouraging further contributions from each participant at the end of the interview, I attempted to create the scope and opportunity for the participants to express themselves clearly and openly. My experience as a counselling psychologist who has worked with children and adolescents informed my manner and tone with the participants, which I hoped allowed them to speak openly where possible. In the analysis, the system within which the participant lived - the family, school, and society in general - was considered. In the literature review and discussion, findings from previous research, including those pertaining to different neurodevelopmental disorders, such as ADHD, were considered. By keeping a reflexive diary at different stages of the process, I aimed to be aware of my own responses and ideas, allowing space for the participants to expand upon their views without me readily imposing mine.

### **2.9.2 Commitment and rigour**

By constantly referring to the data, through the transcription and analysis, and using explicit quotations to back up my analysis, I hoped to demonstrate commitment and rigour. The selection of the sample was an interesting case in point. I felt that a larger sample was justified, as I wished to have representation from males as well as females and a broad understanding of 'adolescence' as a process of development, therefore, a range of ages needed to be represented. Furthermore, working in depth with the data allowed an extensive engagement with the topic.

### **2.9.3 Coherence and transparency**

Taking a qualitative, phenomenological approach to the analysis means accepting that concrete findings and 'reality' are not the ultimate aim. Instead, this research aimed to explore the reality of the participants - describing and interpreting this within the context of the methodology and presenting the findings as illuminators of that lived experience - allowing space for contradictions and ambiguity. I hope that my detailed description of the process of conducting the research and analysis is evidence of transparency.

### **2.9.4 Impact and Importance**

As discussed, adolescents with DCD form a neglected cohort for academic research, and I hope that this study will add to the now growing body of research that explores their experience. Previous research has shown that life for those with DCD is harder than for those who are TD in many areas; this research aims to understand that from the perspective of those affected, giving professional services the chance to listen to how those with DCD experience life and to consider this when designing appropriate interventions and services.

## **2.10 Ethical Considerations**

The research proposal was passed by City University Ethics committee (see Appendix P) before recruitment was allowed and was additionally passed by the Dyspraxia Foundation Ethics panel (see Appendix C). The research adhered to the BPS Code of Human Research Ethics (2014). As the participants were nearly all under the age of 18, particularly stringent considerations were made regarding the protection of the welfare of the participants, who were legally considered children.

Firstly, it was important to make clear in the documentation that was sent and in person that the participant was in control of what they discussed and under no

obligation to talk about distressing subjects if they did not so wish to do, or to take part or continue to take part if they changed their mind. Information on the nature and aims of the study was sent prior to the meeting. This was also explained in person on the day. Both the parent/guardian and the adolescent signed consent forms. I was careful to discuss this again with the participant in private after they had signed the consent form, as this was mostly completed in the presence of the parents. I was aware that participants might have been pressurised into taking part and wanted to assure them that it was completely voluntary and there would be no penalty for deciding against doing so.

Secondly, I considered the importance of the participants' welfare. As the majority of the participants had never spoken to anyone in any depth about their personal experiences before, it was possible that they could become distressed. As a trainee counselling psychologist and one with experience of working with children and adolescents, I felt comfortable containing and judging the level of distress. I emphasised to the participant that they were in control of the interview and could decide what and if they answered questions or explored topics further. I responded to difficult experiences empathically and allowed the participant time to reflect, offering a short break if they became distressed. During the interviews, one participant declined to give details of bullying, as he found it too distressing and another participant asked for a short break when she became emotional but returned to the subject on her return from getting some tissues/glass of water.

The issue of confidentiality was clearly explained to the participant before starting the interview. In researching adolescents, the issue of safeguarding was taken very seriously, and various scenarios were discussed with my supervisor prior to arranging interviews, regarding when to break confidentiality. It was agreed and explained to the participant that this would only occur should I feel that there was a

potential of harm occurring to the participant or anyone else (e.g., bullying), or that the distress I observed was so extreme that further support was necessary (e.g., potential for self-harm). In this case, I would inform the parent/guardian or other appropriate adult, depending on the situation. If the issue was less severe, I would recommend that the participant speak to an appropriate adult - parent, family member, or teacher - and signpost them to further services or helplines - however confidentiality would not be broken. In the event, only one participant raised issues of concern regarding self-harming. With the agreement of the participant, we discussed the situation after the interview with the parents, who had full knowledge, and the participant was awaiting further assessment by CAMHS.

Each interview took place in a private room, so that the participant was able to speak freely. An adult was present in the home at all times.

In this thesis, participants are referred to by pseudonym, and any details that could lead to their identification have been altered or removed, e.g., geographical locations, names of teachers/schools. All sensitive files have been password-protected or are kept in a locked filing cabinet (e.g., consent forms). They will be deleted after completion of the doctorate.

## **2.11 Reflexivity**

Personal reflexivity was important to me during this process. Immediately after each interview, I recorded my thoughts. Sometimes, this was a few words recorded on my phone, but at other times, it involved a more detailed description. I reviewed these prior to transcribing/reading the interviews and updated them where appropriate. Keeping notes of thoughts, feelings, and responses enabled me to understand better my own responses and whilst I did not entirely 'bracket' them from the research, it

facilitated a better awareness of them and their potential impact.

### **2.11.1 Methodological**

A key area for reflection was my role in the study. I was nominally a researcher, but I am also a mother of an adolescent with DCD and a trainee counselling psychologist. It was often difficult to stay 'in character' as a researcher. I felt myself drawn to explore difficult emotional responses, and while this was, of course, important for the research, I had to temper that with the knowledge that no matter how 'safe' I perceived the discussion to be, this was not a therapy session, and I was not the participant's therapist; there would be no 'follow up' session. I was information gathering, albeit in an empathic and sensitive manner, and 'dropping in' on the participant and their lives. Furthermore, as the interviews took place in the family home, I was welcomed and engaged in conversation before the interview took place. I openly offered that I was a mother of a son with DCD and that therefore I had a personal interest in the research. In light of the conversation, this seemed appropriate and hopefully positioned me as less of an outsider in the role of 'professional' or 'academic' in regard to my interest; however, it also positioned me in the role of parent, and this, too, would have affected how the participants responded to me - perhaps they could have spoken more freely to an 'impartial' observer. I was aware of feeling parental concern for many of the participants and identifying strongly with the parents, who often told me of their struggle with schools or in getting support. I am aware that this must have affected how the participants responded to me and what they told me. My possible over-identification as a 'parent' figure had the potential to blur my ability to see from the perspective of the participant. Being aware of this pull was important in the research, and I aimed to be aware of my own position whilst still being able to identify with the participants.

Due to the greater proportion of girls in this study, I gave great thought as to whether

I should change the thesis into a study of the impact of DCD on adolescent girls and exclude the three young men. In addition to the higher number of female respondents, I found the boys much more difficult to engage in an exploration of thoughts and feelings. They often gave short answers to open and probing questions. This can be shown in the overview of themes by participant (Appendix O), where the three boys have three, four and five subthemes respectively, whereas the girls have between five and nine. All the boys were in early adolescence (under 15), and it would be understandable that minimising the impact of DCD and not wanting to discuss emotional repercussions could be important at this stage. However, despite the interview process sometimes feeling as if I was 'drawing teeth', after consideration, I felt it was important to include the male participants, as each of them had something important to say about their experience. The themes that emerged from their data were similar to the themes that were explored by the girls and revolved around their sense of wanting to fit in and of developing identity, that is, typical teenage preoccupations that were further accentuated by the experience of living with DCD. Working with the male participants' interviews often meant being more interpretative and more aware of body language and contradictions. One of the issues with qualitative research based on transcribed interviews is that it is very difficult to describe non-verbal information. As an example, Rory, who was my first interviewee, gave me fairly short, succinct answers to my questions, often not holding eye contact and speaking in a relatively quiet tone. However, when I asked him where he saw himself fitting in with his class at school, he pulled his shoulders back, looked me in the eye and said clearly that he was 'at the bottom' and laughed. I believe this change in body language and eye contact told me about the importance of what he said, in ways he could not convey with only words.

For my own part, I also noticed that my interviewing skills improved considerably as I continued. At the beginning, I found myself holding faithfully to my questions and

prompts. Re-listening to early recordings was sometimes a painful process, as I noticed cues and potential avenues of information from participants that I failed to follow up on as I moved on to the next question on my list. However, by the end of the interviews, I was able to be more fluent and responsive to the participants, which perhaps indicates that more extensive testing/piloting or practising of questions may have been helpful.

### **2.11.2 Personal**

I was surprised by how much the stories of the participants affected me. I came away from each interview thoughtful and with emotional responses ranging from sadness and concern, anger and frustration, to light-heartedness and admiration for the stoicism and sometimes wisdom shown by these resilient young people. However, I was also aware that all the participants I interviewed came from supportive, loving families and that no matter how difficult their lives were, they could rely on family support when life got hard.

Regarding my own history, my son was diagnosed with DCD aged twelve. I was aware that he developed differently as a child; he was accident-prone, and when he fell over, his movements were awkward and heavy, and he rarely came home from school without a bruise or a cut. He found fine motor coordination difficult, but his gross motor coordination was acceptable if somewhat behind usual development - he was able to ride a bike without stabilisers, write semi-legibly, and (eventually) tie his shoelaces - but he was often tired, as if the normal day was exhausting for him. I was concerned about his social skills, especially after we moved house and he started a new school, where he was bullied. He was prone to emotional outbursts, but could be funny and charming, especially to adults, whom he treated as equals.

I found very little help was available. The school and my GP told me that he was 'just

a bit clumsy' and did not have DCD. I concluded that I was being over-anxious and, perhaps, giving my son a complex.

On the advice of a good friend, when my son was twelve, I paid for a private educational psychologist's report. She reported that he had a dyspraxic profile. Although his limitations are not severe, I was also aware that he now had 'a label'. Many of our past experiences started to make sense. I also began to feel guilty that, in the past, I had unknowingly expected more of him than he could give and may have been dismissive of or angry at him for things he could not control. As a trainee psychologist, I am painfully aware of how our parents' expectations and reactions can shape our view of ourselves and the world. I felt angry that this information had not been made available to us before and that I had needed to 'find it'.

After the diagnosis, we felt as a family that we were very much left 'high and dry', with no further help offered by the NHS, as he was already 'too old'. We are in a privileged position in that we have been able to pay for further help for our son, which has encompassed both learning strategies and support. My son has found this help invaluable. However, for economic reasons, many parents will not have this option. I feel that as a result of the low profile of DCD, many parents also have difficulty in getting a diagnosis for their children, and this delays the access to help and an appropriate response, which may further negatively affect their child's self-esteem, an issue that is increasingly important in adolescence.

I have felt that DCD is very much an ignored/hidden disorder. Most people know little about it and understand less - I find myself explaining it again and again, if it comes up in conversation, in a way that I feel I would not need to do, if my son had dyslexia or ASD. Since my son's diagnosis, I have considered my own childhood and wondered how many of the children at school who were bullied - or considered

odd/outsideers may have had DCD. I have become more aware of the difficulties faced from early social isolation to self-esteem.

I am also very much aware that as the mother of an adolescent boy with DCD, I have already developed a perception of the disorder and its effects and attempted to keep in mind that the adolescents I was interviewing could have a very different perspective and experience. However, ultimately, I believe my personal interest has been beneficial to my ongoing commitment and understanding of the obstacles that those with DCD face. On looking at the research, I was shocked at how little has been based on the experiences of individuals with DCD, and at how little they have been involved in studies to date. I feel angry that their voices are not being heard.

Finally, on telling my son that I was researching DCD, I was delighted by his positive response and cooperation and by his very helpful suggestions.

## 3. Analysis

### 3.1 Introduction

For many of the adolescent participants interviewed, this was the first time they had been asked about or given thought to their own understanding of DCD, the impact on their lives, and how they made sense of that. Conducting the interviews for this research and thereby giving them the opportunity to reflect on the meaning of DCD in their lives was an extremely satisfying, sometimes surprising and often challenging enterprise. This was clear in interviews, which reflected both the expansive and the succinct approach and varied in duration from 35 minutes to twice that length, depending on the ease and comfort with which the participant felt willing to explore and reveal their experiences.

To give a flavour of the diversity within the sample, I have included in this section a more detailed participant list, which illustrates the differences not only in age and gender, and in my perceptions of personality, but also in the participants' perceived impact of dyspraxia on their lives. There was a seven-year age difference between the youngest (11) and the oldest (18) participant, which naturally meant that the maturity and developmental perspectives varied greatly. However, despite this age variation, it was clear that there were many strong themes reflected in all the participants' experiences. I have tried to capture, as effectively as possible, a faithful reflection of their experience, that is of what it is like for them, as a young person, to have DCD. This section details that analysis and interpretation.

As I explore the relevant themes and subthemes, I have illustrated each one with quotations from the participants - sometimes from one single participant, sometimes from several. The analysis does not draw on theory at this point, but in line with IPA, looks to show both a descriptive and an interpretative representation of the

participants' experience. The descriptive level aims to develop an empathic representation of the participants' world, and the second, more interpretive level, which is held more tentatively, aims to give further insight and meaning to those experiences (Eatough & Smith, 2008)

### **3.2 Descriptive Participant List**

Before the session, a brief discussion was held with the participant and parent to establish how/when the participant was diagnosed and if there were any other diagnoses. The participants are listed in the order in which they were interviewed. It is important to note that all the participants came from supportive homes, with families who were engaged in helping them understand and manage their DCD. However, the participants had very different understandings of DCD and diverse experiences of how DCD affected them and their lives.

#### **1. Rory**

Rory, aged 11, had been diagnosed with DCD approximately two years earlier through a private OT, after his parents experienced difficulty and delay in getting a diagnosis on the NHS. Rory was quietly spoken, but quite deliberate in his speech. He came across as intelligent, thoughtful but somewhat sad when reflecting on friendships/social acceptance at school. Rory referred to dyspraxia as DCD (he was the only participant to do so). He described the impact of DCD as 'PE, handwriting, and memory'. He seemed most concerned about the impact of DCD on his social status (which he perceived to be low), as he was not good at sports. At home, he had strong family support and academically was ambitious and optimistic about his future.

#### **2. Skye**

Skye, aged 11, had only just started at secondary school. She was diagnosed aged 7 by a paediatrician and was also diagnosed with Sensory Processing Disorder (SPD), which further increased her difficulties with motor coordination and balance. At the time of the interviews, she was also being assessed for dyslexia. I experienced Skye as a very

perceptive and highly imaginative participant, who delighted in creating stories and was often humorous in her descriptions of difficulties. She was generally upbeat and light-hearted. She described the impact of DCD as 'physical wise...and kinda like making friends'.

### **3. Megan**

Megan, aged 12, was diagnosed aged 10 or 11. She had been referred to the GP, paediatrician, and OT. She also had a diagnosis of SPD. Megan was quietly spoken and seemed quite shy. She was struggling with 'PE, being clumsy and hurting myself, coordination (buttons etc.) and handwriting.' Megan was also very concerned with the impact her dyspraxia had on her ability to form friendships and felt the dyspraxia led to her often being excluded. She struck me as quite sad and lonely when talking about school, but was happy at home with the family. She enjoyed academic work and was ambitious for her future.

### **4. Sophie**

Sophie, aged 14, was diagnosed aged approximately 8/9 after the school referred her. Unusually among the participants, Sophie loved sport, especially running, which she was very good at, and she also reported good social support at school. She spoke quickly, sometimes mumbling, but not without confidence. Her conversation had a typical teenage cadence - peppered with 'like'; she moved swiftly from one subject to another and seemed easily distracted. The main impact of dyspraxia for Sophie appeared to be her concentration and memory, and she referred to herself as a 'space cadet'.

### **5. Florence**

Florence, aged 15, was diagnosed aged approximately 5/6 by an OT. She was thoughtful and warned me before the interview that she found it hard not to become emotional and cry, and she did indeed need a break within the interview when she became upset. However, she accepted this 'emotionality' as part of her personality. She reported the main impact of dyspraxia as coordination (especially handwriting) but mostly 'processing'. Florence seemed

creative and thoughtful - she was comfortable with being 'different' and taking a different path and seemed optimistic about her future.

## **6. Kara**

Kara, aged 14, was diagnosed aged 6/7 through a referral from school to a paediatrician. At the time of the interview, she was being assessed for dyslexia and ASD. Kara described the impact of dyspraxia as anxiety - particularly at school, where she felt stressed. She struggled with handwriting and concentration and reported that she often felt overwhelmed. She described herself as 'over emotional'. She also reported difficulties socially both in making and maintaining peer friendships, often choosing friendships with much younger children. Kara was waiting on an assessment from CAMHS regarding self-harming behaviours and a possible diagnosis of ASD. She had a close relationship with her family, who played an important role in her life, and was engaging and expansive on the impact of dyspraxia; however, the conversation often veered from the topic, and the interview took considerably longer to complete than with other participants.

## **7. Ruth**

Ruth, aged 17, was one of the older participants and the only one who contacted me herself, rather than her parents contacting me. She was diagnosed with dyspraxia and dyslexia aged 16. She was surprised to have the diagnosis of dyspraxia (expecting only a diagnosis of dyslexia), as her fine motor coordination was good - she showed me some very detailed drawings she had done; however, she did find gross motor coordination and sports challenging. She identified the major impact on her life as difficulties with planning, organisation, and memory. I experienced Ruth as highly articulate, determined, and very much focussed on the academic/research implications of the diagnosis.

## **8. Zac**

Zac was 13 years old. He was diagnosed with dyspraxia by an OT at the age of 4 or 5, but then received a further/confirming diagnosis from a paediatrician when aged 8. Despite his 'typical' teenage interests in gaming, Zac struck me as slightly older than his years. He

presented a 'no nonsense' persona with some good-natured humour and was quick to assure me that DCD was not a big deal for him. Socially, he felt he 'took his own path', but was comfortable with his level of social connection. He felt that the major impact of dyspraxia was on his handwriting - which could be illegible - and that it explained why he was 'bad at Art and PE', but otherwise, he did not notice it.

### **9. April**

April was 12 years old and had been diagnosed with dyspraxia aged 4 or 5 by an OT. April was outgoing and chatty - speaking very quickly (so that she sometimes gasped for breath between sentences). She was confident and happy at school, had good family/social support, and reported often using humour in social situations. She felt that dyspraxia mostly affected her in terms of a lack of coordination and spatial awareness. She reported being clumsy and having terrible handwriting, and stated that it took her a long time to write things down, which could be a problem at school.

### **10. Eliza**

Eliza, at 18, was the oldest participant and was in her final year at school. She also had a diagnosis of ASD. She could not remember how she was diagnosed, but said it felt as if it had been there 'all my life'. She understood the DCD in terms of difficulties in coordination, in writing things down, and in the time it took her to process information. Eliza was thoughtful in her answers, taking time to reflect before responding. She reported bullying and having difficulties socially earlier in school, but was now confident with her own friends. She seemed to be very self-assured - happy to take a different path in life. She was interested in writing and music and in finding creative ways to express herself.

### **11. Ted**

Ted was 13 years old. He had been diagnosed aged 11 or 12 'via the NHS' - I am unsure if this was an OT or paediatrician's referral. I experienced Ted as quiet and a little subdued; however, he was keen to help with the study. He described the impact of dyspraxia as not being great at running or catching and defined himself as 'nerdy' not 'sporty'. He also felt

that it affected his academic achievement, as he struggled to process information. However, he looked at the diagnosis as a positive means to ensure extra support. Like the two other teenage boys, he was interested in gaming. He came across as measured and clear in his answers.

### 3.3. Master Themes

#### 3.3.1 Table of Master Themes and Sub Themes

<b>1. Sense of 'Otherness'</b>	<ul style="list-style-type: none"> <li>• <b>Recognising and Reframing Difference</b></li> <li>• <b>Social Acceptance</b></li> </ul>
<b>2. Complexity of Response</b>	<ul style="list-style-type: none"> <li>• Relief</li> <li>• Shame</li> <li>• Ambivalence</li> <li>• Need for acceptance/Understanding</li> </ul>
<b>3. Recognising and Coping with Limitations</b>	<ul style="list-style-type: none"> <li>• <b>Unseen Struggle</b></li> <li>• <b>Not being 'good' at things</b></li> <li>• <b>Emotional Overload</b></li> <li>• <b>Coping strategies</b></li> </ul>

The three themes identified from this study are a Sense of 'Otherness', Complexity of Response, and Recognising and Coping with Limitations - these are discussed in turn, as well as the relevant sub-themes.

#### 3.4 Theme 1 - Sense of Otherness

How the participants recognised and understood a sense of otherness and how that affected their sense of self was reflected in all of the participants' responses.

Difference necessitates comparison, and it was reflected most in how the participants saw themselves in relation to their peers, which naturally in a group of adolescents

revolved around school. Although the giving of a label by others, in that the diagnosing of a 'condition' necessarily defines a group separate from the norm, it also gave validation to some of the participants regarding their own sense of difference. The theme of 'Otherness' was divided into two subthemes: Recognising / re-framing difference and Social acceptance.

### **3.4.1 Recognising and Re-framing Difference**

The initial perception of difference, of being outside the 'norm', was an early experience for most of the participants. This perception or defining usually occurred when they attended primary school and became aware of more direct comparisons to their peers. Some participants described their own almost pre-verbal perception of 'being different'. Here, Florence indicated that she had a sense of this from an early age; the vague 'couple of things' pointed to a nebulous feeling that she was somehow 'other'.

*well I had a couple of other things that I guessed that made me different aside from that I hadn't really clicked that I was dyspraxic, I didn't know anything about it until Mum told me when I was about 7 I think. (Florence: 1,18)*

This sense of difference was internal - she 'guessed' rather than being told, and when she finally was given a label for the difference, it was without a negative stigma or implication of inferiority. For some participants, being seen as different at an early age, without any understanding of where the difference came from led to being subjected to blame and accusation. Sophie spoke about being labelled a 'space cadet' and how, as a young child, she felt that she must be disobedient because she was always getting into trouble at school for forgetting things and being disorganised.

*...and they would also say that I'm really space cadetty and that sort of thing, and I just kind of thought like that; over time, I began to believe it and just sort of thought maybe I am disobedient and maybe I am just like kind of a bit kind of different as in I find it harder than a lot of students. (Sophie: 2,43)*

The fact that the label of 'space cadet' came from teachers - a significant authority in a young child's mind - increased its power. Her lack of organisation was interpreted

as a sign that Sophie was choosing to behave in this way, and Sophie herself came to believe and internalise this interpretation, not having any other explanation at that time. Eliza also reflected the experience of 'knowing' you are different. However, Eliza noticed the difference herself in the development of her own motor skills and those of her peers.

*I thought it was normal, and then you'd see people like catch it really easily, or they'd ride a bike without stabilisers no problem, and I'd think, 'Oh that's not what it is [for] myself, so it's always good to ask', and then they said, 'Oh you have dyspraxia', and I was like,- 'Oh OK'.*

*(Eliza: 2,49)*

The formalistic/medical label of dyspraxia had a neutral and almost non-emotional impact on Eliza. It felt rational - an explanation of a difference that had already been perceived, almost as if Eliza had learnt a new word in a dictionary.

The theme of being 'normal' or 'weird' was prevalent with Megan. She had moved through different perceptions of herself; originally, she had thought she was 'kind of normal', but it seemed that at school, other people's reactions changed this perception.

*...I thought I was, like, OK, like, I was kind of normal as such, and then I got bullied for some things I didn't realise were different, and that's when I started thinking that there was something a bit different about me... And then when I found out, I was just so relieved to find I wasn't just weird. (Megan: 1, 13)*

There is an implied innocence and helplessness in this statement. She was not only 'different', but also she did not realise that she was different; she had had no internal sense of this prior to school. For Megan, the forced recognition of being different was accompanied with the consequence of victimisation. Therefore, for Megan, being different and being weird were to be rejected and avoided; she wanted to be 'OK', to be 'kind of normal'. The diagnosis of dyspraxia allowed her to move away from the label of 'weird'. She was 'just so relieved'; it is easy to imagine the weight dropping from the child's shoulders. As one of the younger participants, who was still very

much struggling with feelings of social exclusion, the diagnosis of dyspraxia had allowed Megan to re-frame her difficulties with coordination as something that is not 'wrong' or 'weird', but rather 'just different'. However, there was still a sense that Megan was trying to convince herself.

*I've had to tell myself that a lot...like, it's not something wrong - it's just different from most people. (Megan: 5,132)*

Due to the negative impact of bullying, it seems Megan had internalised a sense that she was 'wrong'. The diagnosis had allowed her to challenge this - she still saw herself as 'different from most people' but was working towards an understanding of this that was not negative.

Having conceived of a version of themselves as different to the norm at an early age, many of the participants were re-framing and reviewing this as they reached or progressed through adolescence and were beginning to develop and determine their own self-concept. Sophie had re-claimed the word 'space-cadet'. She described herself in these terms, but seemingly without negative judgement, pairing the word with 'friendly' rather than 'disobedient'. We can see that it was an accepted term for her, one that she volunteered as a description of herself.

*I think, like, friendly, and also I used 'space cadetty'. That's just kind of a big part of my life I guess. (Sophie: 10, 237)*

Whereas initially the term 'space-cadet' was linked to how other people saw her and to their perception of her 'disobedience', the label of DCD had allowed her to claim ownership of the term. However, Sophie did not minimise the difficulties her memory problems had brought.

*Sometimes I forget what I'm saying, like, in the middle of a sentence, and I think, 'Oh that's just, like, how it is and it's just like a humorous thing', but sometimes it's difficult. But a lot of the time, I just kind of move on and just kind of think it's fine. (Sophie: 10,241)*

This indicates recognition of the complexities of responses and an emergent self-awareness. She seemed to imply an acceptance of the limitations that dyspraxia can

bring; she used 'I' rather than 'because of my dyspraxia' - there was a sense that this was about Sophie rather than about her diagnosis. Some of the participants went further in re-framing their difference as fundamental in their sense of themselves. Not being 'normal' was something to be proud of.

*...but if I didn't have dyspraxia, I would think of myself as maybe a little 'normal'. (Skye: 5,132)*

Skye whole-heartedly accepted the diagnosis of DCD and saw it as intrinsic to her own self-perception and identity, which incorporated a sense of being 'quirky', 'crazy' and something that saved her from being 'normal'. April echoed Skye with a consistently positive view of her diagnosis. April was well aware that she was 'different', but saw it as something that made her unique and enjoyed the attention it brought her.

*In a funny kind of way, it makes me happy; it makes me, like, 'happy' is a weird word to describe it, but it makes me 'me' - unique to the other people in my class and things. (April: 10, 329)*

April, who appeared naturally extroverted, was one of the few participants who claimed not to have experienced bullying and reported strong, positive peer relationships. We can see from her responses that she enjoyed the status that her difference had brought to her.

*I was only little. So I found it quite cool that I was different from everyone else. So I was, like, 'Look at me, everyone! I'm different from you'. (April: 10,306)*

However, most participants were re-framing their sense of otherness in a more nuanced manner. The re-framing developed over time, often after reflection on the bullying or exclusion they had experienced in earlier years. As they developed through adolescence, many participants had begun to embrace their difference and to enjoy the sensation of not following the crowd. Florence seemed proud when she told me that she was not on social media and that she did not have an interest in what she considered to be 'typical' teenage things. Her sense of being different had

been embraced as a positive attribute - and 'different', 'differently', 'positive' and 'unique' are words that she used to describe herself - or rather to describe people with dyspraxia (she used 'us'), which indicates a further sense of identity and inclusivity. There was also a sense that the 'norm' is slightly dull and predictable, and that positive advantage can come from an alternative point of view.

*...that we sort of see the world differently, like, in a more unique way, and I think that's kind of a positive thing about it. Because I think we sort of have different perspectives. I'm not sure because I've never really been anyone else, but when I think about it, I think we are more unique in our outlook than other people. (Florence: 2,54)*

Although Florence was careful to use words such as 'quirky' and 'unique', rather than 'odd' or 'weird' in her description of herself, she was aware that other people may not perceive her in such a positive light.

*Because I am quite quirky, I am definitely unique ...erm, but people... I've just learnt that when people say, 'Oh that's weird isn't it?' to just brush it off. (Florence: 6,178)*

Re-defining her difference as 'unique' allowed Florence to defend herself from other people's comments that defined her as 'weird'

Not all of the participants had been able to accept or 're-frame' dyspraxia, and Kara in particular was unable, at the time of the interview, to find anything positive to say about her experience, despite encouragement from her family.

*I don't like being different. I just kind of want to be the same as everyone else. But my Mum's always said, 'Don't be like that because it makes you who you are, because if we were all the same it would be boring!', but I always think that I would like to be the same as other people. Not, like, look the same, but, like, inside, like, not have dyspraxia, basically. (Kara: 13, 411)*

Kara whole-heartedly rejected DCD and could not embrace it as a positive. However, there is an ambiguity to her dislike of being 'different'. For whilst, on the one hand, she wished she was the same as others, she also admitted that she also did not want to join in with the crowd and often had little interest in topics that her peers

found important. She found that she could be bored socially with others and would take her own path, making friends with different peer groups, both younger and older.

*So I was more to myself. Which I find quite a bit when I do things with my friends, when there's a load of us, I just find I'm more to like myself. (Kara: 7,229)*

For some of the participants, the sense of otherness could mean enjoying not being part of the crowd. Zac described himself as 'strange' (5, 162) and a 'bit on the odd side for a couple of bits' (5,145), but without any sense of negative appraisal. He rejected typical peer group social activities, without any obvious sense of upset or disappointment or exclusion.

*I prefer doing my own thing. (Zac: 13, 409)*

Ted also felt that the diagnosis allowed a sense of uniqueness and helped foster a sense of identity - even though there was still ambivalence in his response.

*I'm not completely, like, good about it, but I don't, but I'm happy that I am it. I kind of, it gives me a way to identify myself. (Ted: 7, 208)*

Ted was not at a stage where he saw the label of dyspraxia as wholly positive, but he spoke clearly of a sense of identity inferred by it - and this was not negative. Ted, like the other male participants, divided his peers into categories or groups who were either nerdy or sporty. His dislike of sport transferred into a sense of identity, and he sought the companionship of other 'nerds'.

*No, because a lot of people are quite sporty, and they're not kind of types of people I want to hang out with. (2,56)*

### **3.4.2 Social Acceptance**

For many of the participants, being perceived as 'other', at times, had meant emotional pain as a result of victimisation, exclusion, and isolation. This was often reflected in identification as someone who was 'on the outside'. Many of the group had historically struggled to make friends and had felt socially disadvantaged. However, during adolescence, there was a pattern of re-assessing what this meant in

terms of their identity and how it affected their own views of friendship and perceived social status.

Feelings of loneliness and exclusion, particularly in younger years, were expressed as painful memories, with a real sense of being a bystander on the outside of society. Here, Skye mentions that the pain of not having friends could be too much for her to bear, and she would attempt to get in trouble so that she could avoid the emotional cost.

*Yeah, so if I don't have any friends and no one to play with, I go to that person (not a child) and talk to them the whole break. And when I was little, I used to want to stay in and get in trouble because I didn't want to go out and watch everyone play.... Yeah. Because when I was little, I didn't have any friends. I didn't want to watch them play and me just sitting on the bench.*

*(Skye: 27, 862)*

For Megan, at the onset of adolescence, the sense of being on the outside was still very much present, and this was because she did not 'fit in' rather than others not being accepting of her.

*I kind of see myself maybe on the outside, kind of. Because I don't really feel like I fit in to my class very well. (Megan: 10, 309)*

Difference, for Rory, seems like an unchangeable fact. He is on the outside and therefore cannot be 'social'; there is no sense of a doorway to the inside.

*I'm pretty unsocial because I'm not, like I said about fitting in, and if you don't really fit in, it's pretty hard to be social. (Rory: 5, 52)*

Bullying and/or exclusion at an earlier age was related directly or indirectly to the participants' otherness. Eliza, now 18 and happy within her social group, experienced social rejection in school because she was 'a bit odd'.

*...but I used to find it very difficult to make friends or keep friends, you know; I'm always... I like to talk to people, but I think people found that a bit odd, you know. I'm one of those people that*

*if I saw somebody in college that I hadn't spoken to and their top would be nice, I would say, 'Oh I like your top', and people seem to think that's a bit odd or something. (Eliza 9, 270)*

This experience of not being included and not knowing how to make friends seemed to be common, particularly in primary school. Skye identified that being 'weird' was an obstacle to social acceptance for some people, but also as something that made her who she was. Her 'weirdness' was something that others could decide to accept or reject.

*If they're, if they understand me, and they accept who I am ... cos some people think, 'She's weird, crazy, I don't like her, bye, bye'... Some people think, 'She's wonderful, she's great, she could be my friend. (Skye: 24,753)*

Not being 'social' was also perceived as having a lack of social skills. Kara reported feeling uncomfortable with her peer group and liked to mix with younger children or with adults. Her experience was that she did not know how to engage other people in conversation and that other people were not interested in her and or in what she had to say. Social interactions become laden with anxiety.

*I always feel like they don't want to know. I'm just like, Oh well, what do I speak about?' I don't know what to talk about because I always end up just like blurting it out, and then I'm, like – 'What do I speak about now?' (laughs) I just have no idea what to say, so I just randomly start rambling about random things, and they're just like 'Well, we don't want to hear.' I think they - I'm thinking that they don't want to hear it. (Kara: 14, 429)*

Because of these feelings of not fitting in or not being liked, many of the participants worked very hard at strategies to make themselves more popular. They often cited lack of social skills, lack of sporting prowess, and general lack of coordination as a reason for isolation and exclusion. Skye felt that her lack of coordination affected her social standing, as she found it hard to catch or throw, and this automatically excluded her from many games that children play. Therefore, she worked very hard, practising catching at home or with teachers, in the hope that she could get better

and be able to join in with games at school. Skye equated being good at sports with popularity:

*And I got so annoyed because I was like...that close to catching that little ball, and then I could win a point, and I could actually be popular for the day, you know. (Skye: 26, 835)*

Not being able to play sports well meant that she saw herself as less important socially, and that she had to do something exceptional to gain status. She related how she had once managed to achieve a task nobody else had on a school trip and how much that had meant to her; however, this was a one-off and ultimately short-lived.

*It kind of gets you popular when I do something nobody else has done, like in X. I got a little bit popular for a day, and then everyone forgot about it. (Skye: 26, 839)*

The levels of coordination difficulties varied among the participants, but for some, like Megan, it became a focal point for her sense of being excluded and not part of the group - even to the point of being humiliated.

*If people are, like, playing ball games at lunch and things, that if I take part, then I'm not gonna be able to throw it, and everyone is going to laugh at me, and that's not very fun. (3,68)*

Kara also identified sports as a major issue, reiterating that it made her feel 'uncomfortable'. She used the word 'uncomfortable' often to describe social interactions with others. Her discomfort in sport lessons was in part because of her own awareness of her lesser of ability, but also because it invoked 'nastiness'. Here, Kara lists all the things she 'can't' do, thus highlighting her sense that her abilities were fixed at a low level.

*It makes me really, that's where I've probably had the most nastiness, really, because I can't run properly, or I can't do gymnastics, or I can't do something that anyone else can, or, yeah - when I've had people make me feel really, really uncomfortable and say things and, erm, it just makes me ... I get really, really anxious in there. (Kara: 11, 352)*

The impact of DCD on coordination and on organisational/processing skills means that the participants were often singled out at school. Most claimed that they wanted

to be seen as the same as others, but had to balance this with the extra help that they needed in order to keep up with others.

*If you don't finish, you have to do something at lunch, but, like, my teacher is, like, 'You don't have to do it at lunch; take it home, take your time - and do it, cos I know you're, yeah you're different'. (April: 13, 401)*

But even April, who was unique within the group in that she only reported positive experiences socially, was reluctant to have a Teaching Assistant (TA), as she felt this would affect her ability to be sociable at school, which she loved attending.

*I think if I had one to myself, I'd be a bit more, I'd be like, I'd feel like I couldn't enjoy my lessons as much, as I'd have my friends there, I'd be sitting there next to my friends trying to have a conversation with them, but I'd know there'd be a teacher there. (April: 3, 93)*

Likewise, Kara said that she would refuse aids such as a writing slope, which she felt would make her stand out; she was very aware about feeling 'judged' by others. For this reason, she rarely talked about DCD even though she wanted to. She feared further rejection:

*...but I feel dead, dead uncomfortable about it, and it just scares me too much about telling them, and I, honestly, I've thought about it so many times, but I've just thought to myself - nah, I'm not going to do it because, I'm just scared of people's reactions. (Kara: 13, 395)*

With the exception of April, all of the participants reported having struggled socially with their peers at some point, often experiencing bullying and/or isolation, and they were often acutely aware of their perceived social status. Skye talked about herself as a 'middle kid' and not having 'appeal'.

*Yeah. You kind of get popular a little bit in that day, and I don't really that much have that appeal. I've always been a middle kid. (Skye: 26, 844)*

Rory made his position even more explicit. In answer to the question as to how he saw himself in class, he replied.

*Academically, I'm quite good. But apart from that, err...bottom (laughs). (Rory: 7, 266)*

Up to this point, I had experienced Rory as polite and helpful if a little shy; however, with this reply, his body language changed, and he looked at me quite directly. He put this low social status directly down to his lack of sporting prowess.

*People who are good at things like sport, they are usually the ones that everybody wants to be friends with. (Rory: 5, 156)*

Many of the participants saw the impact of the early struggle to gain social acceptance/status as an important aspect of their development and of how they saw friendships today. For Megan, there was still a sense of sadness and struggle regarding school and social relationships. Although she had made friends, she talked uncertainly about them; there was not a sense that they provided her with stability or greater self-worth.

*My two good friends, they are in the same class, but I'm not in their class, so they are my main friends in school and, basically, some of my only friends. Like I have kind of friends, but they're not proper friends. (Megan: 10, 322)*

However, many of the others had more positive experiences of friendships that encompassed their previous experience of problematic social relationships.

*But my friends appreciate who I am and what I have, and they like who I am exactly as I am... (Skye: 5, 130)*

Likewise, the friendships that Rory had were extremely important to him - the first word he used to describe himself was 'loyal' (5,145).

*Yeah - but I have a very small friendship group, and the friends I get along with, I get along with. (Rory: 6, 169)*

Ruth reflected on the way her early experiences with isolation and exclusion had affect how she saw friendships now. She stated that she came across as quite an open person, but that this was not the case, and that she was wary of other people and took her time to trust them.

*I just got a reluctance to open up to people in many ways - I've got a lot better at that, but I still keep a lot of things to myself. There's only very few people that I would open up to even now, and I have opened up to even now. So, yeah. (Ruth: 26, 825)*

She felt that she had become more aware of other people and was learning to trust her instincts.

*It's weird; I can pick up if someone is nice or not very, very quickly. ... I pick up on it really fast, and I'll probably think there's something not quite right. (Ruth: 27, 856)*

It seems that for many of the participants, difficult experiences in early childhood may have led to friendships and a sense of 'true friendship' being more important than social standing. Eliza also found herself in a position where having drawn from those earlier experiences, she now felt that she was comfortable in herself.

*I honestly think kindness, and that's really strange, but I always like to make sure that people are alright; like, I'm one of those people that I don't like seeing people upset, so I'll try my best to help them. (Eliza: 9, 288)*

### **3.5 Theme 2: Complexity of response**

The response of the participants to being diagnosed with dyspraxia and therefore having a label was complex and depended on many factors, such as the age and manner of the diagnosis and the social impact at school. Four subthemes were identified: Relief, Shame, Ambivalence and Need for acceptance/understanding.

#### **3.5.1 Relief**

Most of the participants did express relief at a diagnosis. The medicalisation of their 'difference' answered many questions that otherwise were often answered with a far more internalising and shaming stance. Megan's and Florence's responses were fairly typical, seeing the diagnosis as a way of understanding themselves as 'not weird'. The authority of a 'medical' diagnosis, of having a recognised 'disorder' allowed the participants to distance themselves from the shame of 'weirdness'

*When I found that out (having dyspraxia) I was just so relieved to realise that I wasn't just weird (Megan: 1, 17)*

*I think it was just because to make sure that I wasn't just 'weird' (laughs) human being, there was actually a proper medical reason to why, erm I felt the way I did and I had problems doing stuff. (Florence: 1, 31)*

For Ruth, the DCD diagnosis was a surprise diagnosis at a later age, but she also found relief in it. In Ruth's case, the relief was that she was not 'weak' rather than 'weird'.

*I wasn't expecting it - I think it's because I'd been told for a long time it was just weaknesses that I had, so I think I was expecting it that I was just bad at planning or bad at handwriting and my spelling wasn't that great. (Ruth: 13, 411)*

The diagnosis also helped Ted's understanding of himself. He stated that

*I knew I had something... that stopped me, so when they told me, I was more relieved that I knew. (Ted: 1, 19)*

There was an understanding that there was a barrier that was stopping him from progressing. It felt external to Ted - '*I had something*'- and this external thing was standing in his way. Understanding this as 'dyspraxia' gave Ted relief.

Rory was also very relieved to get the diagnosis. He stated that having the diagnosis made him feel better about how he was, and it was something that he liked talking about.

*I have to tell people like my teachers and my friends, but at the same time, I kind of wear it as a medal - I like telling people that I have DCD. (Rory: 10, 303)*

*It's a good conversation starter! (Rory: 10, 309)*

Rory welcomed the diagnosis and had no ambivalence in his attitude towards it.

Many participants felt awkward talking about it to others and chose carefully with whom and when they discussed it. However, Rory enjoyed letting other people know about it.

*Yes, because I've always been terrible at catching balls and things like that, and I was quite relieved that I had an excuse. (Rory: 1, 16)*

April was also totally accepting of the diagnosis and in a way that seemed quite defiant, referred to herself as 'dyspraxic' rather than 'having dyspraxia'. She did not see any downside to the diagnosis or the condition and seemed to take ownership of it as we can see in the quotation below.

*It's what makes me 'me'. If I didn't bump into things all the time, and if I didn't fall over thin air and stuff, it wouldn't be me because...this is me at the end of the day. I am dyspraxic -end of. (April: 10, 327)*

Compared to the other participants, April saw the dyspraxia as very much integral / internal rather than an external force. There was no boundary between dyspraxia and herself rather than 'it' being something external that impeded her.

*Well, it's [dyspraxia] completely me. (April: 10, 317)*

*Yeah, it's part of me now. (April, 10, 324)*

The expected improvement in access to support and help was a major source of relief for the participants, who had either received extra help and support because of it or were anticipating extra help in the future.

*Now my teachers know, and if I'm finding something really tricky, they'll adapt it maybe and things like that. (Megan: 2, 64)*

Ruth was even more specific, stating that the extra time was the main reason that she was relieved.

*I guess knowing that you have dyspraxia is good in a sense that you will get the help with the extra time. That was the main thing that I was relieved about, is knowing that I could actually get the help, that would be useful (Ruth: 32, 1025)*

Ted also mentioned getting more help as an important factor in his sense of relief; and again, he had a very pragmatic expectation that this would help him cope with life and that it would mean that other people would understand him better.

*Erm...I get a bit more support so, I like that. I will hopefully get a better job when I'm older - they would like understand (Ted: 6, 176)*

### **3.5.2 Shame**

At the other end of the spectrum, many of the participants experienced shame because of their DCD, either due to their clumsiness or due to processing issues. These were mostly apparent at school.

*Well, I only really notice it when I forget things at home, but other than that, I think it's just school where it's mainly, like, where I really struggle. (Sophie: 17, 412)*

The shame often came from other people noticing and pointing out the participants' shortcomings in a critical or disparaging way. Often this was other pupils, and the impact of being called names left Sophie feeling criticised and judged.

*In year 6, people used to call me things like 'butter fingers' and things like that, like, all the really horrible boys, they were just really arrogant. (Sophie: 18,4 30)*

This increased the perception that other people really do not understand what it is like to have dyspraxia and also increased the sense of isolation. Here, Sophie expresses her frustration that she could be criticised / shamed for something that was not under her control and her wish that other people could understand how it was for her.

*Yeah - especially when other people notice it and they go 'oh God why are you so clumsy' and stuff like that and I just feel like turning round and just saying why don't you try and overcome this. (Sophie: 18,430)*

Sometimes, it was not the other students who increased feelings of shame, but the teachers, who had the position of power and whose criticisms could feel even more public and poignant.

*Then he was like, 'Oh we'll just wait for Sophie', and I was like, 'Oh God'. The whole class, and I was feeling, like 'Oh God'; it's just teachers who just make it stand out. (Sophie: 5, 103)*

How the participants responded to telling others about their dyspraxia was an interesting example of shame. Even participants who claimed to be mainly unaffected by the diagnosis were sometimes reluctant to talk about it or even disclose it to others. There was a sense that it was still a taboo subject and that disclosing you have DCD could open you up to judgement, isolation, or victimisation.

*Because I told some people, and they told someone else, and they told someone else, and they told someone else, and that basically went on, and because no one knew exactly what it was, they kind of froze me out. (Megan: 16, 503)*

Many of the participants emphasised the need for trust before they disclosed that they had DCD, indicating wariness that the information could be used against them.

There was a sense that knowing the participant had DCD was information that needed to be restricted in its availability to close, trusted friends, and once again, the importance of having good friends was emphasised. Eliza talked about ‘admitting’ you had DCD, as though it was something shameful, and was also very careful about whom she confided in. The lack of understanding from others regarding DCD gave it a sense of instability, and also increased this feeling that knowledge of it should be limited.

*They might tell other people, and then if they don't have the correct understanding, they might twist it a bit, and people might, you know, give a different opinion of you, so it's important that they know exactly what it is. (Eliza: 2, 35)*

Interestingly, Zac, who claimed not to be particularly ‘bothered’ by DCD, had not revealed it to others.

*As a matter of fact, I actually haven't gone openly out about it in school. Mainly because a lot, rather a few people in my year, not the nicest of people, especially if they found out I had a disability; oh boy, would they have a lot of stuff to taunt me about! (Zac: 2, 65)*

Zac was clear that public knowledge of his DCD would lead to ridicule; he also used the word ‘disability’ rather than ‘disorder’ or ‘difficulty’. For Zac, having DCD could be viewed as ‘disabling’ and could make him a potential target for abuse, and therefore, he shut it away.

### **3.5.3 Ambivalence**

However, responses to a diagnosis of DCD were not always simple or clear. Some participants, such as Ted and Zac, felt that DCD was not important to them and had very little impact on their lives, and so they used non-emotive language.

*It didn't really affect me much. (Ted, 1, 17)*

*No, not really. [Do you consider yourself to be different?] (Zac, 8, 252)*

Often, the participants were not sure how to react or what it really meant for them. They expressed a need for understanding, but were aware that this was finely

balanced between being helpful and being over-bearing. There were fears that other people could react awkwardly towards them.

*I wouldn't want them to treat me any differently; I wouldn't want them to start saying, 'Oh, do you need me to help you with this? Do you need me to help you with that?' I would just want them to kind of just say, 'Ok'. Obviously, I wouldn't just want them to carry on saying, 'Your homework is scruffy', or something like that - I would want them to understand that it was a lot harder for me than it was for them, but I wouldn't want them to be, like, to kind of pity me or say anything like I had some sort of horrible illness or something. (Sophie: 27, 642)*

Sophie was concerned that the diagnosis could be seen as somewhat disempowering, with others pitying her and overcompensating with 'helping behaviours' rather than understanding where she found things difficult and making appropriate allowances. She just wanted them to say 'OK'.

Several of the participants were keen to point out that DCD was only a part of their story and should not be over-emphasised. It affected only an element of their behaviour.

*Because it's not like the be all and end all of me. I have a personality and my own interests, it's not just, that's it about me. It's still quite an important part of me. It is important part of who I am but it's not it. I have other aspects of me as well. (Megan: 5, 150)*

For Skye, this was the 'thing before' - the original Skye that others saw, that was not DCD.

*Well, I don't think it would cover completely who I am. You've still got the thing before that people actually take me for. (Skye: 6, 177)*

Florence and Ruth were also keen to emphasise that DCD was not the main element of how they saw themselves. Florence was keen not to be defined. She wanted to be defined by what she was 'good at'; she saw DCD as an indication of impairment that narrowed her view of herself.

*Well yes it affects me and yes, it's part of who I am but it's not the main bulk because, I don't want to be defined by it. I guess. I want to be defined by who I am as a person, what I'm good at, what I like and stuff - as opposed to just being defined by just one thing (Florence: 5, 155)*

The theme of knowing or determining what is 'me' and what is 'DCD' was explored by Ruth, who researched the issue as a means of gaining clarity.

*I guess when you said before, 'How do you know when you are being dyspraxic? [author's note - not my actual words] and when you're not? I guess because I did all that research, and I looked into the specific... erm things that a dyspraxic person, traits or something, it kind of highlighted when I was doing certain things that I would associate with dyspraxia. (Ruth: 18, 588)*

Ruth was very much still coming to terms with where or how DCD fitted in to her sense of self. She was, at first, keen to point out that it was not a big part of her life; however, on reflection, she thought that this was because she may not be aware of the effect that it played.

*I'm not really fussed about it. I don't know if it's a big part of me that I actually need to... (Ruth, 18, 576)*

*It's actually quite hard because it does influence a lot of the way I work and how I organise my ideas and the things that I come out and say, in a sense. But then... so that would probably suggest that it affects me quite a lot, but then... I guess that I'm not really conscious of it in a way. (Ruth, 18, 581)*

Whilst the diagnosis was mostly seen as positive by Ruth, as a means of helping her understand herself and enabling the development of techniques to improve her planning and organisation, she admitted she was initially worried about the implication of a diagnosis and whether it would actually stop her from trying. There was a sense that diagnosis could bring a defeatist attitude to problems, and this was something that Ruth also needed to address.

*So I was worried at one point that I was starting to go, 'Oh this is because of my dyspraxia, so therefore, that's why I can't improve it or anything with that', but then I've stopped doing that now, which is good. (Ruth: 2, 47)*

#### **3.5.4 Need for acceptance, understanding, and support**

Getting support from others was dependent on an actual understanding and acceptance of DCD, and many of the participants expressed frustration, disbelief,

and irritation that this was often not the case. Having been given a diagnosis that helped them understand themselves, this understanding was often not being utilised in the environment around them. When their wish for others to understand their difficulties, and to be able to respond to their needs in light of this understanding was mostly unfulfilled, this increased feelings of not being important and not being understood and a sense of being ignored. Sophie describes the different approaches in her school to dyslexia and dyspraxia awareness, which highlight this sense of being unimportant.

*We had these two weeks in our school, which was dyslexia awareness week and following that, was dyspraxia awareness week, and for dyslexia awareness week, they like did up all the library, and they put like dyslexia posters everywhere about, and they put a book about dyslexia there about awareness, and for dyspraxia, nobody even knew there was a dyspraxia week, It was, like, there was like no - all the boards were still on dyslexia, and there was nothing there. (Sophie: 22, 520)*

Participants often felt very frustrated that others simply did not understand either them or DCD, and this was often highlighted by the different responses they perceived between dyslexia/dyspraxia, which left them feeling a little like a poor relation.

*Probably people just generally not understanding you. So if I tell people...I had someone, I was explaining to someone, and they said, 'Do you mean dyslexia?', and I'm like, 'No, it's different'. You try to explain to people that you can't physically write, but you can read and everything, you just can't write; they just automatically assume it's either dyslexia or dyscalculia. (Florence: 2, 63)*

The lack of clear understanding was sometimes mirrored in responses from the participants themselves. Zac was unable to give me a definition of his understanding of DCD, and Florence reflected that there was some confusion in defining exactly what it DCD is. Skye admitted that when she was told she had dyspraxia, she had no idea what it meant.

*Dyspraxia is from what, they're not really sure, but from what like, from scientists and doctors, as I understand, it's a coordination disorder, which means that I have sort of slow processing skills. (Florence: 4, 104)*

*I was like, 'What is this word? I don't know what this word is!' (Skye: 1, 20)*

Many of the participants cited their frustration with the low profile and the lack of understanding regarding DCD as a key reason why they wanted to take part in the study. There was an expression of need for other people to understand them and be able to respond appropriately.

*Not really [do people know about dyspraxia]. Or the most response I get are, 'Oh I think my friend has that'. That's why I was kind of happy when I got asked if I wanted to do this, as I wanted to make people more aware about dyspraxia as a thing. Because it's real, and lots of people don't get diagnosed with it because no one knows what it is, so ...yeah. (Megan: 4, 188)*

Even when participants did explain DCD, they were still often met with confusion and misunderstanding, which added to their frustration.

*Just...accepting it works like that. I remember being, I think, 11 or 12, because I came from a tiny primary to a secondary school, and I was trying to explain to some girl in my class why I got to use a laptop, and she said, 'Yeah, but you're so smart, surely you don't need it', and I was like - yeah, it doesn't work like that. It can be frustrating sometimes trying to explain to people. (Florence: 3, 72)*

Whilst this was irritating for the participants in terms of peer groups, sometimes it was the teachers that did not understand or fully comprehend the impact of DCD. The lack of an 'authoritative' response increased frustration and a sense of neglect/unimportance. Eliza felt as if she had a tick by the box 'special needs', but that support was limited and patchy, with the onus often on her to explain the situation to teachers rather than getting support.

*Definitely more support in high school, like, definitely teachers should be more aware and more knowledgeable about things they could do to help because I had extra time, but I think they just felt that was because I'd been written down as extra time... (Eliza: 16, 499)*

For Eliza, the burden of explaining herself highlighted a sense of being different and needing to be treated differently. She became so frustrated with having to explain

herself repeatedly that she not only gave up talking about it / asking for help, but also became anxious that she was overly demanding - an 'attention seeker'.

*Nobody ever seemed to talk to me about it. Like people knew in P.E., but the thing is, we had different teachers a lot because we had supply teachers, and I think the teacher would forget to tell them, and they'd forget, and in the end, you just stopped mentioning it because, I don't know, I think people thought I was attention seeking as sometimes. (Eliza: 16, 505)*

### **3.6 Theme 3 - Recognising and Coping with Limitations**

Participants expressed a sense that DCD caused limitations and boundaries for them. Many of these limitations were unseen but resulted in them having to struggle and work hard, often with little appreciation by others of the difficulties they faced. Emotionally too, many of the participants felt that the impact of DCD was a further burden that was not appreciated by others. The participants employed a range of strategies to cope with the extra burden that they felt they carried. Some of these were explicit and thought through; others were more unconscious responses to their circumstances. The following subthemes were identified: Not being 'good' at things, Unseen Struggle, Emotional Overload and Coping Strategies.

#### **3.6.1 Not being 'good' at things**

A sense of not being 'good' at things compared to others is a common experience for those with DCD. There can be a feeling that DCD creates obstacles that cannot be overcome.

*Something that stopped me from being able to reach my full potential. (Ted: 1, 13)*

Without DCD, Ted would be someone different - someone who could realise his full potential. With DCD, Ted was a lesser version of himself. He repeatedly stated that he was not as 'good' as other people.

*Erm...it's just that I was different. I couldn't do stuff as well as other people, and I wasn't very good at sports or somethings. (Ted: 1, 24)*

*Not really, I guess; it's just daily activities, like maybe I'm not as good as other people at. (Ted: 18, 571)*

Seeing yourself as less able than others can affect the goals set for the future, with participants needing to strike a balance between acceptance / being realistic and unintentionally limiting their options.

*Well, erm... to be honest, I first wanted to be a football player, but every time I kicked the ball, it went that way, not this way. Then I wanted to be a police officer - Ahh (sigh) I trip over my own legs so many times. (Skye: 5, 143)*

Skye's answer to the question 'What would you like to do when you are older' shows a process that many adolescents go through, giving up on unattainable goals (such as being a footballer) and trying to find a realistic, grounded role. However, underpinning this for Skye was a greater sense that she just was not 'good at things'. So much of her life was defined by what she could not do, compared to others; she found it hard to focus on what she was good at.

*Maybe...I haven't really thought about it to be honest. Because I'm trying to put all my abilities together and try to think of what I would be good at. I'm not really. I don't think I could really pull it off, and also I don't want to try and make stuff that I'm not really good at dodging - like an astronaut, that I might get hit by a meteor. Or as a ninja, I might get hit or something, and I don't want to die. (Skye: 31, 980)*

The sense of not 'being good at things' was reflected in the language used by participants. Megan listed all the things that she was 'not good at': P.E, sports, hand-eye coordination, doing up buttons, catching and throwing, and writing for any length of time and focussed on being clumsy and walking into things, concluding -

*I don't do anything really well, to be honest (Megan: 6, 196)*

Sports lessons were an area in which being 'less good' was apparent to the participants. Sometimes, this was due to deficits in motor coordination, but the processing of information demanded by team games could also lead to difficulties.

*So, in team games, whenever you get the ball, you like, your brain has to work out who to throw it; well who's the most likely to catch it from you, you know, who's the most likely to get it especially as you do it with another form, as you do it two forms at a time, because we are one form that know you like...who do I throw it to? (April: 6, 169)*

For those with DCD, regardless of whether the issue is physical coordination or cognitive processing, there is a feeling that something is not as effective - there is 'a bit missing'.

*Like people's brains are like a wheel, and they go round and round; you know they work fine, and sometimes, it's like us, like people with dyspraxia who have a wheel, and it works, but there's a bit missing, and I think that's different. (Eliza: 5, 134)*

### **3.6.2 - Unseen Struggle**

Although the DSM definition of DCD covers only motor coordination, many of the participants discussed the impact on their lives of memory, organisational, and processing issues. These issues caused many problems for the participants, and they often expressed sadness or frustration at how this affected them and at a perceived lack of understanding/support. For Florence, the 'processing' issue was an example of something intrinsically 'wrong' within her mind. Something 'doesn't click' in her brain - when it would click for other people.

*Sometimes, a lot of my things, I have, like, a process; it's not like a problem, but it's a processing thing, so if you gave me a drawer of socks, and I wanted to find a red pair, I could see the pair are red, but it wouldn't, like, click in my brain until the third time I'd scanned over it. So, like, then I'd have to pick it out; so, some things it takes me slightly longer and stuff. (Florence: 2, 38)*

Many of the participants recognised that they found it hard to plan and organise, and had devised strategies, which ranged from texting themselves to writing everything down. They were often aware that other people experienced them as forgetful and 'rambly'.

*But then, I know it's definitely about planning and my organisational ideas. Those are the two main ones, and then I have a tendency to... I find it very difficult to actually plan my thoughts and everything, so when I speak, it sounds quite rambly, and I flip between topics quite often, which does happen quite a lot. (Ruth: 2, 52)*

Unlike motor coordination difficulties, which can be observed easily in sports lessons or with writing skills, these processing issues were less acknowledged and often not addressed, meaning that the participants were left to struggle to assimilate information - often finding their own strategies.

*I find he doesn't have a teacher assistant, and also, he doesn't explain it as well as, like, I think he crams a lot of information in it, and I struggle to pick up the parts... (Ted: 3, 97)*

For Kara, the struggle was in concentrating, particularly in lessons, and she felt that it was harder for her than for others. She was easily distracted by noise or by things going on around her.

*it gets quite annoying because you've got to think about so much, so many things and you just don't get it done on time, and so you fall behind with your work, and you get distracted because you want to talk to your friends, and you've got friends around you, and you just end up talking to them, and nothing just gets done. (Kara: 4, 127)*

There was a sense of frustration that others did not realise how difficult she found processing information, that little accommodation was given to her, and she was expected to adapt to the situation no matter how hard this might be for her.

*I'm trying to listen to them explaining and trying to write as well. Doesn't work. Does not work. ... I can't do it - I can't listen to you because I'm trying to write this thing off the board which you've just wrote in about 30 seconds or something, and then you're talking about something else now and for the rest of the class, and I'm trying to hear as well because you're trying to say it to me as well, and it just goes (signs whoosh overhead). (Kara: 16, 513)*

### **3.6.3 - Emotional Impact**

Many of the participants stated that they could become highly anxious, especially in situations that were new and could potentially prove problematic for them. The anxiety encompassed the risk of injury to themselves due to their lack of coordination, and a more psychological anxiety of failure.

*In DT, we had to use a soldering iron ... my friend who sits with me in science, she burnt herself by accident on it, and that scared me so much. It wasn't that bad, the burn - but it*

*scared me so much that I actually got the DT teacher to do mine for me because I didn't want to burn myself because I'm more likely to burn myself than other people. (Megan: 21, 654)*

Often the fear revolved around letting other people down, either at home, by disappointing parents with poor grades, or at school, particularly when playing team sports - which was one of the reasons often cited for avoiding sport whenever possible.

*I: Do you feel you let people down?*

*P: Erm...sometimes, sometimes.*

*I: And how do you let people down?*

*P: It's more like in school with sports. (Kara: 32, 1022)*

Sometimes, the emotional cost of rejection was the feeling of being defeated and giving up. Rory, in reply to a question on whether he took part in sports, commented:

*I try to get involved, and then slink away. (Rory: 7, 196)*

Furthermore, participants expressed guilt at the burden they felt they imposed on their family and others by needing extra support.

*She gets dead upset when I'm upset, and if I'm quite anxious about stuff, she gets dead upset and that, and it really puts her in a bad ... She got in trouble with her boss because she's not been doing as much work, and I kind of feel that it's partially my fault because I'm coming to ... I'm coming home from school, and I'm ringing her (Kara: 22, 708)*

Ruth also expressed anxiety about letting other people down, particularly in sport, but she also felt 'bad' when she needed more support despite all her extra effort.

*I ran out of time to practise and stuff, so I felt bad that I kind of wasn't actually putting in the practice that I should be doing, and I stayed at the same level, and I felt bad asking the teacher to help me when all I was doing was not getting very far. (Ruth: 10, 307)*

For some of the female participants, there was a sense that DCD was linked to a feeling of 'emotional overload'. Feelings could bubble over and burst out, and this could have a negative impact in regard to victimisation.

*I think because she picked up on the fact that I was more emotional, she used to pick on me a bit more. (Florence:5, 132)*

The emotions were sometimes referred to as 'frustration' or 'stress'. Getting stressed was often identified as a major problem.

*I just sometimes feel that I have this sort of stress inside of me - that is just really frustrating that I just kind of want to say out - like some things, like, sometimes get to me like that sort of thing I feel like I have lots of frustration. (Sophie: 13, 304)*

For Kara, there was the sense that this could be completely overwhelming:

*Look, I'm constantly trying to think of my writing and my spelling and what I'm actually putting into my work, and then I'm losing concentration or something because I end up daydreaming, and it's gets annoying because I get just stressed about it and it just stresses me out. (Kara: 3, 98)*

In extreme cases, these feelings of anxiety /stress/ frustration can spill over into self-harming behaviours.

*Recently, I've been thinking about it quite a lot because I've been quite anxious about things, erm, and I've just haven't really wanted to speak about anything, and my mum's been quite upset, but I haven't physically gone and done like that (indicates cutting harm) because no, no, no, no, no, no - it's not worth it, and I'm getting help from CAMHS as well, so it's not like I'm on my own in the dark or anything; it's... I am getting help, which is good, but it's just taking quite a while. (Kara: 24, 758)*

### **3.6.4. Coping Strategies**

#### **3.6.4.1 Stay positive, don't give up!**

Many of the participants identified that they needed to try really hard and often talked about struggling to keep up. There was a sense that trying harder was the 'norm' for them. Life could be a battle, as was demonstrated in the answers below (question: What would life be like if you didn't have dyspraxia?)

*I think it would be a lot easier, like I wouldn't have to battle, like my Mum wouldn't have to battle the school (Sophie: 6, 139)*

*...my life would probably be easier I guess because I wouldn't have to struggle as much (Megan: 3, 81)*

Along with this sense of life as a battle/struggle, there was an acceptance that life would often be difficult, and in advice to other teenagers with dyspraxia, the response was normally not to give up - to find a way through.

*Just to not let anything stop you I think. Like I said 100% at everything and then give...try your best and just...don't, don't mind what other people think and just go for it. (Eliza: 8, 247)*

Participants indicated that they expected to work harder than others and that they needed to ignore the negative comments from some others. Ruth, a very academically able student, felt that she needed to work twice as hard to keep up with her peers. She summed up the impact of dyspraxia as follows:

*...I say it doesn't really hold me back and it doesn't because I got used to it, but it would be nice to know that it wouldn't take me four days to write one sentence. That would be nice - really nice. (Ruth: 29, 950)*

Ruth demonstrated a readiness to make sacrifices in order to 'stay in the game'.

*...I find that I spend most of my time trying to catch up on stuff that I need to do and not stuff that I want to do - which is why I do tend to have to put anything social or fun in the background until a specific date. (Ruth: 29, 953)*

Not giving up was hard for some of the participants, and Megan admitted that often the DCD and people's responses to it did stop her.

*...because I kind of want to write a book and it's kind of stopped me from doing it because I know I could type it like and some things like tests and writing, I lose a lot of marks and that (Megan: 3, 94)*

However, despite admitting that sometimes she did give up or even avoided school at times, she was still focussing on succeeding and 'not giving up'.

*I want to be able to do those things because I want to be able to live by myself, I want to be able to be independent (Megan: 20, 646)*

Staying positive was important to the participants and many concentrated on developing a mindset that accepted and embraced challenge.

*Maybe living life to the full is definitely an important thing to remember (Eliza: 17, 532)*

However, this was not always possible, and Kara in particular, was irritated by advice from her father that she should think positively. For Kara, 'having a positive mindset' was not something that she could just switch on. Here we can see her response to school's attempts to instil a positive mindset into their students

*'cos have you heard about positive and negative mindset? Because they are drilling - literally drilling that into our heads. Yeah - yeah - they are literally drilling it into our heads and it is really annoying because I'm like 'yeah - yeah - well done' I try and have a positive mindset and things because otherwise, if you have a negative mindset you - as people have told me at school - you're never going to get anywhere so I try and have a positive mindset but sometimes, I'm not in the right frame of mind. (Kara: 30, 960)*

Many of the participants were keen to point out that things had become easier for them as they became older, both socially and in terms of the impact of dyspraxia.

*Like, I guess doing my buttons up; when I was younger, I struggled a lot with that - I'm fine with it now, I think, but when I was younger, I didn't. (Zac: 18, 574)*

*I think it's just keep doing what you're doing. Keep working hard and keep using the support you've got and everything works out fine, I think. (Florence: 8, 261)*

Furthermore, the participants showed a high level of reflection in their approach to success and what that meant for them; the struggle involved in keeping up with their peers and the extra (often unseen) work often required just to be able to take part also helped define the importance of success and an appreciation of their own efforts.

*Well I guess it kind of means if you work a lot harder, then it, I guess, it kind of means more to me if I understand something in maths or just something in a lesson that everyone else seems to get. Once I get it, it just feels really good... (Sophie: 4, 90)*

*And finally I got one sticker. I celebrated so much. I think I kind of like laughed so hard my belly kind of hurt...One sticker - I've got it right on my notice board...(Skye: 22, 696)*

### 3.6.4.2 Minimising and rationalising

Acceptance, pragmatism, humour, and sometimes keeping quiet and not getting noticed were all expressed as ways of dealing with DCD. Many of the participants were keen to inform me that DCD was not a 'big deal'. Florence repeatedly told me that the impact of DCD was not 'a massive problem' for her

*It's a coordination disorder, which means that I have sort of slow processing skills and I struggle with coordination-based activities. Erm, it doesn't affect me - or it slight affects me in my day-to-day basis. It's not like a massive part of my life. (Florence: 4, 107)*

It was also something that was considered often best not thought about - it was easier to pay it little attention.

*I also guess it could act as a barrier mentally, you know, thinking that you have a learning difficulty, but then I guess in that sense, I'd prefer not thinking of having it at all. (Ruth: 33, 1028)*

Many had a sense of resignation about it; it was something that you 'got used to', something to be accepted:

*I think, growing up I suppose because I'd known all along, so it hasn't really been a massive effect, and sometimes, but otherwise, I'm just like 'oh' (shrugs). (Eliza: 2, 55)*

A pragmatic approach to 'picking your battles' was expressed, as participants experienced frustration and difficulties in obtaining support/help.

*There are just things that just can't be changed about the school - there are just things that even if you sent a thousand emails about it, there is nothing that can really be changed because that's how it's set. (Sophie: 12, 281)*

Most of the participants did not welcome the attention that DCD inevitably caused them and were keen to point out that they did not want sympathy or any type of 'fuss' or any type of attention focussed on themselves. Ruth admitted that she would 'remain' under the radar in sports; as she could run fast, she concentrated on 'running into a space' where nobody would pass to her. She was also reluctant to talk about it to other people.

*I don't like using dyspraxia as a label as such. That's probably the worst part that I don't like. Because the second you say to someone you have like a learning dis... err... difficulty, they seem quite shocked, because unless you highlight it a lot, I don't think it's something I'd worry about in a sense. (Ruth: 17, 553)*

Stumbling over the 'right' terminology for DCD occurred in several interviews. Some participants would talk about a disability, a difficulty, or a disorder. DCD was often downplayed, and participants were frequently uncomfortable with the possibly shaming or alienating attention that it might bring,

*I don't want them to react really (Answer to how would you like your friends to react if you tell them you have dyspraxia). (Ted: 14, 453)*

The participants often used humour to minimise the impact of DCD. For April, this was a very important strategy in dealing with her lack of coordination and one that she felt strengthened her social bonds

*And then I start laughing, and then my friends come round, and they take one look at me because I'm like absolutely having hysterics, and the next thing you know half the class is, so it's quite good. (April: 11, 345)*

#### **3.6.4.3 Finding an escape**

As the participants were used to acknowledging or coping with their deficits, be it in terms of sport or cognitive processes, the sense of being 'good at something' was hugely important. Being as good as, or better than others helped boost confidence by giving a sense of a level playing field. For the boys, gaming was often cited as a means of escape:

*It gives me confidence - something that I know I'm quite good at. (Ted: 8, 259)*

*I've got a knack for computer games, and I'm able to do things as well as other people. (Rory: 8, 260)*

With the exception of Sophie, school team sports were mostly avoided. However, Sophie, who struggled primarily with memory and processing issues, regarded sport, as an escape - it was somewhere she could be anxiety free.

*You don't need to remember anything, you don't need to remember any homework, and every time I just go into a lesson, I go 'Oh God, C (my best friend at school) - what's the homework, what's the homework?', and she's like, 'It's OK, we don't have any', and I'm just like 'pew'. I'm, like, terrified all through the lesson that I've forgotten something, but in sports, you don't have any homework, or you don't have any books - I feel really relieved. (Sophie: 25, 614)*

For many participants, physical activities outside school, such as climbing, were able to give them a sense of achievement, allowing the individual to enjoy and use their body without being measured against others and possibly open to shaming comments when their performance did not meet expectations.

*It was really quite fun because there's, like, a scale of walls you could do - there were some which were easy, some which were harder, so the idea was that you sort of picked it. And when I got to the top of a wall, I remember feeling really pleased about it. (Florence: 13, 399)*

Hobbies tended to be less 'mainstream', and participants listed joining the cadets; spending time with family, including older relatives, and making connections with other people with DCD who understood their difficulties as important outlets for them. There was a sense of being 'accepted' that was key to these hobbies, with participants finding people who were like-minded and where the focus was not on schoolwork or sport.

*But I love going to cadets because they're all different age groups, and I feel comfortable talking, just hanging out with them and having a laugh and doing a bit of First Aid as well. (Kara: 9, 286)*

Creativity was also cited as a means of escaping from struggles in life, with many participants emphasising that they enjoyed writing stories or developing comic books. Whilst many young people are creative, the experience and opportunity for those with DCD seemed to take on further poignancy.

*No one can change that - this is like my space - that's the one thing people cannot change if you write something down on paper. Unless you have to go back and proof read it just for changing a couple of adjectives and stuff, it comes out exactly how you want it in your head.*  
(Florence: 7, 201)

Creativity can mean freedom and can give the participant an opportunity to express and explore emotions and situations. Creativity can also mean control, that is, creating a world that meets their needs and which supports them.

*You can express your emotions; you can make somebody new and whoever you want to be, and you can make the characters however you like... So, like, you can express whoever you want to be... There's no boundaries when it comes to writing.* (Eliza: 8, 238)

Skye was particularly immersed in the world of the imagination. She spoke of having imaginary friends who helped her in certain situations - often providing support and comfort, such as when she needed to abseil off a high wall on an activity day or when she was new at secondary school and did not know anyone. These 'friends' populated a world in her head, but she also drew them and made comic book stories about them. They helped her make the world bearable and containable, and they helped her win.

*They used to be like ninjas fighting villains. And like a reality and a ninja life, and they used to all like fight villains and defeat bad guys.* (10, 305)

Skye was aware that she could be considered a little 'crazy', but was also aware that the imaginary friends were imaginary, and her (real-life) close friends and mother knew about them. But creativity and imagination had proved a safe-base for Skye during difficult times. It was also a means of literally creating - owning something exciting that reflected who she was.

*My mind is basically like paper... That you draw on it to make it... like a graph or a diagram or something. And you can literally see on it, just staring at a wall... and then I kind of trace on it and draw on what I think it is. I kind of make something.* (Skye: 8, 251)

### 3.6.3.4 Accessing Support

Getting support from others was an important element in coping with DCD for most of the participants. Although they had varying experiences of the extent of the support from school and other services, all the participants came from very supportive and nurturing homes - family support was a given. The participants were aware of their parents 'going in to bat' for them and often saw the world in an 'us' vs. 'them' situation, particularly regarding school and support services.

*Like, if I went to a meeting with my mum, then they said we're going to do this that and the other, but then they don't do them, it's just to make my Mum happy so she'll stop, like, saying, 'Why do you do this? Why do you do that?'" (Megan: 17, 551)*

Generally, being at home felt comfortable for the participants and home was a space of retreat, as opposed to the outside world. But there was sometimes guilt regarding the support that parents gave.

*I think it would be a lot easier, like, I wouldn't have to battle, like, my Mum wouldn't have to battle the school [if I didn't have dyspraxia] (Sophie: 6, 139)*

The support received from schools was very variable among the participants and within their own school careers. Some reported getting support as a battle that was constantly being fought. There may be small gains, but often, these were not consistently seen through. A lack of consistent support led to feelings of not being listened to and not mattering - others could be untrustworthy and let you down. In reply to the question what would help, Megan replied:

*Maybe people keeping their promises. (Megan: 18, 573)*

Being noticed - being someone who matters and who is deserving of help - was important, but often, the experience was more underwhelming, as can be seen in how Eliza describes the support she had received over the years.

*I think especially, then, over the years, they didn't really... and then in Year 7, they took a bit more notice, but then as you were getting older, they thought, 'Oh well!' (Eliza: 6, 162)*

'Oh well' is a resigned shrug, an indication that there really is not anything to be done, and that it really does not matter.

For many of the participants, having a good group of friends was the key to feeling supported. For Megan, the Dyspraxia Foundation had enabled her to make connections with people who understood what she was experiencing, and as someone who was struggling with friendships at the time of the interview, she had found this very rewarding.

*Well, I think what kind of helped is to meet other people in the same situation because through the Dyspraxia Foundation, I met four other girls who have dyspraxia. I have seen one of them again, and we went to (climbing wall) and had a fun session, and I have her phone number, and another one, I follow her on social media, and we kind of communicate through that.*

*(Megan: 19, 609)*

Friendship was especially significant, as most reported some difficult years involving bullying or exclusion, and many felt that building this network of good friends helped them feel accepted and able to cope and thrive.

*I think my friends just see me as Florence. They are prepared to give me hugs if I need them.*  
*(Florence: 9, 282)*

## **4. Discussion**

### **4.1 Introduction**

In this section, I will discuss the important themes that arose from the analysis.

Firstly, I reflect on each of the themes that arose from the study in order. Due to the qualitative and phenomenological nature of this research, which aims to give voice to the participants and explore their experience, many themes identified do not lead to direct comparison to previous findings, which were based on overwhelmingly quantitative research. However, there were many areas of crossover and similarities, which I discuss. In doing so, I have taken the perspective of a counselling psychologist; therefore, some concepts, such as 'shame', which do not hold a prominent place in previous DCD literature, are explored here.

Secondly, I reflect directly on the findings of this study in relation to the emotional and psychological well-being of those with DCD, drawing on previous research findings. The implications of this research are discussed both in general terms and specifically for counselling psychology, before considering its strengths and limitations and my final personal reflections.

### **4.2 Sense of Otherness**

The participants reported that being an adolescent with DCD engenders a sense of otherness, of being different. This major finding of a sense of otherness ties in with Lingam et al.'s (2014) qualitative study of young adolescents. However, whereas those findings reflected a sense of 'we're all different', which is almost a negation of difference and an attempt to seem the same, in this study, the participants were more likely to embrace and celebrate a sense of otherness. The participants' experience of a developing identity and of the on-going process of defining and understanding themselves as they approached adulthood was critical in this research. The participants' understanding of the impact of DCD was interwoven through this process. This sense of otherness was mostly recognised in childhood by

the participants themselves; however, for some, it was thrust upon them by the reaction of their peers or even teachers at school. I have used the term 'otherness' even though this is not a term used by the participants, who spoke mostly about 'difference' or about being considered 'weird'. 'Otherness' implies a difference that is outside of what is expected, that is perhaps not understood or even feared or rejected, that is remarked upon and linked with a sense of exclusion; 'otherness' puts you outside the norm. The theme of otherness has two subthemes - social acceptance and reframing difference: the first refers to the need to find a place in the world, while the second refers to how the adolescent makes sense of this difference. One is external, and the other is internal, although both are related to self-esteem, shame, and stigma.

#### **4.2.1 Reframing Difference**

In line with previous research, nearly all the participants discussed difficulties with social relationships and often bullying at school when they were younger; indeed, some were still struggling socially to develop and maintain friendships in secondary school. The need to belong and to be accepted was very much evident. However, the participants were mostly contemplative of this experience and had developed their own understanding of what it means to be 'different' and of the importance of peer group acceptance/relationships. Adolescence for most of them had created a space to step back and explore their own understanding of themselves and their position in society. The reframing of difference was not universal, but it was marked, especially as the participants moved from mid to later teens. They tended to no longer describe themselves in terms of inferiority, i.e., being less good or less able; instead, they were more likely to use terms that implied difference but without negative connotations.

Reframing is a technique that is often used in cognitive behavioural therapy (CBT) - particularly with clients who are depressed or have low mood and who may often display a tendency to focus on negatives, such as failures and disappointments, and can be biased towards negative interpretations of events. Cognitive therapy aims to effect change in the client's cognition and the premises, assumptions, and attitudes that underlie them (Beck, 1970). The technique of cognitive reframing focuses on adapting maladaptive beliefs, i.e., beliefs that are self-defeating or thoughts/cognitions that are distressing, so that they become more beneficial to the client / situation. This is assumed to improve the client's ability to cope with distressing situations and to reduce their psychological burden and unhealthy coping mechanisms (e.g., withdrawal, substance abuse). Crucially, for real change to take place, this must be more than a change of narrative or vocabulary; it must reflect a change in perception - an opening of a door to other interpretations.

In this research, adolescence has allowed the participants space for the reappraisal of their childhood/accepted view of DCD, and for it to be filtered through different eyes. In some examples, we see the participants 'reclaiming' words, such as 'space-cadet' and incorporating it with humour into their own sense of identity, while in other examples, we see the participants move to more 'positive' terminology, such as 'quirky' or 'unique' or 'being my own person', which emphasises the positive sense of being different. Regardless of the word, the importance rests on the fact that it is the participant who has chosen this definition - it is no longer being thrust upon them by others. Many of the participants were keen to discuss what they were good at and what gave meaning and joy to their lives - often describing creative endeavours such as writing, drawing, and drama, and social interactions, such as gaming with friends. They were proud of their achievements, whether academic or extra-curricular, which is not surprising in a world where they were often forced to openly confront what they struggled to do well and risk exposure to shaming situations. Being academic, having

good friends, being kind and thoughtful, working hard, being different, and being able to see the world differently were all named as important qualities.

Social relationships seemed to settle for most of the participants as adolescence progressed, and their descriptions of the social world seemed confident and thoughtful - far removed from the exclusion and loneliness often described in primary school and at the beginning of secondary. However, the impact of those times was still evident, as nearly all the participants emphasised the importance of friendships and loyalty. I experienced a sense of maturity with the participants, a distinct lack of playing games; in my own interpretation, I saw earnestness beyond their years.

Reframing 'weird' to 'quirky' is more than using a different word: it indicates that the participant's beliefs and assumptions about themselves have changed. The concept of cognitive reframing implies a change of conceptual viewpoint towards a situation or experience. It indicates a positivity and potential, that is, a rejection of the model solely of deficit. A step to the side, a change of perspective can have a meaningful impact on lives.

In recent years, the call for greater acceptance of diversity in society has increased. This has been reflected in the development of movements promoting neurodiversity, particularly in regard to ASD, where self-advocacy groups have begun to challenge the notion of autism as a 'dis-order' and have called for a greater acceptance of diverse experiences, thinking, and ways of relating to the world; the aim is to stand in direct opposition to the medical model, which describes autism as a deficit or weakness (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). However, there is little indication of this trend being reflected among those with DCD. In line with previous research, which found that those with DCD (or, here, dyspraxia) did not have a strong identity with the label (Lingam et al., 2014), these findings did,

however, indicate the development of a more positive self-image that was inclusive of DCD rather than dismissive of it. The participants in this research indicated a sense of being 'other' but not of having an alternative identity - it is almost entirely an identity of difference. The fact that DCD is so little known among the general public and even less well understood must be considered as a factor in the limits of neurodiversity language or awareness expressed by participants. That all but one preferred the term Dyspraxia to DCD is interesting, but perhaps not surprising as the participants were recruited from the Dyspraxia Foundation and the term 'dyspraxia' is still commonly used within the UK. The word, dyspraxia, is generally not used in academic literature, which again contributes to a sense of uncertainty / vagueness regarding definitions and a confusion between the reality for the participants and the world of professionals. The disparity in the use creates a further gap between the world of the professional or researcher and the world as experienced by those affected. It literally means that we are speaking a different language. Many of the participants had not even heard of 'DCD' as a term. Although reasons for the use of the preferred term was not a specific question within the study, it would be interesting to research further how/why this has developed within the UK – is this solely due to the 'Dyspraxia' Foundation being the main place of support and information? Despite the complaints of many participants that dyspraxia was often misunderstood or mistaken for dyslexia or dyscalculia – it may be that the similarity in terms to these other more recognised conditions lends a security that this is a 'real' condition and therefore something that already has credence. Although Developmental Coordination Disorder is more descriptive of the condition, it also states that it is a 'disorder' which can be perceived negatively, whereas dyspraxia could be considered more neutral in that the meaning is more obscure. In practice, it would probably be reduced to initials 'DCD', which is mostly unknown within the general population and would therefore demand further explanation from the participants and perhaps even justification that the condition exists. Again, there seems to be little or no research

into how those with DCD/Dyspraxia feel about the term / description and their preferences in the matter.

Edmonds (2012) argues that those with DCD are excluded from and discriminated against by an educational system that is organised for 'left-brain thinkers' rather than 'right-brain thinkers', which he claims is a better description for those with DCD (and dyslexia). However, there is scant research to confirm this dichotomy of neurotypes by left-brain/right-brain regarding DCD. Likewise, in the literature, those with DCD may often be described as having positive attributes, such as being determined, being creative and original thinkers, having a good sense of humour, having empathy, being genuine and sincere, and being persistent and determined (Drew, 2009). Indeed, all these qualities were either observed in or identified by the participants in this study. However, there is little or no quantitative evidence in the literature regarding this issue. Whether this is through a lack of research due to researchers identifying with and following the medical model of 'disorder', which concentrates on deficits, or whether these qualities cannot not be empirically or statistically verified is harder to determine.

This lack of effective advocacy is detrimental. Many of the participants struggled with 'normal' modes of teaching - copying from the board, remembering instructions (especially if rushed or shouted out at the end of a class), or focussing in busy environments. Unfortunately, the adaption of teaching styles or techniques so that those with DCD could more easily learn and thrive was reported to be inconsistent or even absent. New research, in line with neurodiversity inclusion, is beginning to explore the possibilities. Oram's (2018) paper discussing how best teach to drama to students with dyslexia and DCD regarding their differing needs draws on the social model of disability (Oliver, 1996), which makes a sharp distinction between impairment and disability. 'Impairment' refers to non-standard states, e.g., lacking a

limb. Such impairment is a description and may or may not be considered negative by the person affected. 'Disability' refers to the disadvantage or restriction that society places on the individual with the impairment and whereby they are excluded from participation, e.g., an employer whose office building has stairs, but no lift excludes wheelchair-users from gaining employment, rather than the impairment itself being the cause. Likewise, schools that do not accommodate the needs of students with DCD regarding having clear lesson plans, or sufficient time to copy down work can be seen as creating a disabling environment. More research is needed into how those with DCD can best learn; for example, are there genuine differences in terms of being 'right-brain' focussed, or are there different sub-sets depending on EF impairment? At the moment, the concerns of the participants indicate that schools should be doing more to support the students; the study shows that they are often considered a nuisance in mainstream education, outside of the SEN department, and that the onus is on the student to keep up. The burden of adapting is still very much with the child affected rather than the system.

The lack of evidence regarding possible positive or favourable elements of DCD makes identification and self-advocacy more problematic, but not impossible. It is also clear that not only was there no strong sense of 'DCD' identity, nor was there much evidence of alliance with others with DCD (although two participants had made contact with others through the Dyspraxia Foundation and found it helpful). Some participants were still not openly identifying as having DCD, and many were careful about whom they shared this information with, which is not surprising. Despite advances in research and understanding, stigma and shame are still very much evident and present a barrier to open communication and understanding, and ultimately, support.

Woods (2017) argues that the social model should be applied to those on the autistic spectrum - including the removal of negative language, such as 'disorder' or 'impairment'. It would be interesting to apply this to DCD - the medical model is premised on disorder and impairment. The sense of being 'just different' expressed by the participants is still remote. Regardless of whether the term 'dyspraxia' or 'developmental coordination disorder (DCD)' is used, deficit and impairment are at the heart of the definition. Language matters, as this research shows. The participants used language to change their view of themselves - they redefined and reconstructed the opinion of themselves, not by denying the obvious difficulties they had in some spheres, e.g., sports or self-organisation, but by expanding their view of themselves as not just someone who is bad at something. It would be interesting if the academic world could meet them in this arena.

#### **4.2.2 Social acceptance**

##### **4.2.2.1 Identity**

The participants' experience of a developing identity, that is, the on-going process of defining and understanding themselves as they approach adulthood was critical in this research. In his psychosocial theory of development, Erikson (1968) refers to this stage as 'identity vs. role confusion'. It is a crisis of adolescence, where identity is deconstructed, and by implication, if the 'crisis' is successfully negotiated, reconstructed. It is important to note that Erikson did not claim that identity became fixed in adolescence, but that successfully completing the 'crisis' of this stage would enable the individual to grow and develop towards further life stages.

During this psychosocial stage, adolescents are concerned more and more with how they appear to others, most importantly, to their peers. Cliques are often formed, and teenagers can be cruel to 'outsiders' and exclude those who do not fit in. Blakemore and Mills (2014) highlight the increasing evidence from neurocognitive studies that

adolescents are more sensitive to peer group exclusion than adults or younger children and that adolescence is a period of enhanced social sensitivity to social signals in the environment. This was reflected in the interviews where the younger participants were often still grappling with identity, peer acceptance, and challenges to their sense of self. The participants' understanding of the impact of DCD was interwoven through this process. In contrast, the older participants often expressed satisfaction with their sense of self and had embraced an identity that constructed DCD in a more positive and accepting light.

Adolescence is a time of near constant change and has wide-reaching impact on development – physically and cognitively. The brain developments that begin at puberty are extensive; the plasticity of the brain allowing more inter-connection and specialisation in function (Giedd, 2018). Decreases in grey matter and increases in white matter have been shown to continue well into the third decade of life and the structure of the brain continues to change. Areas of the brain that are known to subservise EF, as well as language functions, continue to develop in a fairly lineal manner across childhood and adolescence, whereas sensory and motor areas develop more rapidly and earlier (11-15 years) (Alexander-Bloch, Giedd, & Bullmore, 2013). During this time of development, there may be heightened responsiveness to emotional cues / rewards, whilst emotional and cognitive regulation is still relatively undeveloped/immature (Somerville, Jones, & Casey, 2010). In some respect the difference between the older and younger participants' understanding of themselves in terms of identity and social acceptance can be understood with reference to this development, as older participants were more able to rationalise and regulate emotional control.

However, in addition to this general adolescent developmental process, it is known that those with DCD are often found to have impairment of EF. In research into

ADHD, it has been found that some cognitive impairment is due to a 2-3 year developmental delay in cortical development (Shaw et al., 2011; Shaw et al., 2007) but that in the majority of cases age brings about a partial remission in functioning (Faraone, Biederman, & Mick, 2006). This brings about a further complication in researching an adolescent sample, especially one as broad as described in this research. How far are the difficulties reported by younger participants related to a developmental delay in EF, which would not only make the processing of complex emotional situations difficult but also enhance a sense of difference to TD peers? Are the older participants generally reporting more positive attitudes to identity / self-esteem and social acceptance due to a 'normal' process of maturation despite ongoing EF difficulties or did the improvement occur when their EF/cognitive development caught up with TD peers? Likewise, were the younger participants adversely affected by 'immature' EF development? Although difficulties with EF, especially in planning and organisation, have been found to impact those with DCD into adulthood (Tal Saban & Kirby, 2018), the research into DCD and EF is relatively limited and it is hard to assess to what degree (or if at all) either delay or impairment is an issue.

In regard to sex differences and the impact of sex hormones during puberty, an increasing level of testosterone during adolescence has been associated with an increase in approach-related behaviour and risk taking, as well as sensation seeking for boys and sensitivity to rewards among both boys and girls. There is evidence that testosterone increases motivation to attain higher status – but the behaviour this engenders will depend on the social context. Aggressive behaviours may occur if the individual feels threatened and boys who were bullied were found to produce more testosterone than non-bullied boys. Social context both mediates the effect of hormones and influences the level of hormones but is crucial in understanding behaviour. If social status becomes of greater importance due to an increase in

testosterone, this will increase the likelihood of behaviours that will attain that status, as well as the sense of frustration if that status is not achieved (Crone & Dahl, 2012; Peper & Dahl, 2013). What constitutes 'status' will of course vary in context both situationally and regarding gender. Sporting success may be more frequently rewarded as a high-status achievement in boys than girls and may lead to further frustration/lower self-esteem among boys when this is unattainable. The importance of boys finding alternative means of achieving status is critical.

Furthermore, females mature earlier than males. Robust sex differences in the structural development of the brain have been found – with development in females generally occurring 1-3 years earlier than in males (Giedd, 2018). The higher number of female participants, especially those older adolescents, may have given the impression of a more emotionally mature cohort, than if the sample had been majority male.

Although there are many sociological examinations of 'otherness', this concept has tended to refer to how the 'other' is regarded by society. This can be seen in studies into race, religion, or disability (Harma, Gombert, & Roussey, 2013; McEvoy et al., 2017; van Dijk, 1993), which discuss the impact of being designated as 'other'. Theories of otherness are strongly rooted in social identity theory (Tajfel, 1974), which explores the forming of social groups and the stereotypes and behaviours applied to 'in-groups' and 'out-groups'. It is a theoretical framework for how we relate to others, either accepting or rejecting others socially, and how this affects our behaviour and attitudes. This is also closely related to stigma, as explored by Goffman (1963), in that those who fear stigmatisation also fear being designated as the 'out-group' and of not being acceptable to the 'in-group' and thus excluded. Due to their increased sensitivity towards peer-group exclusion, adolescents typically

devote time and effort to avoiding this (Blakemore & Mills, 2014). Having an identity or quality that puts the adolescent at risk of exclusion will be painfully felt.

Whilst Tajfel's social identity theory (1974) explored differences such as race or religion, the issue for the adolescents with DCD is far more complex. DCD is a heterogeneous condition, as reflected in this study: whilst some participants struggled with mathematics or art, others excelled, and whilst most disliked and some detested sports lessons to the point of absenting themselves from school, others claimed it was an escape from the pressure of academia, where they struggled with memory issues and organisation. Some of the children were obviously clumsy and were teased for it, while others managed to hide their lack of coordination by avoiding situations where this could be noticed. The 'otherness' of children and adolescents with DCD cannot be easily categorised or even described - it is not always visible and may only be apparent in certain situations - and yet, the participants were aware of it and reported that their peers and teachers perceived it – regardless of diagnosis. The heterogeneity of the group in terms of age, comorbidity and differing limitations (or perceptions of limitations) is an added complexity in the research and cannot be completely disentangled from the complexity of the response to the diagnosis. There is a 'messiness' inherent in the 'heterogeneity' of DCD. There is not simply an issue regarding the prevalence of comorbidities – how this affects the participants self-perception and identity, but also the fact that some of the participants were awaiting further diagnoses (which may or may not have been confirmed). This confusion and lack of coherence regarding DCD must also impact the participants' coherence regarding identity. And indeed, a strong identity regarding DCD / Dyspraxia was not found. This is an issue that has long been recognised in research into DCD and calls have been made to move beyond a 'one-size-fits-all' approach to both assessment and intervention (Smits-Engelsman et al., 2017).

The 'otherness' is a vague notion, a feeling that the label of DCD or dyspraxia gives shape to, but still does not seem to completely describe. As discussed in the literature review, the categorisation and definition of DCD has emerged and developed over the years, and there still remain questions regarding the extent and inclusion of comorbidities and the role of EF. Furthermore, even some of the participants found DCD hard to explain, and one was not able to offer any explanation at all. A definition needs to be accurate and relevant in order to be useful. As Klasen (2000) points out, labels are helpful if they increase a sense of coherence. By restricting the definition of DCD to 'motor-disorder' when the majority of the participants also struggled with and complained of EF problems, the label could be seen to increase the vagueness and confusion for those affected and those who support them. The participants needed to explain to their peers why they had extra support or why they were sometimes treated differently. If DCD is defined as a condition that means you are less coordinated, how does this relate to your difficulties remembering homework, copying from the board, or doing more than one thing at a time? The participants were being put in a position of having to explain difficulties with attention, focus, sense of direction, and memory without being given the 'label' that describes this. Many of the participants avoided discussing their difficulties with their peers, claiming that often, their peers did not understand or even could not really believe that they struggled (as they were 'clever'), which caused further frustration. In addition, identifying with a label has further complications should that label change, or further diagnoses follow. Although this was not a subject of discussion in this study, the high rate of comorbidity within DCD has implications for identity. Many parents discussed difficulties getting a diagnosis which inevitably leads to delay and among the participants, the age of diagnosis varied greatly from early childhood to sixteen. The impact of age of diagnosis on identity and self-esteem and/or the possibilities of further or later-diagnosed comorbidities or even a change of diagnosis, as can sometimes happen (Baird, 2013) is an area that needs further

research. Those with an earlier age of diagnosis would be expected to have had greater access to support both in an educational setting and in the home, as well as a better understanding of their own limitations. This would therefore be expected to have a significant impact on self-esteem.

Those with DCD are seen as 'other', but unlike with a better-understood and well-recognised disorder such as dyslexia, the participants reported that the 'otherness' is not necessarily evident and is rarely understood by their peers. Miyahara and Piek (2006) found that self-esteem was affected to a greater degree among children and participants with minor disabilities rather than major and more visible ones and the frustration shown by the participants regarding the lack of understanding and recognition of DCD seems to support this.

#### **4.2.2.2 Self-Esteem**

IPA is concerned with the experience of the individual and how they live in the world. In regard to 'otherness', the question in this research is not how society sees the participant, but how the participant experiences this, that is, how feeling 'other' impacts their sense of self, and how they see themselves and their place in the world. Indeed, how, as an adolescent, do they make sense of this 'otherness' in a way that is meaningful and allows growth?

The impact of bullying has been well documented, and nearly all the participants reported incidents of bullying or social difficulties in primary school or early adolescence, sometimes so severe that they changed schools. Whilst none of the participants reported active bullying, many of the younger participants still felt excluded and uncertain within their social sphere. Jaspers (2012) found that within teenage years, exclusion was more likely to occur than blatant bullying, and that exclusion often leads to negative self-evaluation.

#### **4.2.2.3 Stigma - the role of shame**

Looking again at Goffman's (1963) work on stigma, we can see that difference is only stigmatising if it is so considered by the social group. This was highlighted in the variety of responses of the participants. Those who were confident in their social sphere, identified strongly with DCD and felt little shame or stigma regarding it. Others felt the need to keep quiet about it or be careful to whom they spoke; knowledge was considered dangerous and potentially humiliating and could lead to stigmatising situations and exclusion. Among the peer group, many participants felt there were people who could use the information against them, and talked about being 'careful' whom they told for fear of humiliation. For others, telling others about DCD was a conduit that diverted the shame and stigma from the person towards the label. The aim was to avoid stigmatising situations.

All these responses reflect the role of stigma and, by definition, shame. For most of the participants, the response was more nuanced, but there was still a sense of protecting oneself from shame, whether that was the shame of having a 'disability'; the shame of not being good at sport and letting the team down; the shame of being clumsy and slow, and of holding everyone up; or that of being laughed at or pitied. This shame could be compounded by casual remarks from teachers or hurtful comments from peers. Shame is a crippling, painful emotion, and defending ourselves against it is important psychologically but cognitively demanding. Morrison (2011) describes shame as

*... a painful burden that permeates the whole body and envelops one's complete sense of self. It is, perhaps, the most agonizing of human emotions in that it reduces us each in stature, size, and self-esteem, such that we wish to disappear, to sink into the ground. (p. 23)*

Shame is the emotion that causes us to want to disappear. Although often confused with guilt, when psychologically defined shame pertains to our sense of self, that is the idea of who we are, whereas guilt is related to what we have done (or not done). In such a way, guilt can be resolved, if we can make recompense for our perceived wrong-doings. Shame, however, is always intrinsic; it strikes at the heart of who we are and cannot be so easily repaired (Lewis, 1974). Shame can be defined as

*the intensely painful feeling or experience of believing we are flawed and therefore unworthy of love and belonging (Brown et al., 2011) (p. 354)*

We can see the link between the sense of self as impaired, flawed - of being weaker or insignificant and ultimately not being worthy or belonging. Although shame can emerge from many sources, it always has the quality of the self somehow falling short - of there being a gap between the self that we are and the self that we 'should' be - that we in ourselves are not enough.

Avoidance of shaming situations is one strategy for avoiding shame and stigmatisation. However, for the young participants, whose lives were structured around a school curriculum, this avoidance was often impossible. Learning how to defend yourself on a daily basis from shame, whether that is in the playground, in the sports lessons, or during class takes its toll on the individual. Taking the role of the coach during classes, running fast into empty spaces so nobody passes you the ball, frantically copying from the board rather than asking for help are all strategic attempts to avoid the shaming situation, the point when you are seen as not good enough, where you can be mocked and laughed at or where you can be blamed for letting other people down. The effort of monitoring and adopting strategies to avoid this shame demands exhaustive cognitive effort, and seems encapsulated in Sophie's frustrated exclamation, 'Why don't you try and overcome this!'

#### **4.2.2.4 Status**

Baumeister and Leary (1995) identify the need to belong as crucial in terms of self-esteem. A sense of 'belonging', of ultimately not being 'other', has a positive impact on our thoughts and emotional responses. However, self-esteem is not solely dependent on peer acceptance. Recently, research has also focussed on the importance of perceived status and its role in self-esteem (Mahadevan, Gregg, Sedikides, & de Waal-Andrews, 2016).

Many of the participants were acutely aware of their lack of status in childhood and adolescence, and of being considered the 'unpopular' or 'middle' kid, that is, the one who does not make a mark or excel. Particularly for the boys in this study, the sense of not being 'sporty' was often explored and being 'not sporty' was an often identity in itself; in this case, all three of the boys found status in being 'nerdy', which typically involved gaming (however, one of the boys also claimed to be an excellent baker). In our increasingly technologically driven world, the words 'geek' or 'nerd' have also become a type of alternative status symbol, and playing games on the console or internet also levelled the playing field for the male participants with DCD, where they were able to compete at a similar level to their friends, something they described as being difficult or that they could be excluded from in the physical realm. For the girls, the techniques of finding status (something they were good at and regarded themselves as good at) were more diverse, ranging from creative writing to sports (such as climbing, running, and swimming). Having something to be 'good at' was important for the participants. For those who were not academically gifted, these were mostly found outside the school environment.

#### **4.3 Complexity of Response**

Taking a phenomenological approach allowed this research to explore complicated feelings that may not always be easy to quantify. This was true in relation to the

participants' response to having DCD as well as to their understanding of the boundaries and limitations they felt the disorder imposed on them.

#### **4.3.1 Response to diagnosis**

It was not simple to untangle how individuals felt about having a diagnosis of DCD, and naturally these feelings were not uniform among the group, who were of different ages and genders and who were affected differently in terms of severity and area of impact. However, the initial feeling of relief at having a 'diagnosis' and appreciation of the utility of the label as an explanation was widespread. The sense of not in themselves being 'wrong' but of 'having something' again shifted a burden. The impact of internalised shame for their shortcomings (of **being** clumsy, of **being** disorganised, of **being** inattentive) - a sense that the participant was to blame and was not paying attention or was being deliberately awkward, was lessened. However, a new type of shame - that of having a 'disorder' - was bestowed, which resulted in the participants guarding to whom they revealed the condition and how much information they gave away.

#### **4.3.2 Need for acceptance, understanding and support**

All the participants reported that they expected and needed a supportive structure, especially at school. They expressed frustration that this was often not realised. Particularly in terms of support, having to ask repeatedly for help or being promised help that does not then materialise caused feelings of hopelessness and worthlessness and a sense of 'attention seeking' rather than rightfully getting needs met. Passing the burden of repeatedly seeking help on to young students must be considered a failure on the part of the system. The participants were very aware of the role their parents played in supporting them and in 'going in to bat' for them with the schools - sending emails or meeting with teachers. Often, the participants expressed guilt that they demanded so much time and attention from their parents.

Many of the students covetously compared the attention and understanding given to dyslexia. The description of school walls lined with posters for dyslexia awareness week, and empty walls for DCD was telling and apt, and sadly, seems a fitting metaphor for how the participants considered DCD to be valued, that is as a poor relation, one that had little attention and was not understood.

There was frustration that others did not understand their experience - that the participants could feel judged as 'lazy' or 'attention seeking'. This tallies with earlier findings that DCD is very much unknown or misunderstood among the general public and that responses from educational professions are considered poor (Novak et al., 2012). It is naturally disappointing that this situation is continuing. Although some of the participants identified exemplary teachers or support workers, many reported issues of a systematic failure of support that was seen as typical of their school experience, sometimes involving head teachers. Many of the participants gave up seeking help out of frustration for this reason.

The research also revealed the huge frustration regarding the lack of understanding, in particular, how demanding the many aspects of day-to-day life can be for someone with DCD. The lack of knowledge regarding DCD has a direct impact on the lives of adolescents with the condition. There was disappointment and concern expressed over the type and level of support given by some school staff who do not understand the condition and where it was felt that it was not made a priority in comparison to other developmental disorders.

Developmental disorders are not simple concepts; understanding them and their impact on the child/adolescent takes effort on the part of both the individual and the school, with the school needing to implement and maintain adequate training of their staff. Furthermore, the impact of DCD is broad and varied. There is no one-size-fits-

all solution, and teachers and schools need to be up to the task of supporting students in the school environment. Sports lessons provide an ideal example of this complexity. For some participants, particularly those with more severe motor skills impairment, these lessons could be felt as humiliating and shaming and yet they were forced to take part at the same level as other children. It would be hard to imagine teachers treating a visually impaired child in the same way; however, as the level of impairment with DCD is not always easy to determine, this is problematic for teachers to assess. In contrast, one or two of the participants enjoyed sports and many participants believed it was important to 'give it a go' and not just give up; it did not matter if you were not any good at it, as the important thing was to try. Here we see the complexity that dealing with DCD involves for professionals. On the one hand, there is the risk of shaming and humiliating an already fragile and disheartened child and on the other hand, there is the risk of teaching a child to give up and not participate.

Sport is significant in that it has the potential to pose a serious threat to the adolescents' status, particularly for boys, and it is a subject that may have an impact on future physical health. Sports teachers bear a critical responsibility towards students with DCD and need to be supported in this by adequate training.

Adolescents are old enough to understand and discuss these issues. Indeed, it is the adolescents themselves who understand more than anyone else where the boundary lies between 'giving up' and 'not being able to do it'. Historically, children and adolescents have been left out of the research (Magalhães et al., 2011); however, in this study, most of the participants were clear about how having DCD affected them and they were more likely to express determination to 'give it a go' rather than to give up; thus working with them would seem to be the obvious solution. Poorer levels of physical fitness and attitudes to sport have been noted in the literature (Cairney et al., 2005; Meek & Sugden, 1997), with Hands and Larkin (2006) arguing that

educators and other health professionals needed to find ways to reach this group and develop their physical fitness. However, in this research, a dislike of and disinclination towards sport (at least the sport practised in school) was in the majority. This is a disappointing finding, considering this aforementioned research is between 10-20 years old; it seems that little has changed to affect the attitude of children and adolescents with DCD towards sports or that typically much effort or imagination has been applied to consider how they may be involved in sports and encouraged to develop health-promoting activities.

#### **4.4 Recognising and Coping with Limitations**

##### **4.4.1 Unseen Struggle**

Tying in with themes regarding the lack of understanding surrounding DCD, the participants felt that their difficulties and struggles were often unrecognised. Working really hard was normality for this group, who identified that they often had to finish work in the lunchtime or at home or make extra effort just to keep up with their peers. This may be due to the lack of clarity regarding DCD. As long as it is seen as a purely physical/motor disorder, it is hard for others to understand the impact of possible EF difficulties regarding memory, planning and attention, in addition to the impact of negotiating physical activities. Simply getting through a typical school day demands much more from a pupil with DCD in terms of mental and physical effort - and this is largely unseen. O'Dea and Connell (2016) identified fatigue due to extra cognitive and physical load as an issue for adolescents with DCD, and this is often not taken into account.

##### **4.4.2 Not being good at things**

In terms of self-esteem, the adolescents had all been made painfully aware of things they were 'not good at', mostly in terms of sports, but they also recognised various problems with EFs, e.g., memory and processing. Asking what the participant

struggled with often led to the citing of a plethora problems, in contrast to the considered and limited number of things the participant considered themselves to be good at (if any). All the participants understood at an early age that they were often less able to do things that other people found easy or took for granted; early in life this could be seen in basic tasks such as riding a bike without stabilisers or doing up shoelaces, while later it became more specific to school attainment, social skills and sporting prowess. It is easy to see how if this is left unchallenged, if no alternative is given, the adolescent, who begins to examine his/her place in the world would see themselves in a lesser light than their peers. This sense of limitation in comparison to peers seem to agree with the literature identifying lower self-esteem in adolescents with DCD, especially when their limitations are not recognised by others (Eggleston et al., 2012; Ferro & Boyle, 2013; Miyahara & Piek, 2006).

Being able to accept limitations without becoming disheartened was another area of complexity that the adolescent participants were beginning to explore. The limitations imposed by DCD were felt by many of the participants to be very real and almost external; as one participant stated, he had 'something that stops him'. The participants were negotiating between a mature acceptance of limitations and a sense of giving in to passivity. Whilst some expressed concern that the diagnosis might have a negative impact on them and create a tendency to give up or not try, the participants were all clear that they worked very hard, and they would encourage others with DCD to do the same. The line between realism and passivity was not always clear cut; however, the participants were aware of the dilemma specifically as it applied to them. Importantly, the participants did not feel that DCD had significantly affected or influenced their choices for their future careers.

#### **4.4.3 Emotional Overload**

Some of the participants described being unable to control their emotions - leading to outbursts either of anger or tears. This was often linked to anxiety, especially when in a new situation or feeling overwhelmed. Adolescents with DCD typically report higher levels of anxiety (Pratt & Hill, 2011; Sigurdsson et al., 2002). What is unclear is whether the emotional overload reported by these participants is purely a result of the anxiety due to increased stress, or if there is a further impact of EF impairment. If response inhibition is impaired, as is indicated in the research, (Bernardi et al., 2018) this would also impact the ability to inhibit more extreme responses such as crying or shouting etc. This is discussed further in section 4.5.

#### **4.4.4 Coping strategies**

Understanding the pressures and difficulties experienced by adolescents with DCD was an important element of the research; however, despite the numerous hardships recounted, most of the participants did not express themselves as defeated or negative. In fact, they often gave the impression of resilience and maturity far beyond their years. Looking at the strategies they used to cope with difficult experiences was informative in terms of understanding what makes a difficult situation potentially bearable and as a means of understanding how other adolescents with DCD could find strategies to deal with negative emotions and experiences.

Coping can be defined as the thoughts and behaviours that are used in order to manage the internal and external demands of stressful situations (Folkman & Moskowitz, 2004). Coping strategies are based on previous successful engagement with stressful events and are often categorised into three types: problem focussed, emotion focussed, and avoidance (Endler & Parker, 1990). Problem-focussed strategies tackle the problem head on, i.e., the individual finds ways to take action; emotion-focussed strategies are used to reduce emotional distress, i.e., taking time

out, talking to friends; while avoidance strategies mean neither engaging with the problem, nor finding strategies to cope with the issue. This occurs when we put off an important task because it makes us stressed. Whilst it was previously believed that problem-focussed strategies were the more psychologically effective and adaptive, some studies have indicated that emotional and avoidance strategies during the active period of stress are equally adaptive. For example, forgiveness or acceptance may be a useful strategy for coping in a situation where there is no feasible action to be taken rather than constantly attempting action that will be unsuccessful (Folkman & Moskowitz, 2004).

#### ***4.4.4.1 Staying positive***

Participants related several problem-focussed ways of coping, such as writing down as much information as possible or texting themselves/setting reminders on their phones, organising their bag the day before, and so on; sometimes, the participants had come to these solutions themselves, while other times they were supported at school or through OTs to overcome certain issues. It may be that the help of specialist intervention such as OTs and SEN teachers may have encouraged the child/adolescent to adopt problem-solving coping strategies, and so engendered a sense that problems can be managed. It was common for the participants to preach resilience, encouraging others with DCD not to give up, to stay positive, to keep trying, and not to let other people get them down. There was a sense that you learnt to pick yourself up again, often literally. Working hard was the norm, and most of the participants took it for granted that they needed to work harder than their peers to keep up; however, success, when it came, was truly appreciated and savoured. Most of the participants indicated that they were very positive and felt that by working hard they could improve their situation and gain advancement.

#### **4.4.4.2 Minimising**

Humour was often used as a way of coping with difficulties, with several participants claiming that they laughed with their friends when they fell over or were clumsy. For many of the participants it was important to portray DCD as not particularly important or not creating major difficulties for them. Issues were often minimised as 'not a big deal', particularly by the boys. This could be a true reflection of how they felt but could also be an attempt to maintain self-esteem and a view of themselves as somebody who can 'cope' and 'get by'. Adolescence is a time of increasing independence and discussing vulnerability or need is particularly difficult at this time. However, an attitude of minimising can lead to a reluctance to ask for support or help. This is something that teachers, parents and SEN staff need to be aware of - that it may be difficult for these young people to admit to difficulties, particularly when trying to become more autonomous.

#### **4.4.4.3 Escape**

Many participants mentioned finding an escape from their issues, which could be seen as an avoidant coping mechanism; however, this was often in the form of creativity, such as making up stories or engaging in drama. The creative control over what happens in a story was cited as an antidote to real life, with one participant expressing joy that in her writing everything was possible - nobody could tell her what to do, and nobody could stop her. One very creative participant had developed a whole world of characters whom she used as a source of encouragement in difficult situations. She had a complete world she was able to escape to when needed - she also drew them and created comic strips. Physical activities, non-team sports such as climbing, swimming, or running, or social activities with friends, such as gaming or jumping on the trampoline, were also referred to as means of coping with stress. Escape was often twinned with stoicism, an acceptance that there was only so much that could be done. Although this sometimes seemed a world-weary stance for

teenagers, it reflected their experience of battling for support and the acknowledgment that their needs are not always met; furthermore, it may also reflect their acceptance of their limitations. Many participants talked about secretly practising catching a ball, or another motor activity but admitted that it made minimal difference to their performance. A 'realistic' stance regarding what can effect change may also have been learnt at an early age.

#### **4.4.4.4 Accessing Support**

In general, the participants were keen to utilise support, and although in the school setting, it was sometimes sporadic and difficult to access, when it was present, it was truly appreciated, with many participants affectionately mentioning specific teachers who would go the 'extra mile' by ensuring they had hand-outs and allowing them extra time to copy from the board or re-write sections; or SENCOs, mentors, or counsellors who were available to them when they felt unable to cope. Some explained that they relied heavily on friends to help them organise themselves, and many reported gratitude and awe in respect of family support, but also guilt for the extra burden that they perceived they caused.

Missiuna et al.(2008a) found that 'resilient' adults with DCD had more positive recollections of support by family and peers rather than from therapeutic situations. However, they were particularly appreciative of accommodations made to allow successful participation rather than exclusion, e.g., keeping score during a sports match rather than taking part. Being 'realistic' but still being involved is important.

#### **4.5 Psychological impact - comparison to previous research**

This research is concerned with the experience of adolescents with DCD, and specifically with their emotional and psychological wellbeing. Although only one of the participants reported needing (and awaiting) further support for psychological

issues, many identified feeling emotionally overloaded, tending towards stressful responses, or struggling to control anger. Considering the difficulties and struggles that most of the participants reported encountering on a daily basis, just to be able to maintain a 'normal' presence, it is not surprising that negative emotional responses in terms of frustration and/or anger occurred. The lack of understanding from others increased this sense of frustration. All the participants discussed the fact that they tried really hard, and that their struggle was unseen. There was exhaustion in always going the extra mile, taking work home to re-write, re-reading texts repeatedly in order to understand, worrying about what they had forgotten to do or even managing situations so that they were not stigmatising. However, this 'going the extra mile' seemed to be normalised. This was an everyday occurrence. There was a strong sense of resilience: advice from almost all the participants to others with DCD was to 'never give up'. They understood the value of working hard towards 'success' at an early age, especially in regard to the amount of work that was needed. There was no lack of discipline; working hard all the time seemed to be a default response. Everyday school and chores demanded attention and effort above and beyond that of their friends and certainly without the expectation of notice or praise. Therefore, the frustration could be seen in relation to the gap between how they were expected to relate to the world (keep up, cope) and how the world related to them (little acknowledgement of difficulties, little support).

Using the environmental stress hypothesis in relation to DCD, Cairney, Rigoli and Piek (2013) considered the role social and individual factors might play in psychological distress, e.g., possible impairments in motor ability may make participation in playground games more difficult for children with DCD and therefore increase likelihood of exclusion/bullying. In this model, the impairment of physical coordination is seen as a primary source of stress, as it disrupts normal social activities. The lower performance presents a vulnerability that can be stigmatised by

peers. It looks at the direct and indirect connection of stress (e.g., exclusion) to psychological distress (sadness/anxiety). The model considers not only the stressors (limited ability to participate in games) - named the stress erosion pathway, but also the protective factors or 'buffers', such as good social support, family structure etc. - named the stress buffering pathway. According to this model, the stress experienced by those with DCD is inherently social and arises from interactions with others. The feelings of stress and frustration expressed by the participants seem to substantiate this model, as they were often directed at the attitude or lack of support given by others and the lack understanding the participants came up against or explored in relation to feelings of social exclusion of lower social standing.

However, impairment to EF may also play a role. 'Hot' EFs is a term given to EFs linked to ventromedial prefrontal cortex activation and that are implicit in many real-life situations, which also involve a level of affective or emotional involvement. A study of children with DCD found heightened sensitivity to emotionally significant distractors and revealed that this sensitivity may undermine self-regulation (Rahimi-Golkhandan, Steenbergen, Piek, & Wilson, 2014). In short, those with DCD may struggle more to control their emotional responses in situations that cause stress, upset, or anger. This was described by several of the participants, who felt sometimes overwhelmed with emotions, such as sadness or anger, leading to tears or outbursts; however, they also described these emotional outbursts as temporary. One participant felt her tendency to cry when she was upset had made her more vulnerable to bullying.

#### **4.5.1 Anxiety and depression**

There has been considerable research connecting symptoms of anxiety and depression to DCD (Farmer et al., 2016; Missiuna et al., 2014; Piek et al., 2007; Rigoli et al., 2016). The girls in this study were far more likely to discuss and express

anxiety, which could indicate that there is a gender difference at play, or it could be that the boys were less inclined to discuss such problems; historically, gender differences have not been well explored with DCD and, unlike here, girls tend to be under-represented. The reasons the participants in this study gave for anxiety were often connected to fear of failure, either in areas that are known to be difficult, such as social gatherings or sports, or in new tasks, e.g., learning to work with a Bunsen burner, which corresponds with Farmer et al.'s (2016) findings on anxiety with children and adolescents with DCD. However, some of the participants also discussed disliking crowds and loud noises, as well as feeling overwhelmed and anxious in unfamiliar settings/situations, such as shops and busy town centres. Furthermore, the participants cited exam and academic stress as a reason for anxiety, particularly due to difficulties with memory and attention, although whether this was above and beyond the experience of their TD peers is not clear. Only one participant discussed feelings of depression/sadness and self-harm. However, although 'depression' was not a term used by the participants, the high incidence of stress due to bullying and exclusion during younger years implies a level of emotional distress that some participants were reluctant to discuss further in our interviews.

#### **4.6 Strengths and Implications**

I am confident that this research provides a rigorous and valuable contribution to the field of study regarding DCD and highlights the experience of adolescence as a critical time period. The use of IPA allowed the participants to explore the complexity of their feelings, and this allowed not only negative and difficult issues, such as stress and frustration to come to light, but also allowed the participants to explore positive qualities and reflect on their own development and understanding.

#### **4.7 General Implications**

The school environment remains the focus of difficulty for many of the participants, due to issues with social skills, sports, or EF impairment within the academic realm. This highlights the issue of teacher training regarding development disorders and DCD specifically. Research has found that teachers are expected to be responsive to a wide-range of student needs but feel they are poorly educated in preparation for this responsibility (Graham, Phelps, Maddison, & Fitzgerald, 2011). Understanding the impact on students both on a physical and emotional/psychological level is essential.

This study highlights that adolescents can express themselves clearly and make a valuable contribution towards academic research and policy. In line with recommendations on adolescent mental health in the Lancet (Patton et al., 2016), the involvement of adolescents themselves in designing and structuring additional support should be crucial in providing a meaningful response to the challenges they experience.

Research into DCD is often divided into papers that approach DCD from a medical/OT or neurocognitive perspective as opposed to those papers which aim to explore the lives of those affected. These papers are then published in differing journals that represent the original researcher's perspective. Whilst this is understandable, this mind/body dualism has contributed to a fragmentation of the understanding of the impact of DCD. This false delineation between the emotional/psychosocial impact and physical/cognitive impact has contributed to a less than ideal treatment and understanding. It is important that research, which explores the emotional response to DCD is seen and appraised by medical, OT and educational staff as well as psychologists. Coping with EF impairment in a fast-paced

and stimulating environment such as school, as well as potentially attempting to avoid stigmatising situations in the playground or sports lessons can be cognitively exhausting. The added stress experienced by many of the participants during a 'typical' day as they attempt to hold their own in an environment designed for TD children, is perhaps easy to forget - particularly as many of the participants claimed not to want to stand out or make a fuss. However, not providing adequate support or even recognising the needs of this group, is exacerbating their sense of not only being 'other' but also forgotten and unimportant.

#### **4.8 Counselling Psychology Implications**

Counselling and clinical psychologists have been largely absent in any type of research regarding DCD, leaving research to their developmental, educational and neuroscience colleagues. There are no articles in the Counselling Psychology Review or Counselling Psychology Quarterly regarding DCD or ASD (although a small number were found on ADHD) and a review of recent clinical psychology publications found that they fare little better. There is a sense that those with DCD, once again, do not fit neatly into the right criteria to get support, this time, our model of the acceptable client. However, we are now aware that for many, the psychological impact of DCD continues to have a detrimental effect that lasts into adulthood (Hill & Brown, 2013). The evidence indicates that people with DCD will find their way to mental health services later in life as they battle with additional stresses to self-esteem and report higher rates of anxiety and depression, and therefore, this is an area that should demand our attention. Understanding the significant, particular stresses of life with DCD is important and needs to be borne in mind when dealing with any client who has DCD. In their review of the literature, Tal-Saban and Kirby (2018) urged a multidisciplinary approach to interventions centred on the needs of the individual in order to address reported lower participation and quality of life among young adults with DCD. That is not to say that all those with DCD are in need

of therapy or intervention. As discussed, many of the participants have managed to negotiate adolescence well and seemed reflective and happy with their lives; this can also inform our practice. As psychologists, we can endeavour to research further the psychological implications of having DCD, making sure that the views and opinions of those affected are represented. We should aim to provide support and consultation on the possible development of programs, working collaboratively with other healthcare professionals to provide an integrated and inclusive response based on research that understands the psychological needs and experiences of those with DCD.

At present there is very little research regarding psychological interventions specifically for those with DCD; therefore, it is difficult to advise on concrete steps without more specific research. However, areas to consider could be:

#### **4.8.1 Interventions to improve resilience**

Resilience refers to a dynamic process that encompasses positive outcomes for an individual in spite of negative or significant experiences of adversity (Luthar, Cicchetti, & Becker, 2000). Resilience interventions focus on a range of cognitive and behavioural skills. Interventions aimed at adolescents with ADHD may receive training in social skills components, such as initiating and maintaining conversations, whilst also providing psychoeducation on 'protective factors', such as mood regulation and self-mastery. Resilience training is strength focussed rather than deficit driven (Alvord, Rich, & Berghorst, 2014).

#### **4.8.2 Interventions to manage stress**

For adolescents who struggle with making friends or feel excluded/victimised, there is the possibility of developing interventions based on the incremental-theory of personality, which teaches the possibility of personality change; i.e., the view that social difficulties are events that can be overcome and be seen as challenges, thus

encouraging adaptive coping. Several small-scale studies have reported a reduction in global self-reported stress, behavioural aggression, and clinically significant depressive symptoms, as well as improving academic performance (Yeager, Lee, & Jamieson, 2016).

#### **4.8.3 Online CBT Interventions for anxiety**

A randomised controlled trial in Australia found that online delivery of CBT was equally efficacious as clinic-based therapy in the treatment of adolescent anxiety disorders. Such an approach could be cost effective after initial development and would allow greater accessibility to therapy and could be specifically tailored to participants with DCD (Spence et al., 2011).

### **4.9 Limitations**

#### **4.9.1 Methodological Limitations**

As discussed by Willig (2013), IPA has possible limitations regarding the role of language, especially as the approach assumes that the participant can richly express their experience in language. I have already reflected how I felt the male participants found it hard to give a full construction of their experience; however, I felt that they did give a representation of their world, and even if it did not expand to the level of the female participants, their contributions corroborated many of those of the female participants and added further depth to the study. Data gathering methods such as structured diaries or male-only focus groups, rather than an interview could have drawn further information. Having a female interviewer may have inhibited the male responses, and perhaps they would have expanded further with an interviewer of the same sex.

Although a more focussed and structured interview was used in line with guidelines for IPA with younger people (Smith, 2004), it may have limited the findings by being too directed, especially with the older participants.

In line with other qualitative studies with small sample sizes, the findings are not automatically generalisable to or representative of larger populations. However, the aim of this study was to build upon previous research and expand our knowledge of this under-researched population. Thus, delving deeper into the experience of the participants. I feel this research supports earlier findings regarding the impact of social exclusion and executive function on the lives of adolescents with DCD and has also revealed further areas of interest, such as adaptive methods of coping, e.g., reframing of identity during adolescence.

Future research could expand on the building of resilience and identity with adolescent or young adult populations, using focus groups and collaborative research methods, as well as further researching the differing impact of gender, e.g., different coping styles. A greater understanding and coherence regarding a diagnostic label and description, which more accurately reflects the experience of the population could have a dramatic impact on understanding and acceptance.

Continued research into EF within this group, so that the impact is better understood would be beneficial. Furthermore, research into possible 'positive' traits, such as creative thinking, humour, and kindness, would be a welcome change from the research into impairment. However, given the major need for awareness and acceptance within schools and the wider community, research could usefully focus on how this can be expanded so that support is routinely offered rather than sought.

#### **4.9.2 Procedural Limitations**

As all the participants were recruited from the Dyspraxia Foundation, the sample was skewed towards families who actively support and take an interest in their child and were motivated to help them further. These families were already in touch with the Dyspraxia Foundation, and actively monitoring and choosing to respond to research

opportunities. It would have been preferable to recruit students from schools where parental support was not necessarily in evidence to better reflect the population – especially in terms of psychosocial health, where parental support and encouragement may play a crucial role. Although the families were diverse in geographic location and to some extent in social economic status (although no specific data were collected on this), there was no doubt that all the participants were well supported. Furthermore, the fact that the participants agreed to participate may also indicate that they were (in general) more resilient or felt more able to cope with difficulties and confident in their ability to express their concern. This may have had a large impact on the findings especially regarding the re-framing and general resilience expressed and this may also be a factor in the limited reporting of anxiety or depressive symptoms.

IPA typically demands a homogenous group; however, DCD is a heterogeneous disorder. Some of the participants had more extreme difficulties with coordination but were academically very able; others may have had more obvious EF difficulties regarding memory and attention, which affected their academic achievement. There was a challenge in researching a group with varying comorbidities and limitations (or perceptions) of limitations. Furthermore, the age group ranged from 11-18. Being an 18-year-old is obviously very different to being an 11-year-old; however, I felt that all the viewpoints together gave a cohesive picture of the journey of adolescence as reflected in Erikson's psychosocial developmental stage. Allowing for a larger sample of 11 meant that this was feasible. My interest was in the process of change experienced during adolescence rather than a 'snapshot' of one particular age, which due to the variation in development during adolescence will always be somewhat artificial as regards providing homogeneity.

Dealing with the numerous complexities of age, gender, ability and comorbidity, whilst trying to find commonality was naturally not a simple process. However, within a critical realist stance, the complexity described was that experienced by the participants within the framework of a diagnosis of DCD. The participants themselves also had to make sense of their experience within this complex and multi-faceted framework and this is reflected in the findings of this research. A straight-forward sense of identity formed behind the label of DCD or Dyspraxia was not apparent in responses, however a recognition of otherness was prevalent as an integral part of self and was placed in connection to DCD. Likewise, healthcare professionals, researchers and those involved in education also need to operate in this world where there are no simple and permanent delineations and where comorbidities are common or may emerge.

#### **4.10 Personal Reflexivity**

One of the key themes emerging from this research for me is how to deal with complexity: What we do when answers are not 'cut and dried' and there is no simple definition? This thought accompanied me throughout the process, but particularly in regard to my own role. Being aware of my stance and position during this research was important, but this changed as the research progressed. Initially, I was aware of the duality of my role as a mother of a son with DCD and as an interviewer / researcher. I often had to remind myself to stay close to the participant during the interview and analysis and not to take on a maternal role even though I sometimes felt indignant about reported treatment at school. Keeping this in mind during the analysis and, ultimately, the discussion stage was important to me. This study aims to give voice to adolescents with DCD and whilst IPA recognises the impact of the hermeneutic circle - holding my own interpretations lightly, or rather firmly at bay, was important.

Secondly, during the interviews I was aware of a duality between researcher and therapist. Working at the same time in Early Intervention in Psychosis, I often saw teenage clients, and making a clear distinction between these two groups was not always simple, especially with the participants who were struggling emotionally. Being empathic and providing support in terms of contacts and information to the participant and family was allowed, but I was aware I was keeping myself back.

The final duality of stance came in the recognition of my own motivation for this research. Initially I embarked on this as the mother of a teenager with DCD. Apart from the natural interest I had in this area, I felt this would allow me to explore his world further and enable me to provide him with more support. However, during the research, I reflected on my preference for working with teenage clients and came to consider that this research may have far more to do with my own difficulties during adolescence, particularly early adolescence. I was struck by the ability of many of the participants to negotiate difficult feelings - feelings of shame and awkwardness - and ultimately to accept difference. I reflected on the possible connection with attachment style within this process.

Ultimately, I felt extremely grateful to the participants and their families, who allowed me access to their worlds. I hope this study will create further interest in continued research and support.

#### **4.11 Concluding Comments**

This research provides a useful insight into the lives and experiences of adolescents with DCD and consolidates previous quantitative research findings on the impact of DCD at this stage in life. The study highlights that adolescents with DCD feel their difficulties are often unrecognised and that there is a lack of knowledge regarding DCD within the general population. It also reveals a disparity between the definition

of DCD as a motor disorder and the experiences and difficulties of the participants, especially in terms of EF, and considers the implications of this as creating further confusion and inhibiting support. It also further highlights the challenges in understanding and dealing with heterogeneity within DCD, not only for professionals but also for the individuals concerned, who are faced with a variety of symptoms and comorbidities that may make identification with others difficult and thus a limit a sense of identity in itself.

In the school environment, the participants identified often feeling unsupported and neglected; they highlighted the stress of having to battle to gain resources and support. This increased their sense of not being important, their feelings of guilt concerning the role of their parents, and their shame for needing to ask for support. The support received was inconsistent and some participants commented on insensitive responses from teachers. Participation in sports was still a difficult issue for many of the participants within the school environment and could be associated with humiliation and stigma.

Nearly all the participants reported having experienced social difficulties in early life, including victimisation and exclusion. However, later in adolescence most of the participants reported satisfaction in their social relationships and a heightened experience of the importance of friendship and loyalty.

The study identified challenges to self-esteem in that most participants reported a sense of 'otherness'; they recognised a difference between themselves and their TD peers and that this could be related to shame and stigma, particularly early in their lives. However, during adolescence many were able to begin a process of re-framing that difference in a more positive light and to take greater ownership of their difference - seeing it as diversity that had positive as well as negative connotations.

Only one of the participants reported concerns regarding mental health at the time of interview. Although many of the findings were positive in terms of resilience and coping, studies have shown that victimisation may have a long-term negative impact on emotional wellbeing (van Dam et al., 2012), therefore the additional stress of managing the impact of DCD and the high incidence of previous bullying reported is a warning of possible future difficulties for adolescents and adults within this population, especially those without stable support at home.

This study has implications for counselling / clinical psychologists, who have been largely absent in researching or designing interventions to improve the psychological health of this population, as well as other researchers, healthcare and educational professionals, who may wish to consider the on-going psychological impact of diagnosis and consider how best to address this within their own work. Greater collaboration between those with DCD and professionals should be encouraged, to ensure that appropriate and effective support can be provided.

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# Appendices

## Appendix A: Journal Information and author guidelines

Research in Developmental Disabilities - journal information and guide for authors (abridged)

**DESCRIPTION** Research In Developmental Disabilities is an international journal aimed at publishing original research of an interdisciplinary nature that has a direct bearing on the understanding or remediation of problems associated with developmental disabilities. Articles will be primarily empirical studies, although an occasional position paper or review will be accepted. The aim of the journal will be to publish articles on all aspects of developmental difficulties using rigorous research methods. Our aim is to publish the best available and most current research possible. Benefits to authors We also provide many author benefits, such as free PDFs, a liberal copyright policy, special discounts on Elsevier publications and much more. Please click here for more information on our author services. Please see our Guide for Authors for information on article submission. If you require any further information or help, please visit our Support Center AUDIENCE . Psychologists, Social Workers, Rehabilitation Specialists and Sociologists IMPACT FACTOR . 2016: 1.630 © Clarivate Analytics Journal Citation Reports 2017

### **Article formatting and style**

Formatting and style in the text should follow the style used by the American Psychological Association, You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5,

### **Word Count**

The maximum word count for articles submitted to the journal is 8,000 words, including references and tables. Please enter the total number of words in your paper.

### **Subdivision - numbered sections**

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

### **Introduction**

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

### **Material and methods**

Provide sufficient details to allow the work to be reproduced by an independent researcher. Methods that are already published should be summarized, and indicated by a reference. If quoting directly from a previously published method, use quotation marks and also cite the source. Any modifications to existing methods should also be described.

### **Theory/calculation**

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

### **Results**

Results should be clear and concise.

### **Discussion**

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

## **Conclusions**

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

## **Appendices**

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

## **Essential title page information**

- **Title.** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- **Author names and affiliations.** Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. You can add your name between parentheses in your own script behind the English transliteration. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
- **Corresponding author.** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about Methodology and Materials. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**
- **Present/permanent address.** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

## **Abstract**

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

## **Structured abstract**

Authors should structure their abstract with the following sections:

- Background
- Aims
- Methods and Procedures
- Outcomes and Results
- Conclusions and Implications

The abstract should be no more than 200 words.

## **What this paper adds?**

After the abstract, authors should include a section 'What this paper adds?'. The section should be no longer than 250 words.

## **Highlights**

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). You can view [example Highlights](#) on our information site.

## **Keywords**

Abbreviations should be held to a minimum and should appear only after the full length term has been spelled out once in the text.

## ***Acknowledgements***

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

## ***Formatting of funding sources***

List funding sources in this standard way to facilitate compliance to funder's requirements:

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, please include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## ***Figure captions***

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

## **Tables**

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

## **References**

### ***Citation in text***

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

### ***Web references***

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

### ***Data references***

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references

should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

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Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

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Most Elsevier journals have their reference template available in many of the most popular reference management software products. These include all products that support Citation Style Language styles, such as Mendeley and Zotero, as well as EndNote. Using the word processor plug-ins from these products, authors only need to select the appropriate journal template when preparing their article, after which citations and bibliographies will be automatically formatted in the journal's style. If no template is yet available for this journal, please follow the format of the sample references and citations as shown in this Guide. If you use reference management software, please ensure that you remove all field codes before submitting the electronic manuscript. More information on how to remove field codes.

### **Reference style**

*Text:* Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5, copies of which may be ordered online or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK.

*List:* references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

#### *Examples:*

Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51–59.

Reference to a book:

Strunk, W., Jr., & White, E. B. (2000). *The elements of style*. (4th ed.). New York: Longman, (Chapter 4).

Reference to a chapter in an edited book:

Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). New York: E-Publishing Inc.

Reference to a website:

Cancer Research UK. Cancer statistics reports for the UK. (2003).

<http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/> Accessed 13 March 2003.

Reference to a dataset:

[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions*. Mendeley Data, v1. <https://doi.org/10.17632/xwj98nb39r.1>.

Reference to a conference paper or poster presentation:

Engle, E.K., Cash, T.F., & Jarry, J.L. (2009, November). The Body Image Behaviours Inventory-3: Development and validation of the Body Image Compulsive Actions and Body Image Avoidance Scales. Poster session presentation at the meeting of the Association for Behavioural and Cognitive Therapies, New York, NY.

## Appendix B: Letter to Head Teacher



Dear xxxx

I am a student of Psychology at City University London and am currently studying the experience of adolescents with dyspraxia for my doctoral research.

So far, much of the academic research on dyspraxia has ignored the people who are most affected, and I am hoping to redress the balance by interviewing young people directly. My study aims to develop greater insight into how dyspraxia can affect individuals and inform ongoing research and support. This will be of benefit to the individuals affected, their families and to those who support them, such as schools and Learning Support Teams. As the mother of a teenage boy with dyspraxia, I believe this research is much needed.

The process involves a semi-structured interview, which I expect to last between 45 - 60 minutes. During this time, I will ask individual students some open questions and invite them to discuss how they view dyspraxia and what impact they feel it may have on their lives. The interviews will be strictly confidential, and all information will remain anonymous. Ideally, I would like to interview the students in the school premises. I have DBS clearance for work with City University London. However, I can arrange to see the students at home, if you, or the families prefer.

If you are agreeable to facilitating this study, please contact me and I will forward detailed information to be sent to the parents of students you deem eligible. My

details are given on this information sheet and parents are free to contact me directly with further questions.

I would be very grateful for any help that you could provide and would be happy to discuss it further with you or your Head of Learning Support. I feel it is incredibly important for young people with dyspraxia to be heard and hope this study will go some way towards that.

Please contact me, should you need any further information.

Kind regards

## Appendix C: Recruitment Poster



CITY UNIVERSITY  
LONDON

Department of Psychology  
City University London

### **PARTICIPANTS NEEDED FOR RESEARCH INTO DYSPRAXIA**

Does your child have a diagnosis of Dyspraxia?

Would they like their voice to be heard?

We are looking for volunteers aged 11-18 to take part in a study on living with dyspraxia.

Your child would be invited to take part in a semi-structured interview on how they feel about dyspraxia and how it affects their life.

The interview would involve one single session of approximately 45 - 60 minutes.

This is an important opportunity for the people most affected by dyspraxia to have their say.

For more information about this study, please contact:

Pamela Kane (Researcher) (email)  
City University London, Psychology Department  
(phone)

Supervised by Dr. Jacqui Farrants: email  
City University London, Psychology Department  
(phone)

This study has been reviewed by and received ethics clearance through the Psychology Research Ethics Committee, City University London [PSYETH (P/F) 15/16 71].

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on 020 7040 3040 or via email: Anna.Ramberg.1@city.ac.uk

## **Appendix D: Ethical permission from Dyspraxia Foundation**

Dear Pamela

We have just heard that our Research Panel is 'happy that we approve this study and for it to be promoted as Pamela requests'.

Congratulations! A good end to the week for all concerned and we look forward to promoting your study in due course.

Have a good weekend.

Kind regards

Jane

**Jane Trowbridge**  
**Operations Manager**  
**Dyspraxia Foundation**

Dyspraxia Foundation, Registered Charity No. 1058352 A company limited by guarantee. Registered in England No 3256733. Registered Office: 8 West Alley, Hitchin, Hertfordshire SG5 1EG  
Helpline: 01462 454986 (9-5 Monday –Friday)

See [www.dyspraxiafoundation.org.uk](http://www.dyspraxiafoundation.org.uk) for a wide range of useful information, free downloads and online shop for books, goods, donations and membership subscriptions

Disclaimer: This email (including any attachments) is intended only for the recipients named above. It may contain confidential or privileged information. It should not be read, copied or used by any other person without the permission of the sender. If you are not a named recipient, please contact the sender and delete the email from your system.

## Appendix E: Parental Information Sheet

### Information Sheet for Parents

I would like to invite your child to take part in a research study, titled:

#### **Dyspraxia, Identity and Self-esteem. What is the experience of adolescents with dyspraxia?**

Before you and your child decide whether you would like to take part, it is important that you understand why the research is being done and what it involves. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?** The aim of this study is to explore the experiences of adolescents who have been diagnosed with dyspraxia and to allow them the chance to influence research. This research is the basis of my thesis, which I am completing for my doctoral research in counselling psychology at City University London.

**Why has your child been invited?** I am interested in the experience of adolescents with dyspraxia between the ages of 11-18.

**Does your child have to take part?** No. Participation in the project is voluntary, and your child can choose not to participate in part or all of the project. It has no bearing on any element of your child's schooling and is solely for research purposes.

It is up to you and your child to decide whether or not to take part. If you do decide to take part you will both be asked to sign a consent form. If your child decides to take part he/she is still free to withdraw at any time up to completion of the analysis without being disadvantaged in any way.

**What will happen if your child takes part?** If you and your child agree to take part, your child will be invited to an interview with me (Pamela Kane). This interview will be recorded and later transcribed for further study. The research is based on qualitative methods - this means, I am aiming to find out how your child feels about dyspraxia rather than gathering statistical data. This research is part of my doctoral degree, which should be completed by August 2017.

**Expenses and Payments (if applicable)** No expenses or payments can be made.

**What does my child have to do?** Your child will be invited to an interview, either in your home (an adult must be present in the home at all times) or at City University or alternative venue if you prefer. The interview will last approximately between 45 and 60 minutes. During the interview I will ask a series of open questions, which will hopefully enable your child to describe their experience of dyspraxia. Your child will be encouraged to think about and explain the effect of dyspraxia on their life; however they are free to refuse to answer any questions or to withdraw from the study, should they so wish.

**What are the possible benefits of taking part?** This is an opportunity for your child to contribute to the body of research surrounding dyspraxia and increase understanding. Dyspraxia is an under-researched topic and understanding the experiences of those living with dyspraxia is an important step in building greater knowledge. Your child's participation will help shape that knowledge. It will also be an opportunity for your child to feel that they have been listened to and that their opinion matters. Furthermore, it could give your child time and space to reflect on what having dyspraxia means to him/her and consider what he/she needs from others.

**What are the possible disadvantages and risks of taking part?** It is possible that your child could get upset if they talk about distressing incidents, although they are under no obligation to discuss anything that makes them feel uncomfortable. However, should this happen, my training as a counselling psychologist and experience as a child counsellor means that I have experience of dealing empathically with distress and I am happy to advise on further avenues of support, e.g. Dyspraxia Foundation, GP, CAMHS.

**Will taking part in the study be kept confidential?** Personal information such as names, schools etc. will only be known to the researcher and kept separately in a locked cabinet, without reference to recordings or research documents. The recordings will be transferred to an encrypted and password protected computer file immediately and be destroyed after completion of the doctorate. All other documents will be password protected. Pseudonyms will be used and any identifying details, such as names or relationships will be changed. Data will only be shared with my research supervisor, Dr Jacqui Farrants.

Whilst the interview is confidential, should any issues of harm to self or others come to light (e.g. bullying or danger of self-harm) or if your child becomes so distressed that I am concerned for his/her welfare, I am required to bring this to the attention of the parents and/or school depending on the most appropriate means of safeguarding the child, as per British Psychological Society Guidelines on Research Ethics. This will be clearly explained to you and your child before the interview.

**What will happen when the research study stops?** The documentation and data will be held securely and confidentially for up to 5 years after publication, before being destroyed. Should, for any reason, the research stop before completion, all data (recordings and documents) will be destroyed.

**What will happen to the results of the research study?** The thesis will be available through University libraries. Anonymity of participants will be maintained. Possible future publications include counselling and psychology journals.

**What will happen if my child doesn't want to carry on with the study?** Your child is free to withdraw at any time up to completion of the analysis, without any penalty.

**What if there is a problem?** If you have any problems, concerns or questions about this study, you may speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Dyspraxia, Identity and Self-esteem. What is the experience of adolescents with dyspraxia?

You could also write to the Secretary at:

Anna Ramberg [Anna.Ramberg.1@city.ac.uk](mailto:Anna.Ramberg.1@city.ac.uk)

Secretary to Senate Research Ethics Committee, Research Office, E214

City University London, Northampton Square

London EC1V 0HB

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

**Who has reviewed the study?** This study has been approved by City University London Psychology Research Ethics Committee, [PSYETH (P/F) 15/16 71].

#### **Further information and contact details**

Researcher: Pamela Kane, Psychology Department, City University London

Email:

Phone: \_\_\_\_\_

Supervisor: Dr Jacqui Farrants, Psychology Department, City University London

Email:

Phone:

**Thank you for taking the time to read this information sheet.**

## Appendix F: Participant Information Sheet

### Participant Information

#### **Dyspraxia, Identity and Self-esteem. What is the experience of adolescents with dyspraxia?**

We are looking for young people between 11-18 to take part in research on what it is like to have dyspraxia.



#### **Who we are?**

My name is Pamela Kane and I am a student of counselling psychology at City University London. I am studying the experience of young people with dyspraxia. Dr Jacqui Farrant is my supervisor. Her role is to guide and advise me on this research.



#### **What are we researching?**

What it is like to have dyspraxia - how does it affect your life, your emotions and how you view yourself? We are particularly interested in what it means to have dyspraxia when going through adolescence.



#### **Why?**

We feel that those people who are most affected by dyspraxia (that's you!) are very rarely asked for their views. This means that the research we have now is lacking and needs more information about the experiences you have. We are also aware that adolescence can be challenging and would like to know more about how it is for you to have dyspraxia at this time.



#### **What do we want from you?**

Your time and your point of view. You will be invited to an interview about what it is like to have dyspraxia. This interview will be recorded and later written down for further study. The interview will take place in a private room, possibly at your school or, if you prefer, in your home. It may take between 45-60 minutes.



#### **Consent**

Taking part in this study is entirely up to you. During the interview, you decide how much you want to tell us about your own experience and if you feel uncomfortable answering a question and don't want to talk about it, that's fine too.

We will ask you to sign a form to say that you understand what the research involves. We will also require a signed form from your parent/guardian. You may also decide to withdraw after the interview (before the analysis is completed).



### Will it be confidential?

Yes - all your data will be held confidentially and securely by myself and Jacqui. Everything you tell me is also confidential. However, if during the course of the interview, you tell me that you or anyone else are in danger of harm in any way, or become so distressed that I am concerned for your welfare - I would need to break this confidentiality and talk to either your parents and/or the school, whoever can best protect you. Your safety and wellbeing are the priority. This will be explained clearly to you before the interview.



### What will happen afterwards?

After the study is completed, a final report, called a thesis, will be available through University libraries. In this final report, any details such as names or relationships will be changed so that you cannot be identified. Possible future publications include specialist counselling and psychology journals.

### What are the positives and negatives about taking part?



This is a great opportunity for you to add to research into dyspraxia and increase our understanding. At the moment most of the research does not include the views and opinions of people like you - the ones who are most affected. This is your chance to change that. It will also give you the chance to consider how you feel about having dyspraxia and talk through your experiences with someone else.

Sometimes experiences are not always good and may be upsetting to discuss. My training as a counselling psychologist means I have experience in dealing with difficult emotions, should this occur. I may also be able to advise you of further support available. However, you do not have to discuss anything you are uncomfortable talking about.

### Ethics

This study has been checked and accepted by the Research Ethics Committee at City University, London. Their job is to make sure the research is completely fair and legal, and that participants are kept safe at all times.

### How to contact us:

Pamela Kane email  
Phone  
Dr Jacqui Farrants email  
Phone

City University London  
Northampton Square  
London  
EC1V 0HB

## Appendix G: Parental Consent Form



Title of Study:

Dyspraxia, Identity and Self-esteem. What is the experience of adolescents with dyspraxia?

Ethics approval code: [PSYETH (P/F) 15/16 71].

Please initial box

1.	<p>I give consent for my child to take part in the above City University London research project. I have had the project explained to me, and I have read the parental information sheet, which I may keep for my records.</p> <p>I understand this will involve being interviewed by the researcher and</p> <ul style="list-style-type: none"> <li>allowing the interview to be audiotaped</li> </ul>	
2.	<p>This information will be held and processed for the following purpose(s):</p> <ul style="list-style-type: none"> <li>To help the researcher understand the experience of adolescents with dyspraxia and to widen the academic body of knowledge on the subject, by giving voice to those who are affected.</li> </ul> <p>I understand that any information my child provides is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party, other than the research supervisor, Dr. Jacqui Farrants, or in cases of disclosed risk to the participant or other. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.</p>	
3.	<p>I understand that participation is voluntary, that I can choose not to participate in part or all of the project, and that my child can withdraw at any stage of the project up to completion of the analysis without being penalised or disadvantaged in any way.</p>	
4.	<p>I agree to City University London recording and processing this information about my child. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.</p>	

\_\_\_\_\_  
Name of Parent/Guardian

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Appendix H: Participant Consent Form

**Dyspraxia, Identity and Self-esteem.  
What is the experience of adolescents with dyspraxia?**

**Participant Consent Form**

	<b>✓ Yes</b>	<b>X No</b>
<b>Someone has explained to me what we will be doing today</b>		
<b>I understand what I am being asked to do</b>		
<b>I have been give the opportunity to ask questions</b>		
<b>I have understood the answers to my questions</b>		
<b>I understand that I can stop the interview at any time</b>		
<b>I agree to the recording of the interview</b>		
<b>I am happy to be part of this study</b>		

Your Name: \_\_\_\_\_

Signed: \_\_\_\_\_

Today's Date: \_\_\_\_\_

My Name: \_\_\_\_\_

## **Appendix I: Interview Schedule**

### **Guide to semi-structured interview**

#### **Key Areas of Interest:**

- Meaning of dyspraxia for the participant
- Self-concept, Self-esteem and self-efficacy
- Peer Relationships
- Physical Well being
- Reaction of others/Support
- Future expectations/aspirations

#### Typical Questions:

#### **Meaning of Dyspraxia for Participant**

- 1) Tell me how you discovered you had dyspraxia.
  - Can you remember what you thought/felt when you were told?
- 2) What does having dyspraxia mean to you?
- 3) How would you explain dyspraxia to someone who had no understanding of it?

#### **Possible further prompts:**

- *What's the worst thing about having dyspraxia?*
- *What's the best thing about having dyspraxia? How would your life be different if you didn't have dyspraxia?*
- *What advice would you give to someone who has just been diagnosed?*
- *Has dyspraxia ever stopped you doing something you wanted to do?*
- **Self-Concept, Self-Esteem, Self- Efficacy**
  - 1) How would you describe yourself?
  - 2) Can you tell me about something that you do really well or really enjoy?
  - 3) Can you tell me about something that you find really difficult?

- 4) Do you (to what extent) consider yourself different to other people your age?

**Possible further prompts:**

- *Can you give me three words to describe yourself?*
- *If your best friend could describe you, would it be different - if so in what way?*
- *What is your best attribute/quality?*
- *What is your worst trait?*
- *What strategies do you use to help you cope with your dyspraxia?*
- *Have you ever had to try really hard to overcome a problem?*
- *How do you feel when you fall over/drop something?*

**Peer relationships**

- 1) How do you see yourself in relation to the other kids in your class
- 2) Have you ever been bullied at school?

**Possible further prompts:**

- *What social activities do you enjoy/dislike?*
- *What aspects of school do you enjoy/dislike?*
- *How do you think other teenagers your age see you?*
- *What do you think other people think about dyspraxia?*

**Physical Wellbeing**

- 1) How would you describe your sports lessons at school?
- 2) Do you do any other sport/physical activity outside of school?
- 3) How important is it for you to stay fit and healthy?

**Reaction of others**

- 1) Do you tell other people you have dyspraxia?
  - a. If not why?
  - b. Who do you tell - what is the criteria?
  - c. How do you feel about telling people?

2) How have other people reacted when you have told them?

- Adults
- Parents
- Peers
- Teachers
- How did their reaction make you feel?

3) In an ideal world how would people react?

4) What support have you been given for dyspraxia?

- a. Have you found it useful
- b. If so, how; If not, why not

5) What support would you like?

6) What would make life better for you?

### **Future Expectations**

1) How do you see your future in education? A 'levels? College?

2) What career aspirations do you have?

3) Has having dyspraxia affected your choices?

### **Closing**

1) How did you find this interview? / Is this interview what you were expecting?

2) Is there anything else about your experience with dyspraxia that you would like to tell me about?

3) Have I missed anything important about living with dyspraxia?

## Appendix J: Debrief



What is the experience of adolescents with dyspraxia?

### DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it's finished I'd like to tell you a bit more about it.

The research I am conducting aims to discover more about the experience of adolescents with dyspraxia. Adolescence is a key time of development: physically, emotionally and socially. For many people it is a challenging time and for those with a developmental disorder such as dyspraxia, there may be added difficulties.

The questions in the interview were designed to give you space to think about what having a diagnosis of dyspraxia means to you; whether it causes you difficulties or is helpful and what response you get from other people. Most importantly it aims to find out what could make your life better.

If any of the questions or topics discussed have raised difficult issues for you, and you feel you may need further support, the following organisation may be helpful to you:

- *Dyspraxia Foundation - [www.dyspraxiafoundation.org.uk/](http://www.dyspraxiafoundation.org.uk/)*
- *Childline - 0800 111 - [www.childline.org.uk/](http://www.childline.org.uk/)*
- *Your school learning support team and your GP can also offer help.*

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

*Pamela Kane-Hamer, Psychology Department, City University London*

*Email*

*Phone*

*Supervisor: Jacqui Farrants, Psychology Department, City University London*

*Email*

*Phone*

Ethics approval code: *[PSYETH (P/F) 15/16 71]*.

## Appendix K: Example of working Transcript (Individual)

(Skye)

783 I: People have always been quite good when you've told  
 784 them.  
 785 P: People might even say wow! Cool! What the? What are <sup>My per bde wow! cool!</sup> all positive?  
 786 you talking about? What? What's happening here? <sup>but confusion underneath.</sup>  
 787 I: How would you describe dyspraxia to somebody who  
 788 doesn't know anything about it?  
 789 P: Meaning wonderful, difficult. <sup>ex memo: both hard + easy not simple</sup>  
 790 I: But if they said, what is it? If they don't know what  
 791 dyspraxia is. <sup>all physical here-</sup>  
 792 P: A disability that people...physical balancing kind of <sup>DISABILITY!!</sup>  
 793 struggles, running, trips over, it just affects a little bit of <sup>a little but struggle.</sup>  
 794 my body but I know I can cope with it. And it will never <sup>COPIING</sup> <sup>rational. I can cope.</sup>  
 795 fade away but...it will get better. <sup>acceptance + hopeful. self reliance.</sup>  
 796 I: And if you met someone who just found out they had  
 797 dyspraxia, would you be able to give them any advice.  
 798 P: if I realised that someone had dyspraxia I would walk to <sup>Confidence??</sup>  
 799 them and be their friend straight away. I would have the <sup>needs a friend? friends lacking?</sup>  
 800 confidence to do that.  
 801 I: And how would you be their friend?  
 802 P: I would say 'heh - I'm pretty swag!' <sup>self-mocking. Ebuilient - aalbbwn? Humour. ✓</sup>  
 803 I: And if they were feeling a bit sad about having dyspraxia  
 804 what would you say.  
 805 P: I would sit with them and talk about it and help them <sup>sit a talk. need understanding</sup>  
 806 understand that it's actually pretty wonderful. <sup>ex memo POSITIVE</sup>  
 807 I: OK. So you feel that it's something...it causes difficulty in  
 808 your life but actually..  
 809 P: It's pretty awesome. <sup>ex memo description. awesome !!</sup>  
 810 I: In an ideal world, let's say you wanted to tell someone, <sup>awesome cool. wonderful swag.</sup>  
 811 maybe when you're older, when you're an adult...how  
 812 would you like people to react.  
 813 P: I guess that's pretty cool yeah. I understand. <sup>cool!</sup>  
 814 I: You'd like them to understand. <sup>need to be understood.</sup>  
 815 P: Wow, awesome, cool. In a positive side - not bye. <sup>-wants positive not dismissal.</sup>

positive  
cool  
good  
awesome

acknowledge  
11mks

needing  
genuine  
friends  
support.

positive  
mindset.

positive  
mindset.

positive  
mindset.

feeling  
disregarded.  
left out.  
→ dismissed.

816 I: Not dismiss you.

817 P: Not like you're a little bit crazy don't want to talk to you. *rejection?* *crazy = not wanted dismissed.*

818 Bye.

819 I: So people might just think it's different and crazy and I

820 don't want to know?

821 P: No they think like what is she talking about she must be *weird = rejection?*

822 crazy talking about this weird thing. *weird and crazy - not understood - different level.*

823 I: Oh, even talking about it is crazy?

824 P: Yeah - because you're going on at something they don't *disregarded.*

825 know. Like what? What are you talking about and just *lack of knowledge / understanding*

826 walk away. When I was little and didn't have any friends *walk away*

827 used to grab in the cupboard of our school and I used to *trying really hard.*

828 get a tennis ball and try and catch it. And it used to go in

829 my hand and drop out. And once we were playing cricket

830 and I was a fielder. And the ball literally went on my hand

831 and then because it hit my hand so hard it fell to the *hurting self to be popular.*

832 ground and I kind of got a mark there because it took a

833 little bit of my skin off as I was trying to catch a ball.

834 I: And what was that like..

835 P: And I got so annoyed because I was like...that close to *needs popularity*

836 catching that little ball and then I could win a point and I *= sport gaining points*

837 could actually be popular for the day, you know.

838 I: Does it make you popular then, when you catch a ball? *Even when does sm. forgotten.*

839 P: It kind of gets you popular when I do something nobody *Trying so hard never really accepted.*

840 else has done like in PGL. I got a little bit popular for a day

841 and then everyone forgot about it.

842 I: So something popular about the person that jumps off

843 really high or being the person that catches the ball.

844 P: Yeah. You kind of get popular a little bit in that day and I *not having appeal*

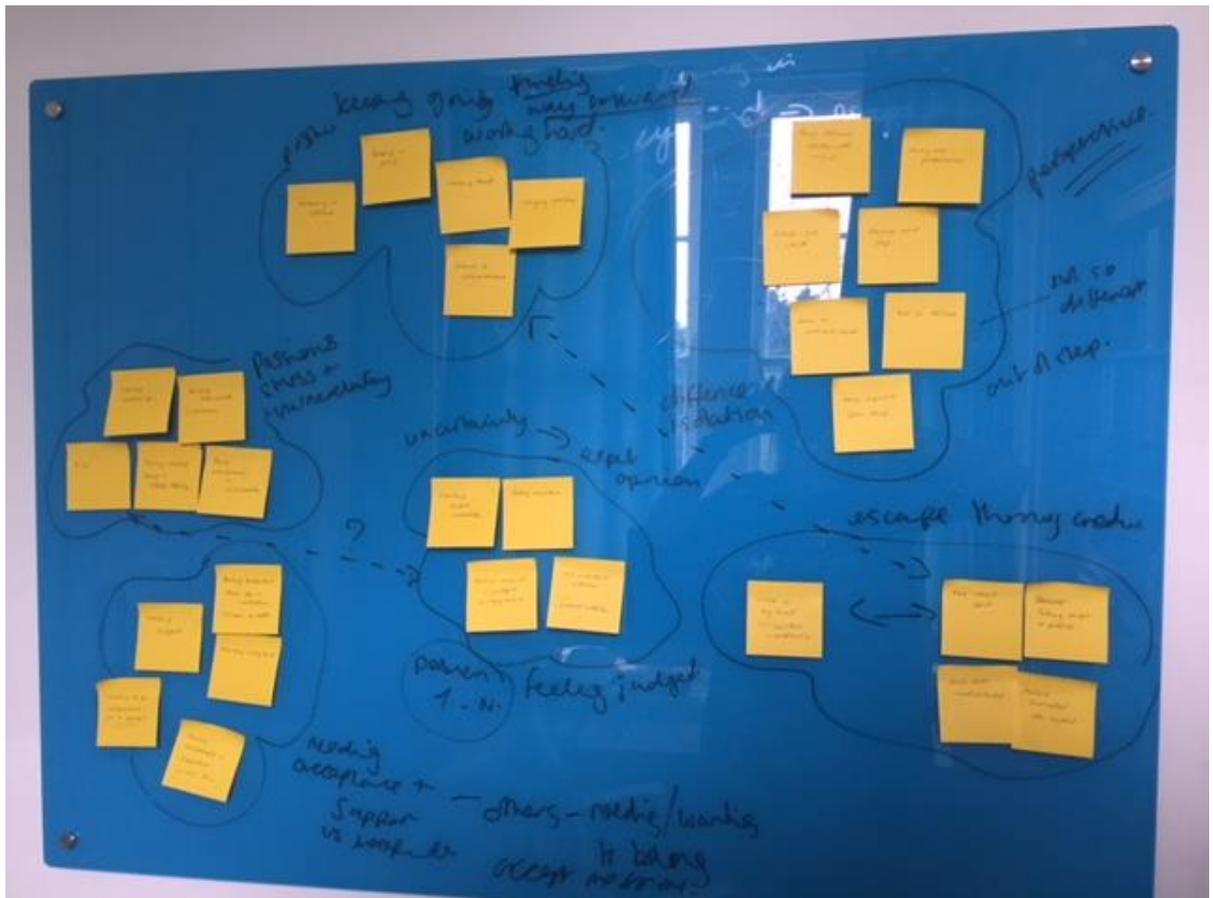
845 don't really that much have that appeal. I've always been a

846 middle kid. *middle kid.*

847 I: It's almost like you're saying you have to find different

848 ways of being popular.

# Appendix L: Visual of Grouping Themes (Individual)



## Appendix M: Themes for Individual Participant

### Themes for Skye

Theme	Pg.	Line	Quotation
<b>Struggle to make friends - being popular</b>			
Keeping safe in the middle	16	517	Somewhere in the middle. Not in the left-hand side with that group not in the right-hand side with that group. Just right in the middle.
	17	522	And then some of the group come to me and go to the side, then they also go to the other group and I'm still staying where I am.
	18	585	I keep to my side, the bullies keep to their side.
	19	587	Yeah and when I look at the bullies on this side, I run the other direction. And I just stay away from them and it's you know.
	19	592	All my life I've kept away from the bullies.
	19	597	I'm scared of them but I'm not scared of them
Feeling disregarded	24	759	Well I did tell them once, but they blanked it out of their mind.
	25	815	Wow, awesome, cool. In a positive side - not bye.
	26	824	Yeah - because you're going on about something they don't know. Like what? What are you talking about and just walk away.
Feeling scared of rejection for being 'weird' Seen as crazy	1	26	Well, it's just; people might think you're a little bit weird.
	1	33	Yeah. And a bit crazy..kooky.
	5	132	but if I didn't have dyspraxia I would think of myself as maybe a little normal
	17	532	Just as a regular person, that could be a little bit of, you know, crazy side, just a normal person.
	13	418	She (Mum) was like, why are you talking to yourself? You can't do that outside!
	24	753	If they're, if they understand me and they accept who I am...cos some people think 'she's weird, crazy, I don't like her, bye, bye'...some people think she's wonderful, she's great she could be my friend.
	26	817	Not like you're a little bit crazy don't want to talk to you...Bye.
	26	821	No they think like what is she talking about she must be crazy talking about this weird thing.
	1	29	And sometimes you'll just out of nowhere fall off the chair...randomly
	2	36	Yeah, but who cares! (when people don't want to be friends with you)
Being the ONLY one	2	52	I was the only one in Year 1 that couldn't really catch...ONLY one.
	15	446	That's why sometimes there are some teachers that go in that quiet corner, where I can literally sit down on my own table with space.
	15	483	Ever since then I've been struggling to sit on the carpet, so I'd have to sit on a chair and I can't sit straight that much, that's why I'm trying to sit with posture, that's why I sit on a chair normally, with my back against the chair.
	16	490	The teacher just sits me on my own chair
Feeling lonely	1	23	sometimes it affects me and kinda like making friends
	12	377	Yeah I didn't really make friends till Friday. So I was like sitting on my own on Monday, Tuesday, Wednesday, and Thursday...I didn't know what to do until I kind of bumped into someone by accident.
	27	855	I would come out of lesson when maybe we're doing 'golden time' or something a little lonely, I'd go to that person and then I sit down and I share and I talk to them

	27	862	Yeah, so if I don't have any friends and no one to play with I go to that person and talk to them the whole break. And when I was little I used to want to stay in and get in trouble because I didn't want to go out and watch everyone play.
	27	868	Yeah. Because when I was little I didn't have any friends. I didn't want to watch them play and me just sitting on the bench.
Working hard to be popular	3	69	Yeah. Tennis ball, throw it against the wall and catch it...my high score was three.
	26	826	When I was little and didn't have any friends I used to grab in the cupboard of our school and I used to get a tennis ball and try and catch it. And it used to go in my hand and drop out.
	5	148	I do actually try a lot
	16	502	And I used to go this one to one thing at my school. That we went outside and we did some ball games, catching and we used to just throw me and the teacher, we used to just throw a ball at each other and catch it. And then never really go that far back (laughs) and we stayed right near.
	26	835	And I got so annoyed because I was like...that close to catching that little ball and then I could win a point and I could actually be popular for the day, you know.
	26	839	It kind of gets you popular when I do something nobody else has done like in PGL. I got a little bit popular for a day and then everyone forgot about it.
	26	844	Yeah. You kind of get popular a little bit in that day and I don't really that much have that appeal. I've always been a middle kid.
	30	959	Once when I was really upset because I didn't make any friends. Until like Thursday and I was like. Why? Why? And I just got really upset so I had to talk to the SENCO about it.
Having genuine friends	5	130	But my friends appreciate who I am and what I have and the like who I am exactly as I am...
	24	767	Yeah. If they understand me and they get who I am.
	25	798	if I realised that someone had dyspraxia I would walk to them and be their friend straight away. I would have the confidence to do that
	7	208	"you're not that awesome!" "over-reacting Skyel!"
	7	219	We're not floating. Not floating on a hoverboard.
			Believing in yourself - 'I'm pretty swag'
Positive Mindset	3	74	It's actually pretty fun I guess, because you get to try new things that you thought you couldn't do because of your dyspraxia. It's actually pretty nice.
	6	165	Because I think dyspraxia is amazing and it actually helps me be who I am so without dyspraxia I wouldn't be myself. I would be a completely different person by with dyspraxia in my life it kind of make me go into the little cuckoo side - the little happy side - every day with rainbows on the top of my head.
	6	188	Yeah - I can do anything
	25	785	People might even say wow! Cool! What the? What are you talking about? What? What's happening here?
	25	789	Meaning wonderful, difficult
	25	802	I would say 'heh, I'm pretty swag!'
	25	805	I would sit with them and talk about it and help them understand that it's actually pretty wonderful.
	25	809	It's pretty awesome.
	30	971	Everything's patched up
Seeing the positive	4	117	Annoyed, but happy that I could even go in the water because my Mum said I couldn't even go in the water
	4	124	Well if I didn't have dyspraxia I don't think I would have made the friends I already have
	6	191	Swag, awesome epic (3 words to describe self)

Celebrating success	3	84	Yeah I have a victory dance...sometimes I have to do it in my head as there are people around me
	21	678	Believe it or not the first sticker I actually got by winning first, second or third was in Year 6 (final year of primary school - age 10/11)
	22	690	I finally got something
	22	696 - 701	And finally I got one sticker. I celebrated so much. I think I kind of like laughed so hard my belly kind of hurt...One sticker - I've got it right on my notice board and I also got a gold that I got from shot put.
	30	965	I made one friend in a week and I got so happy with myself
<b>Coping with dyspraxia</b>			
Acknowledging my limits	1	13	That I would feel a bit down and maybe I would fail, with like my physical actions
	4	99	trying best to balance on it, you know I will fall and tip myself into the water
	5	143	Well, erm... to be honest I first wanted to be a football player but every time I kicked the ball it went that way not this way. Then I wanted to be a police officer - Ahh (sigh) I trip over my own legs so many times.
	25	793	A disability that people...physical balancing kind of struggles, running, trips over, it just affects a little bit of my body but I know I can cope with it. And it will never fade away but...it will get better
	31	980	Maybe...I haven't really thought about it to be honest. Because I'm trying to put all my abilities together and try to think of what I would be good at. I'm not really. I don't think I could really pull it off and also I don't want to try and make stuff that I'm not really good at dodging - like an astronaut, that I might get hit by a meteor. Or as a ninja I might get hit or something, and I don't want to die.
Dyspraxia and who I am	31	988	So I want to try and choose a really suitable job.
	6	177	Well, I don't think it would cover completely who I am. You've still got the thing before that people actually take me for.
	1	20	I was like 'what is this word? I don't know what this word is!'
Keeping safe	1	7	I got a little stressed out, cos I thought it would affect me a lot, but actually it's OK.
	19	592	All my life I've kept away from the bullies.
	32	1013	Yeah when I get anxious and when I get nightmares, I don't go to my room and run around because I used to do that - run to my Mum's bed in the middle of the night. My Mum was sleeping and I used to run to her bed, go in and in the morning she'd get freaked out.
Dealing day to day	2	40	balancing (how does it affect you day to day)
	2	43	Well walking I can easily get tangled up in my own legs.
	2	51	well my hand-eye coordination is not that good; I can't really catch that well. I was the only one in Year 1 that couldn't really catch.
	4	103	I would not go past it: I would take the long way round
	14	478	I also can't cross my legs
	14	426	Upset that you fell down...but I just jump back up
	21	652	But sometimes the ball goes the wrong way. I kick it the right way it's just somehow it ends up over there.
	Coping with pain	14	428
14		434	there was a big bang and my nose went like that - my Mum thought it was broken but it wasn't
14		480	Every time I do it my muscles really hurt. It's like really badly and it's not my leg, I need to strengthen my muscles that's why I have putty for my hand and I just can't cross my legs.

	23	743	We both injured ourselves. I injured my elbow, my leg, my friend injured leg and hand. And that was both in all and different ones. On the first activity I was already tired.
	29	919	I can't write for a long time. I get a mark and bump here, it's because I drag my finger when I write, I can't write properly.
	32	1043	So if something's happened to me, so a tarantula bit me maybe - two things are there (indicates bite marks) when I wake up from a nightmare I can feel it and it hurts. The dream affects me so, if I hurt my leg in my dream, broke my leg in a dream my leg would hurt constantly.
	32	1039	Yeah. And then every time I have a nightmare and maybe something got me, I feel it. When I go out my dream I feel it and it hurts.
	32	1051	I would actually feel it - OW! It hurts.
Fighting to focus	15	459	Somebody's fidgeting! I'm like 'don't look at them Skye, just carry on, you've got a maths test already!' Somebody talking, don't look, Skye, just carry on!
		464	I can't concentrate
			<b>Escape through creativity</b>
Creating your own escape	7	225	Hmm - pretending I'm a ninja. Having pretend bad guys - my teddies in masks. Dressing them up as ninjas. I once made a rocket out of a nerf bullet and a glue stick and a pencil.
	8	240	Because if I looked at 2 things in this room, I'm thinking if I had a few more stuff in this room, what could I make with it.
	8	244	If I had a glue stick with an original hole in it, because it probably got ruined, I put a pencil in it, make maybe a little foam base, I put that in and then I find a tissue and I put that, nerf bullet put that in, put an elastic band around it and....got a rocket/aeroplane.
	8	251-259	My mind is basically like paper...That you draw on it to make it...like a graph or a diagram or something. And you can literally see on it, just staring at a wall...and then I kind of trace on it and draw on what I think it is. I kind of make something.
	9	272	Yes, but making comics, story comics. I once when I was little had a whole booklet of all my comic - a series with my own superheroes and villains
	9	279	I draw them a lot
	9	289	Surprisingly or not all the comic characters are my imaginary friends.
	10	292	I've got a whole world. Called Skyeland Just stuck in my head.
	10	299	And they live inside me
	10	302	Basically I imagined them every time at night. I used to lie down, make sure all the windows were closed and the doors shut. All peace and quiet and they used to have lots of adventures talking to each other; they used to be like ninjas fighting villains. And like a reality and a ninja life and they used to all like fight villains and defeat bad guys. And then I kind of put all of that into a comic. And then I always like daydream, sometimes.
	10	311	And I can literally daydream, even if the cinema is on and there is loads of noise, I can literally daydream in that cinema. And like the background noises just go away
	11	338	Sometimes I laugh on my own and my Mum has no idea what I'm laughing about when they're like dancing on her shoulder. But she doesn't know that does she?
Imaginary characters - real help	10	320	like I went to the PGL (school activity holiday) and there was this Power Fan (?) that was really high and I was climbing it and no one had done it in my group and I climbed to the top, everyone was cheering and I didn't want to jump down even though I had a harness on and was completely safe, like 'it's too high' and I hate heights! And then my imaginary friend sat on my shoulder and held my hand we just jumped together.

	11	330	And it was like nobody was there and I just did it myself. But they give me confidence. So yeah...And help me
	13	393	Sit down and imaginary friends sit down and they're all eating lunch, talking. But I try and be a little bit quiet and not smile all that much because people might think I'm a little bit crazy, talking to myself
	13	403	It's basically only just my mind, but it's basically them.
Rainbows and Unicorns	9	263	That's really tricky. I've got rainbows and unicorns on top of my head every day. I can't decide (what's your worst fault?)
Being a hero and fighting the bad guys	5	148	And then I had a little bit of a side of being a ninja
	9	272	Yes, but making comics, story comics. I once when I was little had a whole booklet of all my comic - a series with my own superheroes and villains
	10	305	they used to be like ninjas fighting villains. And like a reality and a ninja life and they used to all like fight villains and defeat bad guys
	30	977	Well if we're not talking realistic I want to be a space ranger ninja...musketeer...knight.

## Appendix N: Sample of Major Theme with Quotes

### Complexity of Response - Relief (R) Shame (S) Ambivalence (A) Need Support (N)

Participant	Pg.	Line	Quotation	
<b>Sophie</b>				
Feeling judge/criticised by others	6	132	<i>In year 6 people used to call me things like butter fingers and things like that, like all the really horrible boys, they were just really arrogant.</i>	S
Feeling unrecognised	22	529	<i>they just say she probably just has dyslexia and all the teachers they think that, like a lot of teachers if they see you with a blue book they are often like 'oh yeah no she probably just has dyslexia' because they just assume it I guess.</i>	N
Not wanting pity	27	642	<i>I wouldn't want them to treat me any differently, I wouldn't want them to start saying 'oh do you need me to help you with this, do you need me to help you with that' I would just want them to kind of just say 'Ok'. Obviously I wouldn't just want them to carry on saying your homework is scruffy or something like that - I would want them to understand that it was a lot harder for me than it was for them, but I wouldn't want them to be like, to kind of pity me or say anything like I had some sort of horrible illness or something</i>	A
<b>Megan</b>				
Relief	1	17	<i>When I found that out (having dyspraxia) I was just so relieved to realise that I wasn't just weird</i>	R
Confusion	4	118	<i>Not really (do people know about dyspraxia). Or the most response I get are oh I think my friend has that. That's why I was kind of happy when I got asked if I wanted to do this, as I wanted to make people more aware about dyspraxia as a thing. Because it's real and lots of people don't get diagnosed with it because no one knows what it is, so ...yeah.</i>	N
	5	150	<i>Because it's not like the be all and end all of me. I have a personality and my own interests, it's not just, that's it about me. It's still quite an important part of me. It is important part of who I am but it's not it. I have other aspects of me as well.</i>	A
Shame	15	468	<i>No - not unless it comes up. I don't say it straight away. (Do you tell people you have dyspraxia?)</i>	S
<b>Florence</b>				
Uncertainty	13	417	<i>just accepting that it's a little part of me. But it's not - it doesn't define me.</i>	A
Seen as taboo	13	413	<i>Yeah, it's not really a conversation opener</i>	S
Relief at diagnosis (not weird)	1	26	<i>I kind of like...well it was sort of like relief, because I knew then that well to be honest, I don't think it was a massive surprise that there was something massively different I don't think.</i>	R
	1	32	<i>there was actually a proper medical reason to why, erm I felt the way I did and I had problems doing stuff.</i>	R

Not being understood (not dyslexia)	3	82		N
			<i>Because I know a couple of people with dyslexia in my class and other people are like 'oh yes, we know about that.' And with dyspraxia people don't. They don't know about it and you have to explain yourself and then some people just still don't get it afterwards</i>	
<b>Ruth</b>				
Shock/surprise at diagnosis	13	408	<i>I was shocked - I don't know if I was either shocked or relieved. I mean it wasn't the outcome I was expecting.</i>	A
Relief at diagnosis (something behind it)	14	440	<i>Yeah - it wasn't just like, you're going to just have to work harder and find ways round it because I'd been trying to do that anyway but there was something ...if you have extra time it can actually help you get the rest of your ideas down.</i>	R
Confusion about significance of dyspraxia	18	576	<i>I'm not really fussed about it. I don't know if it's a big part of me that I actually need to...</i>	A
<b>Rory</b>				
Sense of relief	1	14	<i>I was actually quite relieved.(On finding out he has dyspraxia)</i>	R
	4	121	<i>I just wish I knew it earlier</i>	R
Seen as an excuse for difficulties	1	16	<i>Yes, because I've always been terrible at catching balls and things like that and I was quite relieved that I had an excuse.</i>	R
I wear (DCD) as a medal	10	301	<i>All the time (Do you tell other people you have DCD)</i>	R
	10	303	<i>I have to tell people like my teachers and my friends but at the same time I kind of wear it as a medal - I like telling people that I have DCD.</i>	R
	10	309	<i>It's a good conversation starter!</i>	R
<b>Ted</b>				
Finding out was not a big deal	1	17	<i>it didn't really affect me much.</i>	A
Sense of relief on diagnosis	1	19	<i>I knew I had something... that stopped me, so when they told me I was more relieved that I knew.</i>	R
Wanting help from teachers	14	460	<i>Teachers - I kind of want them to understand the challenges so that they can help.</i>	N
People don't know what dyspraxia is	5	163	<i>Not really. Well one of my friends did because his mum works with children with dyslexia.</i>	N
<b>Zac</b>				
Dyspraxia is unknown	3	95	<i>No not really, cos it's not something that you hear a lot of. Dyslexia you do, rather a lot, dyspraxia you don't. So yeah pretty much.</i>	N
Dyspraxia is a secret (shame)	2	65	<i>As a matter of fact I actually haven't gone openly out about it in school. Mainly because a lot, rather a few people in my year not the nicest of people, especially if they found out I had a disability, oh boy would they have a lot of stuff to taunt me about. That's why I just leave them to do there own thing and I stay with my little niche.</i>	S
	3	88	<i>Spread it.. Spread the word (what is your fear that other people might do)</i>	S

## Appendix O: Master and Subtheme Overview

Participant	Theme 1	Theme 2	Theme 3	Theme 4	Theme 5	Theme 6	Theme 7	Theme 8	Theme 9	
Sophie	Feeling misunderstood	Getting emotional	Being a space cadet	Struggle - carry extra	Escape: writing, sport, not school					
Megan	Giving up - I can't	Not being good at things	Keep trying hard	Not wrong - just different	Struggle with coordination	Shame and relief	Support vs. being let down	Not fitting in - on the outside	feeling good about myself	
Skye	Struggle to make friends - unpopular	Believing in myself	Coping - just jump back up	Escape through creativity						
Florence	Ambivalent about DCD	Different / Unique	Coping with negatives - keep going	Passion - stress - emotions	Creating world - imagination					
Kara	Hating being different	Emotional overload	Fear and guilt - letting others down	Struggling more than others	Uncomfortable socially	Being rational - accepting				
Ruth	Confused - shock and relief	DCD vs me identifying impact	I will get this - determination hard work	Not getting noticed - minimising	Needing acceptance	Sense of self as different				
April	Needing acceptance	Empathy for others	Staying positive	DCD is me - identity	Useless at sport					
Eliza	Dislike explaining self	Shame - wanting acceptance	Normal / odd / quirky	'Oh well' not making a fuss	Faulty processing - a bit missing	Always trying 100 %	Stressing	Thinking of others	Freedom in creativity	
Rory	DCD is medal - relief	Being 'rubbish' at things	Wanting popularity							
Ted	DCD limits my potential	Nerdy not sporty	Relief and support	Keep positive - I'm fine	Lack of understanding					
Zac	Secret / shame	Not a big deal	Causes problems	Prefer to do my own thing						
<b>Master theme</b>	<b>Subthemes</b>									
<b>Sense of Otherness</b>	<b>1. Recognising and Reframing Difference</b>			<b>2. Social Acceptance</b>						
<b>Complexity of Response</b>	<b>1. Shame</b>				<b>2. Relief</b>		<b>3. Ambivalence</b>		<b>4. Need for Acceptance / Understanding</b>	
<b>Recognising and Coping with Limitations</b>	<b>1. Unseen struggle</b>			<b>2. Not being good at things</b>		<b>3. Emotional overload</b>		<b>4. Coping strategies</b>		

## Appendix P: Psychology Ethics Form



### Psychology Department Standard Ethics Application Form: Undergraduate, Taught Masters and Professional Doctorate Students

This form should be completed in full. Please ensure you include the accompanying documentation listed in question 19.

<b>Does your research involve any of the following?</b> <i>For each item, please place a 'x' in the appropriate column</i>	<b>Yes</b>	<b>No</b>
Persons under the age of 18 ( <i>If yes, please refer to the Working with Children guidelines and include a copy of your DBS</i> )	x	
Vulnerable adults (e.g. with psychological difficulties) ( <i>If yes, please include a copy of your DBS where applicable</i> )		x
Use of deception ( <i>If yes, please refer to the Use of Deception guidelines</i> )		x
Questions about potentially sensitive topics	x	
Potential for 'labelling' by the researcher or participant (e.g. 'I am stupid')		x
Potential for psychological stress, anxiety, humiliation or pain		x
Questions about illegal activities		x
Invasive interventions that would not normally be encountered in everyday life (e.g. vigorous exercise, administration of drugs)		x
Potential for adverse impact on employment or social standing		x
The collection of human tissue, blood or other biological samples		x
Access to potentially sensitive data via a third party (e.g. employee data)		x
Access to personal records or confidential information		x
Anything else that means it has more than a minimal risk of physical or psychological harm, discomfort or stress to participants.		x

**If you answered 'no' to all the above questions your application may be eligible for light touch review.** You should send your application to your supervisor who will approve it and send it to a second reviewer. Once the second reviewer has approved your application they will submit it to [psychology.ethics@city.ac.uk](mailto:psychology.ethics@city.ac.uk) and you will be issued with an ethics approval code. You cannot start your research until you have received this code.

**If you answered 'yes' to any of the questions, your application is NOT eligible for light touch review** and will need to be reviewed at the next Psychology Department Research Ethics Committee meeting. You should send your application to your supervisor who will approve it and send it to [psychology.ethics@city.ac.uk](mailto:psychology.ethics@city.ac.uk). The committee meetings take place on the first Wednesday of every month (with the exception of January and August). Your application should be submitted at least **2 weeks** in advance of the meeting you would like it considered at. We aim to send you a response within 7 days. Note that you may be asked to revise and resubmit your application so should ensure you allow for sufficient time when scheduling your research. Once your application has been approved you will be issued with an ethics approval code. You cannot start your research until you have received this code.

<b>Which of the following describes the main applicant?</b> <i>Please place a 'x' in the appropriate space</i>	
Undergraduate student	
Taught postgraduate student	
Professional doctorate student	x
Research student	
Staff (applying for own research)	
Staff (applying for research conducted as part of a lab class)	

<b>1. Name of applicant(s).</b>
<b>Pamela Kane-Hamer</b>
<b>2. Email(s).</b>
████████████████████
<b>3. Project title.</b>
Dyspraxia, Identity and Self-esteem. What is the experience of adolescents with dyspraxia?
<b>4. Provide a lay summary of the background and aims of the research. (No more than 400 words.)</b>
<p>This research is interested in the experience of adolescents with a diagnosis of dyspraxia.</p> <p>Dyspraxia (also known as DCD) is a developmental disorder that can affect motor skills (such as writing, catching a ball, riding a bike etc.), visual perception, working memory and mental processing speeds. Students with dyspraxia will often need extra support at school and may have difficulties taking exams and feel excluded from some subjects such as physical education and art.</p> <p>Dyspraxia is often misunderstood, and/or overlooked, even though it affects nearly 5-6% of the population. Research has shown that dyspraxia can have a negative effect on self-esteem, mental health, physical well-being and educational achievement.</p> <p>There has been very little research into how those with dyspraxia feel about the condition, and how it affects their lives. This research aims to redress that imbalance and give the opportunity for adolescents to explore the effect of dyspraxia in a semi-structured interview. Adolescence is a crucial time in the development of identity and self and gaining knowledge and understanding the impact of dyspraxia at this time may help inform future support/interventions.</p>
<b>5. Provide a summary of the design and methodology.</b>
<p>The study has a qualitative design as it is primarily interested in the experience of individuals with dyspraxia. It is exploratory and aims to complement the body of quantitative research already available.</p> <p>Data will be collected by means of a semi-structured interview</p> <p>The methodology used to analyse the data will be Interpretative Phenomenological Analysis (IPA)</p>
<b>6. Provide details of all the methods of data collection you will employ (e.g., questionnaires, reaction times, skin conductance, audio-recorded interviews).</b>
Data collection will be by semi-structured interview. This will be recorded on a voice recorder and transferred to computer, where it will be encrypted and password protected.

**7. Is there any possibility of a participant disclosing any issues of concern during the course of the research? (e.g. emotional, psychological, health or educational.) Is there any possibility of the researcher identifying such issues? If so, please describe the procedures that are in place for the appropriate referral of the participant.**

I will make it clear to participants that they are in control of what they wish to discuss and are under no obligation to talk about subjects, if they do not wish to do so. However, as many participants may never have been given the chance to discuss the impact of dyspraxia before, it is possible that a participant may become distressed, depending on what they choose to disclose and what they feel is the impact of dyspraxia on their lives. As a trainee counselling psychologist and one with experience of working with children, I feel comfortable containing and judging the level of distress. I will respond empathically, allowing time to discuss the issue, check that they wish to continue and if necessary offer a short break in the interview. The participant will be assured that they can pause or withdraw from the process whenever they wish.

As the participants will be adolescents, I feel that it is important that confidentiality is maintained with the exception of issues of safeguarding, such as harm or severe distress. For example, the child may become distressed about an issue such as sexuality, which they do not wish to talk about with their parents. In this case, I would respond as above (empathically and offer breaks or to stop the interview), but not inform the parents, if the child does not want this. I would discuss with the child whether they could confide in an appropriate adult (parent, teacher, GP, family friend etc.) or make use of helplines such as Childline. I would discuss my assessment of the situation with my supervisor, to ensure that she agrees with my decision. Should the child become upset/distressed about the impact of dyspraxia on their lives, I would respond as above but encourage the child to confide in their parents and discuss with them whether or not we could disclose this information after the interview. However, if they did not want to, I would respect their wishes. I would recognise how difficult the situation was for them and help them identify alternative avenues of support (GP, trusted teacher, use helplines etc.) as above.

Should a participant indicate that they are in danger of harm, (such as bullying, being a victim of abuse, possible self-harm or that harm may occur to another) or the distress is severe to the point that I am concerned for their wellbeing, I would need to break confidentiality and inform the parents and/or school. In normal circumstances, the parent will always be informed. The only exception would be if the child reports parental abuse, in which case I will speak to the school safeguarding officer or if necessary child protection services (after consultation with my supervisor). If the interview takes place in school, and bullying comes to light, I will inform the school as well as the parents. Protecting the child will be paramount. This will be clearly explained to the participant and parents prior to the interview and after the disclosure. I would recommend appropriate support, either through counselling at the school (if available) or through GP/CAMHS.

**8. Details of participants (e.g. age, gender, exclusion/inclusion criteria). Please justify any exclusion criteria.**

Adolescents (11-18) with a diagnosis of dyspraxia. The research is looking specifically at the adolescent stage, as this is under-researched and also crucial in terms of academic achievement and identity formation. In order to ensure validity, students must have a diagnosis (rather than suspected) dyspraxia.

Those with a further diagnosis of ADHD or dyslexia will be excluded, as this could be a confounding variable.

**9. How will participants be selected and recruited? Who will select and recruit participants?**

Information regarding the study will be sent to schools (either head of learning support or head teachers) and to the Dyspraxia Foundation.

After discussion with the appropriate teacher or relevant contact at the dyspraxia foundation, information regarding the study will be forwarded by them (the school or dyspraxia foundation) to the parents of eligible children. This information will include the flyer (which gives a short summary/overview of the study) and the detailed participant information forms for parents and children.

The parents of participants will be invited to call or email the researcher for further information. Participants will be given a mobile phone number for the researcher to ensure a timely response, as the supervisor (Dr Jacqui Farrants) is only at the University twice a week.

When the parents contact the researcher, further details of the study can be clarified, and confirmation will be required that the child has a diagnosis of dyspraxia and is between 11-18 years old. Children who also have a diagnosis of a further developmental disorder will not be included in the study.

If the parent and child are willing to take part and meet the inclusion criteria, the consent form will be sent, and dates arranged for interview.

**10. Will participants receive any incentives for taking part?** (Please provide details of these and justify their type and amount.)

No

**11. Will informed consent be obtained from all participants? If not, please provide a justification.** (Note that a copy of your consent form should be included with your application, see question 19.)

Yes. A consent form (see appendices) needs to be signed by both the participant and the parent/guardian. In line with City University London Ethics committee guidelines for working with children, I will clearly go through the consent form with the participant and guardian and ensure they both understand the features of the research. I would also explain clearly the grounds on which I would need to break confidentiality and why. I will encourage and allow time for any questions. I will reassure the child that participation is optional, that they do not have to answer any question they are uncomfortable with and I will assure him/her that they may choose to discontinue the interview if they wish or withdraw from the study (prior to analysis taking place) without any penalty.

**12. How will you brief and debrief participants?** (Note that copies of your information sheet and debrief should be included with your application, see question 19.)

Information on the study will be provided prior to consent and after the interview the participants will be debriefed as per debrief interview (please see appendices)

**13. Location of data collection.** (Please describe exactly where data collection will take place.)

Data collection will take place in a private room wherever possible at the participant's school or at a meeting place of the dyspraxia foundation (normally community hall).

Should this not be possible, the interview may take place at the participant's home address. An adult must be present at the home at all times - although not in the room.		
<b>13a. Is any part of your research taking place outside England/Wales?</b>		
No	<input checked="" type="checkbox"/>	
Yes	<input type="checkbox"/>	If 'yes', please describe how you have identified and complied with all local requirements concerning ethical approval and research governance.
<b>13b. Is any part of your research taking place outside the University buildings?</b>		
No	<input type="checkbox"/>	
Yes	<input checked="" type="checkbox"/>	If 'yes', please submit a risk assessment with your application.
<b>13c. Is any part of your research taking place within the University buildings?</b>		
No	<input checked="" type="checkbox"/>	
Yes	<input type="checkbox"/>	If 'yes', please ensure you have familiarised yourself with relevant risk assessments available on Moodle.
<b>14. What potential risks to the participants do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.</b>		
I foresee no ethical or health and safety risks to participants. However, depending on the content of the participant's response, it is possible that the participant may become distressed. As a mother of an adolescent with dyspraxia and a counselling psychology student, I am aware of these issues and am familiar with relevant groups and services which may provide further support (see 7. above).		
<b>15. What potential risks to the researchers do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.</b>		
The only potential risk to the researcher could be in terms of health and safety re. lone worker, when interviews are not taking place in school grounds. To ensure safety, details of participants (address/phone number) will be checked prior to arrangement with school or dyspraxia foundation - and full details of address and timings will be left with colleagues. I will check in with friend or colleague prior to and after the meeting and carry a personal alarm.		
<b>16. What methods will you use to ensure participants' confidentiality and anonymity?</b> (Please note that consent forms should always be kept in a separate folder to data and should NOT include participant numbers.)		
<i>Please place an 'X' in all appropriate spaces</i>		
<b>Complete anonymity of participants</b> (i.e. researchers will not meet, or know the identity of participants, as participants are a part of a random sample and are required to return responses with no form of personal identification.)		
<b>Anonymised sample or data</b> (i.e. an <i>irreversible</i> process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates.)		
<b>De-identified samples or data</b> (i.e. a <i>reversible</i> process whereby identifiers are replaced by a code, to which the researcher retains the key, in a secure location.)		<b>X</b>
<b>Participants being referred to by pseudonym in any publication arising from the research</b>		<b>X</b>
<b>Any other method of protecting the privacy of participants</b> (e.g. use of direct quotes with specific permission only; use of real name with specific, written permission only.) <b>Please provide further details below.</b>		
Not only will participants be referred to by pseudonym, but any details that could lead to their identification may be altered where not detrimental to understanding of data (e.g. participant gender, gender of siblings/friends, type of pets or sports/hobbies referred to). Only the final report, where the data has been assimilated will be available to read through the University Libraries and there will be no details of the participants, schools or geographic location		

At schools only Head teachers / Head of Learning Support will be informed of the study. Their role is to disseminate information to the pupils/parents who then contact me direct. The parents will be offered the choice of an interview in their home or at the school - and I will explain that if they choose home, no further details of their child's involvement will be passed on to the school. The school will have no knowledge as to who takes part. Should the parent prefer the interview to take place in the school, I would ask the staff involved (Head / Learning Support) to keep information about the study to a minimum. This means not to discuss the purpose of the study or the participation of the child with other members of staff or pupils, unless absolutely necessary. No further information will be given to the school regarding publication, but should a staff member obtain a copy of the published thesis, the final report will have only collated material and not identify specific children..

**17. Which of the following methods of data storage will you employ?**

*Please place an 'X' in all appropriate spaces*

<b>Data will be kept in a locked filing cabinet</b>	
<b>Data and identifiers will be kept in separate, locked filing cabinets</b>	<b>X</b>
<b>Access to computer files will be available by password only</b>	<b>X</b>
<b>Hard data storage at City University London</b>	
<b>Hard data storage at another site. Please provide further details below.</b>	

**18. Who will have access to the data?**

*Please place an 'X' in the appropriate space*

<b>Only researchers named in this application form</b>	<b>X</b>
<b>People other than those named in this application form. Please provide further details below of who will have access and for what purpose.</b>	

**19. Attachments checklist.** \*Please ensure you have referred to the Psychology Department templates when producing these items. These can be found in the Research Ethics page on Moodle.

*Please place an 'X' in all appropriate spaces*

	Attached	Not applicable
*Text for study advertisement	X	
*Participant information sheet	X	
*Participant consent form	X	
Questionnaires to be employed		X
Debrief	X	
Copy of DBS	X	
Risk assessment	X	
Guide to questions for semi-structured interview	X	
Letter to School	X	
Letter to Dyspraxia Foundation	X	
Information sheet for parents	X	
Consent Form for parents	X	

**20. Information for insurance purposes.**

(a) Please provide a brief abstract describing the project

An exploratory study into the effect of dyspraxia on the lived experience of adolescents in UK. Six to ten adolescents (aged 11-18) will be interviewed by the researcher. The interview will be semi-structured in order to allow the participant to fully explore/explain the impact and meaning of dyspraxia to their lives.

The interviews will be audio-recorded and transcribed. The analysis will be undertaken by IPA (Smith 1999). All information will be confidential. Any identifying information will be removed or anonymised.

It is hoped the study will make a useful contribution to the limited body of research into dyspraxia, especially regarding the lack of qualitative data and inform possible further intervention and support.

*Please place an 'X' in all appropriate spaces*

(b) Does the research involve any of the following:	Yes	No
Children under the age of 5 years?		X
Clinical trials / intervention testing?		X
Over 500 participants?		X
(c) Are you specifically recruiting pregnant women?		X
(d) Is any part of the research taking place outside of the UK?		X

If you have answered 'no' to all the above questions, please go to section 21.

If you have answered 'yes' to any of the above questions you will need to check that the university's insurance will cover your research. You should do this by submitting this application to [anna.ramberg.1@city.ac.uk](mailto:anna.ramberg.1@city.ac.uk), before applying for ethics approval. Please initial below to confirm that you have done this.

I have received confirmation that this research will be covered by the university's insurance.

Name ..... Date.....

<b>21. Information for reporting purposes.</b>		
<i>Please place an 'X' in all appropriate spaces</i>		
<b>(a) Does the research involve any of the following:</b>	<b>Yes</b>	<b>No</b>
Persons under the age of 18 years?	<b>X</b>	
Vulnerable adults?		<b>X</b>
Participant recruitment outside England and Wales?		<b>X</b>
<b>(b) Has the research received external funding?</b>		<b>X</b>

<b>22. Declarations by applicant(s)</b>		
<i>Please confirm each of the statements below by placing an 'X' in the appropriate space</i>		
I certify that to the best of my knowledge the information given above, together with accompanying information, is complete and correct.		<b>X</b>
I accept the responsibility for the conduct of the procedures set out in the attached application.		<b>X</b>
I have attempted to identify all risks related to the research that may arise in conducting the project.		<b>X</b>
I understand that <b>no</b> research work involving human participants or data can commence until ethical approval has been given.		<b>X</b>
	<b>Signature</b> (Please type name)	<b>Date</b>
<b>Student(s)</b>	<b>Pamela Kane-Hamer</b>	<b>04/10/2015</b>
<b>Supervisor</b>	<b>Dr Jacqui Farrants</b>	<b>13/11/15</b>

### Reviewer Feedback Form

<b>Name of reviewer(s).</b>		
<b>Committee</b>		
<b>Email(s).</b>		
<b>Psychology.ethics@city.ac.uk</b>		
<b>Does this application require any revisions or further information?</b>		
<i>Please place an 'X' the appropriate space</i>		
<b>No</b> Reviewer(s) should sign the application and return to <a href="mailto:psychology.ethics@city.ac.uk">psychology.ethics@city.ac.uk</a> , ccing to the supervisor.	<b>Yes</b> Reviewer(s) should provide further details below and email directly to the student and supervisor.	<b>X</b>
<b>Revisions / further information required</b> To be completed by the reviewer(s). PLEASE DO NOT DELETE ANY PREVIOUS COMMENTS.		
Date: 17 <sup>th</sup> December 2015 Comments:		
<u>Application form</u>		
1. Section 7. Please provide more details of how the researcher will respond <u>to the child</u> during the interview if (a) they become very distressed, or (b) they report difficulties, such as bullying. (For example they may ask for advice or they may simply assume that the researcher, as an adult, will take steps to address the bullying).		

2. In Section 8, diagnoses of dyslexia or ADHD are listed as exclusion criteria. However, elsewhere (e.g., in Section 9 and the information sheets) the term “learning disorder” is used. The committee felt the term “developmental disorder” should be used throughout because other developmental disorders that wouldn’t be considered learning disorders (e.g., autism spectrum disorder) could present co-morbidly with dyspraxia and confound the results. Please adjust this in the application form and on the information sheets.

3. Section 11. Please provide more information on the way in which the study will be explained to the child and how their assent will be assessed and monitored throughout the interview. (Please see the Research Ethics page on moodle for more details on research with children / obtaining child assent.)

4. Section 16. The committee raised concerns about school staff being able to identify individuals from the information provided in the interviews (given that staff may know which children have taken part). Please provide some more details about how you will ensure that data remain confidential.

#### Information sheets

5. The committee felt that the information sheet intended for children would not be well understood by them (particularly by 11 year olds). For example, they are unlikely to understand terms such as “doctorate”, “thesis”, “confidentiality”, “encrypted”, and “pseudonyms”. Please try to make this information sheet more suitable for children. (There are some examples of child friendly information sheets available on the Research Ethics page on moodle.)

6. The committee noted that in Section 7 of the application form, it states “...*should a participant show great distress - to the extent that I feel they are likely to be suffering and in need of further help, I would need to break confidentiality and inform the parents. This will be clearly explained to the participant prior to the interview.*” However, in the parent information sheet it says, “*The only time I would break confidentiality is if I felt your child was in danger of harm in any way.*” Similarly in the child information sheet it says, “*The only time I would break confidentiality is if I felt you were in danger of harm in any way.*” Please adjust the information provided to children and parents regarding when confidentiality would be broken.

7. The committee felt a little more information about the potential applied benefits of the project could be provided in the information sheets.

8. Please correct the mismatch in titles. (At the bottom of the information sheets the title is “*The Awkward Years? What is the experience of teenagers living with dyspraxia?*”)

9. Please provide full contact details (work emails, phone numbers, and addresses)

10. Please clarify who “me” refers to (perhaps by adding the name in brackets).

#### Dyspraxia foundation letter

11. Please add ‘London’ to City University.

#### Consent form

12. Please provide two separate consent forms that are worded appropriately for the parent and child respectively.

#### Letter to school head

13. Please adjust ‘school grounds’ to ‘school premises’.

### Debrief

14. In the Debrief form, please provide full contact details for the supervisor.

### Interview

15. The committee wondered whether there might be too many questions in the interview schedule to fit into a 30-60 minute interview. Please consider this issue and adjust the information provided to participants if necessary.

## **Application Form**

### **Section 7 (pg.3)**

- 1 Further information has been given regarding possibility of dealing with distressed children and reporting difficulties.

Confidentiality will be maintained except in a case of harm - either real or potential harm to the participant, or harm to others, or in a case of severe distress that I do not feel can be contained and could lead on to potential harm. However, in other circumstances, confidentiality must be maintained for the participant to feel secure within the interview and the rights of the participant (particularly as adolescents) not to share information with their parents must also be respected. However, time will be allocated to discuss any difficult issues with the participant and ensure that he/she understands what avenues of support are available. Where it is safe to do so, the child will be encouraged to share concerns with their parents or other responsible adult as well as make use of helplines / seek further advice, but confidentiality will be respected.

### **Section 9 (pg. 4)**

2. Learning disorder has been changed to developmental disorder in Section 9 and Information sheets.

### **Section 11 (pg.4)**

3. More information is given on child consent and monitoring in accordance to City University London Ethics guidelines for working with children i.e. clearly explaining they study, right to withdraw, confidentiality and consent.

### **Section 16 (pg.5)**

4. More information is given about confidentiality regarding staff knowledge of participation and anonymity of published data

### **Information Sheets**

5. A new information sheet has been drafted for participants (see new attachment - Info for children.doc)
6. Information regarding breach of confidentiality was made consistent. It has been made clear that confidentiality will only be breached in case of harm or severe distress (see point 1 above).
7. More information about possible benefits of the study were added
8. Title is now consistent throughout as  
*Dyspraxia, Identity and Self Esteem*  
*What is the experience of adolescents with dyspraxia?*
9. Full contact details are provided
10. Researchers name has been added

### **Dyspraxia Foundation Letter**

11. London has been added to University title in all documentation

### **Consent Form**

12. There are now 2 separate consent forms for adult/child (see new attachment - child consent.doc)

### **Letter to Head Teacher**

13. School grounds are now school premises

### **Debrief**

<p>14. Full contact details have been added</p> <p><b>Interview</b></p> <p>15. Information has been adjusted to 45-60 minutes - a longer time period may be difficult for some of the participants due to possible limited concentration span. The interview questions will be piloted beforehand and if the time is too short, questions will be condensed. (Please note prompts are only to be used if the participant finds the questions hard to answer or expand upon).The six key areas, identified in the guide to semi-structured interview are:</p> <ul style="list-style-type: none"> <li>• Meaning of dyspraxia for the participant</li> <li>• Self-concept, Self-esteem and self-efficacy</li> <li>• Peer Relationships</li> <li>• Physical Well being</li> <li>• Reaction of others/Support</li> <li>• Future expectations/aspirations</li> </ul> <p>The interviewer will ensure that these six key areas are covered within the timeframe.</p>		
<p><b>Applicant response to reviewer comments</b>          To be completed by the applicant. Please address the points raised above and explain how you have done this in the space below. You should then email the entire application (including attachments), with tracked changes directly back to the reviewer(s), ccing to your supervisor.</p>		
<p><b>Reviewer signature(s)</b>          To be completed upon FINAL approval of all materials.</p>		
	<b>Signature</b> (Please type name)	<b>Date</b>
<b>Supervisor</b>		
<b>Second reviewer</b>		

## AMENDMENT TO ETHICS APPROVAL

Katy Tapper <

Mon 13/06/2016 19:33

To:

Psychology Research Ethics

Cc:

PG-Kane-Hamer, Pamela <  
ethics

Hi Pamela

Happy to approve this amendment and am ccing to Hayley for our records.

Best wishes, Katy

## **Part B: Publishable Paper**

Reframing Developmental Coordination Disorder (DCD):  
An interpretative phenomenological analysis of the experience of  
adolescents with a diagnosis of DCD.

## ABSTRACT

Background	Adolescents with Developmental Coordination Disorder (DCD) are at increased risk of mental-health issues and low self-esteem. There has been limited qualitative research exploring their perspective.
Aim	The study aimed to gain a deeper understanding of the lived experience of adolescents with DCD.
Method and Procedure	Eleven adolescents (8F: 3M) aged between 11-18 with a diagnosis of DCD were recruited from the Dyspraxia Foundation. Semi-structured interviews were carried out, audio-recorded and transcribed. The data was analysed by means of Interpretative Phenomenological Analysis (IPA).
Results	This article discusses two major themes. (1) <b>A sense of Otherness:</b> participants identified feelings of difference and earlier social exclusion. Adolescence was a time where many participants were able to re-assess and re-frame their self-concept in a more positive light. (2) <b>Complexity of Response:</b> participants expressed complicated feelings about DCD - ranging from relief at the diagnosis, to shame and ambivalence - they reiterated a need for acceptance and support.
Conclusion	This work highlights the continued lack of attention afforded DCD and the low levels of recognition and support for young people. As adults with DCD continue to report issues with self-esteem, mental health and reduced social participation, this research indicates that adolescence may be a crucial time for interventions to improve resilience.

### **Keywords**

Developmental Coordination Disorder (DCD) - Adolescence - Self-esteem - Identity - Resilience - Reframing - Phenomenological

### **What This Paper Adds**

Individuals with DCD have been shown to be at risk of lower self-esteem, social participation and psychological outcomes, however there is limited qualitative research into their experience. This paper investigates the lived experiences of adolescents with DCD and highlights the importance of social recognition and support, as well as the adolescents' own resilient responses as they re-assess and re-frame their identity.

### **1. INTRODUCTION**

Developmental Coordination Disorder (DCD), also known as dyspraxia in the UK, is defined as an impaired development of motor coordination impacting daily activities (American Psychiatric Association, 2014). It affects between 5-6% of the population, with 2% severely affected (Lingam et al., 2009). Despite this relatively high prevalence, there is little recognition or understanding among the general public, and parents of children with DCD complain about lack of knowledge and support among health professionals (Novak et al., 2012). DCD is found more often in males than females - with estimates ranging from 2:1 to 7:1 (Blank et al., 2012). There is frequent co-morbidity between DCD and other neurodevelopmental disorders - in particular ADHD, where the overlap is estimated to be approx. 50% (Blank et al., 2012; Dewey & Bernier, 2016; Visser, 2003). Despite the accepted DSM-5 definition referring solely to motor impairment, many of those diagnosed with DCD struggle with Executive Function impairments (Bernardi et al., 2018; Purcell, Scott-Roberts, & Kirby, 2015; Sumner et al., 2016).

Numerous studies into DCD during childhood/adolescence have highlighted decreased social acceptance, reduced physical fitness and participation, lower self-esteem and poorer outcomes for psychological health (Campbell et al., 2012; Cermak et al., 2015; Jarus et al., 2011; Jaspers et al., 2012; Lingam et al., 2012; Missiuna et al., 2014; Pratt & Hill, 2011; Raz-Silbiger et al., 2015; Rivilis et al., 2011;

Sugden et al., 2008; Watson & Knott, 2006; Wuang et al., 2012; Zwicker et al., 2013). Although there are comparatively few studies into DCD in adulthood, a continued negative impact on quality of life, self-esteem and rates of anxiety and depression have been found (Hill et al., 2011; Hill & Brown, 2013; Tal-Saban et al., 2012). The few qualitative studies have indicated the social and emotional impact, as well as the impact of exclusion and the need to develop resilience in childhood (Zwicker et al., 2018). In adolescence, the importance of social support and developing identity was highlighted (Lingam et al., 2014; Payne et al., 2013). The purpose of this study was to gain deeper understanding of the experience of living with DCD during adolescence.

## **2. METHODS**

### **2.1 Approach**

The study has a qualitative design; it is primarily interested in the lived experience of individuals with DCD aged 11-18. It is exploratory and aims to complement the body of mostly quantitative research. Data was collected by means of semi-structured interviews and was analysed using Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). The main aim of IPA is to gain insight into the experience of the participant, to develop an understanding of the quality of that experience. IPA is particularly interested in the subtle distinctions of an individual's experience that are hard to capture using positivist methodologies (Willig, 2008).

### **2.2 Participants**

In total, 11 participants between the ages of 11-18 were recruited through an advertisement placed on the Dyspraxia Foundation website. Qualitative research typically has a smaller number of participants than quantitative; IPA is concerned with a detailed individual account of experience. The smaller number of cases allow for deeper and more focussed work. This sample size was in line with the recommendations (Smith et al., 2009). All participants had a diagnosis of DCD from either an Occupational Therapist (OT), Education Psychologist or Paediatrician.

Additional diagnoses of a neuro-developmental disorder were not excluded. As a qualitative study, the aim was to capture the experience of those diagnosed with DCD - and comorbidities are commonplace (Blank et al., 2012). Contrary to accepted male prevalence rates, eight of the participants were girls and three were boys. Geographically, the participants' homes were dispersed throughout the UK.

**2.3 Table 1. Participant List**

<b>Pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>Comorbidity</b>
<b>April</b>	F	12	n/a
<b>Eliza</b>	F	18	ASD
<b>Florence</b>	F	15	n/a
<b>Kara</b>	F	14	Awaiting assessment re. dyslexia/ASD
<b>Megan</b>	F	12	SPD
<b>Rory</b>	M	11	n/a
<b>Ruth</b>	F	17	Dyslexia
<b>Skye</b>	F	11	SPD; Awaiting assessment re. dyslexia
<b>Sophie</b>	F	14	n/a
<b>Ted</b>	M	13	n/a
<b>Zac</b>	M	13	n/a

**Key:**

SPD – Sensory Processing Disorder

ASD – Autistic Spectrum Disorder

**2.4 Ethics**

Ethical approval was obtained from City, University of London and from the Dyspraxia Foundation UK. All names are pseudonyms and any potentially identifying details have been changed.

**2.5 Data Collection**

The data was collected by means of a semi-structured interview. An interview

schedule was prepared with the aim of giving a framework to the interview (see box 1 for sample questions). The interview was piloted on two adolescents with DCD. The schedule consisted of six areas of questions and a closing section regarding how the participant had experienced taking part. The sections were devised based on previous research and covered: a) the meaning of DCD for the participant; b) the impact on self-esteem/self-concept; c) peer relationships; d) physical wellbeing; e) other people's reactions and future expectations. Whilst IPA interviews are generally non-directive and participant-led, Smith highlighted the importance of adapting techniques for different populations e.g. children or adolescents. Smith & Dunworth (2005) also point out that when interviewing children, it can be necessary to put the participant at ease and build confidence by encouraging talk about different areas of their lives not directly relevant to the main topic - such as hobbies or friendships.

Prior to the interview, both the participant and parent had been sent an information sheet, detailing the aims of the study, process of the interview, as well as information regarding confidentiality. The participant and parent or guardian signed a consent form before commencing the interview. The interview took place in the participant's own home. Due to age constraints (all but one of the participants being under 18) a parent or guardian always needed to be present in the house, but not in the same room. This ensured that the participant had privacy to discuss difficult issues, such as guilt concerning the effort/role of parents in supporting them.

**Box 1. Sample Questions and prompts**

**Question: What does having DCD mean to you?**

*Prompt: Is there anything positive about having DCD?*

*Prompt: How would your life be different if you didn't have DCD?*

**Question: Can you tell me about something that you find really difficult?**

*Prompt: How have you coped with that / what strategies have you used?*

Before the start of the interview, the participant once again gave verbal consent and were

reassured that that they could stop or withdraw from the study if they wished. Only one participant asked for a short pause when she became distressed - however, she quickly recovered and wished to continue. At the end of the interview all participants

were asked for feedback on how the experience and if there were any further elements about living with DCD they wanted to discuss or felt had been neglected. The interviews lasted between 35 - 70 minutes.

## **2.6 Data Analysis**

After each interview initial thoughts on the experience were recorded as recommended by Smith et al. (2009). These included descriptions of the setting, how the participant reacted and any thoughts and feelings that arose. After transcription of the audio recordings, the process of reading, re-reading and re-listening commenced. Next the researcher made unstructured comments and connections, noting linguistic usage and significant emphasis - keeping in mind the aim of the note-making which is to make sense of the participant's experience (Smith, 2015). Following on from these initial, loose themes, stronger more consistent 'emergent themes' were developed. Whereas the noting of initial themes stay close to the phenomenological experience of the participant, emergent themes can be seen as moving a little further away and bringing in a stronger interpretative element. Themes were then clustered into master themes for each participant. Larkins, Watts & Clifton (2006) emphasise the importance of interpretation within IPA and caution against taking a wholly phenomenological stance. IPA must be interpretative - it is not merely a representation of an individual's experience but also an interpretation of that experience. Smith et al. (2009) consider this 'one manifestation of the hermeneutic circle' (p.91).

Finally, the emergent themes for all eleven participants were compared and clustered together to form Subthemes and Master themes. This process was long and circular; a constant re-sifting and distilling of data - sometimes involving re-reading sections of transcript or even re-listening to recordings to maintain a connection with participant data. Even though IPA is an idiographic process where each participant is

considered individually in their own right, many themes were found to resonate across participants.

### 3. RESULTS

Analysis of the transcripts produced three Master themes regarding the experience of adolescents with DCD (see table 2). The first two master themes of ‘Otherness’ and ‘Complexity of Response’ are discussed below. Findings from these two themes are presented as they represent important findings such as ‘re-framing’ and response to the diagnosis, that had not been previously discussed in academic literature; as well as themes of social status, self-esteem and self-concept that I felt were the most relevant specifically to adolescence.

**3.1 Table 2: Master Themes and Subthemes**

MASTER THEMES	SUBTHEMES
1. SENSE OF OTHERNESS	2 Recognising and re-framing difference 3 Social Acceptance
2. COMPLEXITY OF RESPONSE	<ul style="list-style-type: none"> <li>• Ambivalence</li> <li>• Relief</li> <li>• Shame</li> <li>• Need for acceptance and understanding</li> </ul>
3. RECOGNISING AND COPING WITH LIMITATIONS	<ul style="list-style-type: none"> <li>• Unseen Struggle</li> <li>• Not being ‘good’ at things</li> <li>• Emotional Overload</li> <li>• Coping               <ul style="list-style-type: none"> <li>○ Minimising and being rational</li> <li>○ Staying positive - don’t give up!</li> <li>○ Escape</li> <li>○ Getting Support</li> </ul> </li> </ul>

As is typical in the UK, most participants use the term dyspraxia over DCD during the interviews.

### **3.2 Theme 1 - Sense of Otherness**

The theme of 'Otherness' was divided into two subthemes: Recognising and reframing difference and Social Acceptance

#### **3.2.1 Recognising and Re-framing Difference**

The initial perception of difference, of being outside the 'norm' was an early experience for most of the participants. This defining of self usually occurred when attending primary school and made more direct comparisons to their peers or were exposed to cruel comments from others.

*...I thought I was like OK, like I was kind of normal as such, and then I got bullied for some things I didn't realise were different and that's when I started thinking that there was something a bit different about me... (Megan)*

Here the 'forced' recognition of being different was accompanied with the consequence of victimisation. Therefore, for Megan, being different and being weird are to be rejected and avoided she wants to be 'OK' she wants to be 'kind of normal'.

However, having conceived of a version of themselves as different to the norm at an early age, many of the participants were re-framing and reviewing this as they reached or progressed through adolescence and were beginning to develop and determine their own self-concept. Some of the participants re-framed their difference as fundamental in their sense of themselves. Not being 'normal' was something to be proud of. Having a sense of personality that incorporated being 'quirky' or 'unique' could be seen as advantageous

*In a funny kind of way, it makes me happy, it makes me like happy is a weird word to describe it, but it makes me 'me' - unique to the other people in my class and things. (April)*

The re-framing developed over time and could be more nuanced, often after reflection on the bullying or exclusion they experienced in earlier years. As they developed through adolescence, many participants embraced their 'difference' and enjoyed the sensation of not following the crowd. One participant was proud to tell me she was not on social media and that she did not have an interest in what she considered to be 'typical teenage things'. Her sense of being different had been embraced as a positive attribute - and different, differently, positive and unique were words that she used to describe herself - or rather people with dyspraxia (she used 'us'), which indicated a potential sense of identity and inclusivity. There was also a sense that the 'norm' is slightly dull and predictable and that positive advantage could come from an alternative point of view.

*that we sort of see the world differently. Like in a more unique way and I think that's kind of a positive thing about it. Because I think we sort of have different perspectives. I'm not sure because I've never really been anyone else. But when I think about it, I think we are more unique in our outlook than other people. (Florence)*

Ted not only felt that the diagnosis allowed a sense of uniqueness, but also helped foster a sense of identity - even though there was still ambivalence in his response.

*I'm not completely like good about it but I don't, but I'm happy that I am it. I kind of, it gives me a way to identify myself. (Ted)*

However, not all the participants had been able to accept or 're-frame' DCD and Kara in particular was unable, at the time of the interview, to find anything positive to say about her experience - she rejected totally the 'otherness' that DCD inferred.

*I don't like being different I just kind of want to be the same as everyone else... but I always think that I would like to be the same as other people. Not like look the same but like inside like not have dyspraxia basically. (Kara)*

### **3.2.2 Social Acceptance**

For many of the participants being perceived as 'other' had sometimes caused emotional pain due to victimisation, exclusion and isolation. Many of the group had historically been bullied, sometimes to the point of moving schools and the majority had at one time struggled to make friends and had felt socially disadvantaged. Whilst feelings of loneliness and exclusion in younger years were expressed as painful memories, none of the participants reported active bullying in adolescence. However, for some of the younger participants, at the onset of adolescence, the struggle for social acceptance was still very much present

*I kind of see myself maybe on the outside, kind of. Because I don't really feel like I fit in to my class very well. (Megan)*

*'I'm pretty unsocial because I'm not, like I said about fitting in and if you don't really fit in it's pretty hard to be social.'* (Rory)

Not being 'social' - was sometimes perceived as being caused by a lack of social skills. When participants felt uncomfortable with within their peer group - social interactions could become laden with anxiety.

*I just have no idea what to say, so I just randomly start rambling about random things and they're just like well we don't want to hear.'* (Kara)

The participants were often acutely aware of their perceived social status.

Unfortunately, sport lessons and break time (particularly in the younger years) could still be seen as potentially humiliating spaces. Being less able at sport was often equated with lower social standing, particularly with the boys and could also be linked with shame and humiliation.

*'People who are good at things like sport, they are usually the ones that everybody wants to be friends with.'* (Rory)

Many of the participants saw the impact of the early struggle to gain social acceptance and status as an important aspect in their development and how they see friendships today. As the participants progressed through adolescence they were more likely to express satisfaction with social relationships. They placed great emphasis on friendship groups and social support and indicated that they significantly valued friendship and loyalty. It seems for many of the participants difficult experiences in early childhood may have led to an importance on 'true friendship' rather than social standing.

*But my friends appreciate who I am and what I have and the like who I am exactly as I am...(Skye)*

*It's weird, I can pick up if someone is nice or not very, very quickly. ... I pick up on it really fast and I'll probably think there's something not quite right (Ruth)*

### **3.3 Theme 2: Complexity of response**

The response of the participants to being diagnosed with DCD and therefore having a label was complex and depended on many factors such as the age and manner of the diagnosis and the social impact at school. Four subthemes were identified: relief, shame, ambivalence and the need for acceptance and understanding

#### **3.3.1 Relief**

All the participants who remembered getting a diagnosis expressed relief. The medicalisation of their 'difference' answered many questions that otherwise were answered with a far more internalising and shaming stance. The authority of a 'medical' diagnosis, of having a recognised 'disorder' allowed the participants to distance themselves from the shame of 'weirdness'

*I think it was just because to make sure that I wasn't just 'weird' (laughs) human being, there was actually a proper medical reason to why, erm I felt the way I did and I had problems doing stuff. (Florence)*

Rory was also very relieved to get the diagnosis as it helped him feel better about himself and allowed him to understand his limitations, particularly in sport, in a more accepting way.

*I have to tell people like my teachers and my friends but at the same time I kind of wear it as a medal - I like telling people that I have DCD. (Rory)*

For many of the participants, relief came not just in the sense of 'not being weird' or for having a non-shaming reason for their lack of sporting prowess or coordination difficulties, but also in the expectation of improvement in access to support - particularly academically. Some were hoping for adaptation to lessons; and for those nearing exams, extra time was stated as an important factor in support. The belief was also that other people would understand their difficulties more

### **3.3.2 Shame**

At the other end of the spectrum many of the participants experienced shame because of their DCD, either due to their clumsiness or due to processing issues. These were mostly apparent at school. The shame often came from other people noticing and pointing out the participants' shortcomings in critical or disparaging way.

*Yeah - especially when other people notice it and they go 'oh God why are you so clumsy' and stuff like that and I just feel like turning round and just saying why don't you try and overcome this. (Sophie)*

This perception that other people don't understand the impact of DCD increased the sense of isolation. For Sophie it was not only other students who increased feelings of shame, but the teachers, who sometimes lacked understanding and insight into the impact of DCD. They have an additional position of power and their criticisms can feel even more public and poignant.

*Then he was like 'oh we'll just wait for Sophie' and I was like 'oh God'. The whole class and I was feeling like 'oh God' it's just teachers who just make it stand out (Sophie)*

Although the participants expressed relief at the diagnosis or even to be unaffected by it, many were reluctant to talk about it or even disclose it to others. There was a sense that it was still a taboo subject and that disclosing you had DCD could open you up to judgement, isolation or victimisation. Many of the participants emphasised the need for trust before they disclosed they had DCD. Information regarding the diagnosis needed to be restricted in its availability to close, trusted friends and once again the importance of having good friends was emphasised. The lack of knowledge about DCD - what it is and how it can impact individuals was a further reason for caution.

*They might tell other people and then if they don't have the correct understanding they might twist it a bit and people might you know give a different opinion of you so it's important that they know exactly what it is. (Eliza)*

Participants sometimes talked about 'admitting' they had DCD, as though it were a shameful secret. Zac, who claimed not to be especially affected by DCD had not revealed it to others. Zac was clear that public knowledge of his DCD would lead to ridicule - he also uses the word 'disability' rather than 'disorder' or 'difficulty'. For Zac, having DCD makes him a potential target for abuse.

*As a matter of fact I actually haven't gone openly out about it in school. Mainly because a lot, rather a few people in my year not the nicest of people, especially if they found out I had a disability, oh boy would they have a lot of stuff to taunt me about. (Zac)*

### **3.3.3 Ambivalence**

However, responses to a diagnosis of dyspraxia were not always simple or clear. Some participants, such as Ted and Zac, felt that dyspraxia was not important to them and had very little impact on their lives. They used non-emotive language describing their response to diagnosis. Often the participants were not sure how to react or what it really meant for them. There were fears that other people could react awkwardly towards them - perhaps overcompensating with 'helping behaviours' rather than supporting with understanding and making appropriate allowances. Several of the participants were keen to point out that DCD is only a part of their story and should not be over-emphasised. It only affected an element of their behaviour. Crucial to this was the fact that DCD - by definition - is seen as impairment/disorder. Being defined by impairment was rejected as negative and limiting.

*Well yes it affects me and yes it's part of who I am but it's not the main bulk because, I don't want to be defined by it. I guess. I want to be defined by who I am as a person, what I'm good at, what I like and stuff - as opposed to just being defined by just one thing (Florence)*

### **3.3.4 Need for acceptance, understanding and support**

Getting support from others was dependent on an actual understanding and acceptance of DCD and many of the participants expressed frustration, disbelief and irritation that this was often not the case. Having been given a diagnosis that helped them understand themselves, this understanding was often not being utilised in the environment around them. When the wish for others to understand their difficulties, and to be able to respond to their needs in light of this understanding was unfulfilled, feelings of insignificance increased - a sense of not being understood and of being ignored. Sophie describes the different approaches in her school to dyslexia and dyspraxia awareness, which highlight this.

*We had these two weeks in our school which was dyslexia awareness week and following that was dyspraxia awareness week and for dyslexia awareness week they like did up all the library and they put like dyslexia posters everywhere about and they put a book about dyslexia there about awareness and for dyspraxia nobody even knew there was a dyspraxia week it was like, there was like no - all the boards were still on dyslexia and there was nothing there (Sophie)*

Schools inconsistent responses also increased frustration and a sense of neglect. For Eliza the burden of explaining yourself highlighted a sense of being different and needing to be treated differently. It seemed that she was not a priority and her views were not sought. The onus was on her, as the pupil, to make demands. Ultimately, she became so frustrated with having to explain herself repeatedly that she not only gave up asking for help, but also became anxious that she was overly demanding - an 'attention seeker'.

*Nobody ever seemed to talk to me about it. Like people knew in P.E. but the thing is we had different teachers a lot because we had supply teachers and I think the teacher would forget to tell them and they'd forget and in the end you just stopped mentioning it because I don't know, I think people thought I was attention seeking at some times. (Eliza)*

Participants often felt very frustrated that others do not seem to understand DCD. The lack of a clear understanding was sometimes mirrored in responses from the participants themselves, one of whom was unable to give me any definition and some showed confusion in defining exactly what they understood DCD to be. Many of the participants cited their frustration with the low profile and the lack of understanding regarding DCD as a key reason why they wanted to take part in the study. There was an expression of need for other people to understand them and be able to respond appropriately. Even when participants did explain DCD to others,

they were often met with confusion and misunderstanding which added to their frustration.

*Just...accepting it works like that. I remember being I think 11 or 12, because I came from a tiny primary to a secondary school and I was trying to explain to some girl in my class why I got to use a laptop and she said 'yeah but you're so smart, surely you don't need it' and I was like - yeah, it doesn't work like that. It can be frustrating sometimes trying to explain to people. (Florence: 3, 72)*

#### **4. DISCUSSION**

The major theme of a 'sense of otherness' resonates with Lingam et al.'s(2014) qualitative study of young adolescents. However, whilst those findings reflected a finding of 'we're all different', which is an attempt to negate difference - in this study the participants were more likely to embrace and celebrate it. The participants' experiences of developing identity; the on-going process of defining and understanding themselves as they approached adulthood was critical in this research. In his psychosocial theory of development Erikson (1968) refers to the adolescent stage as 'identity vs. role confusion'. It is a crisis of adolescence, where identity is deconstructed - and by implication if the 'crisis' is successfully negotiated, reconstructed. Successfully completing the 'crisis' of this stage would enable growth and develop a pathway to negotiate further life stages. Blakemore & Mills (2014) have highlighted evidence from neurocognitive studies that adolescents are more sensitive to peer group exclusion than adults or younger children and that adolescence is a period of enhanced sensitivity to social signals in the environment. This was reflected in the interviews where the younger participants were often still grappling with identity, peer acceptance and challenges to their sense of self. In contrast, the older participants often expressed more satisfaction with their self-concept and had embraced an identity that constructed DCD in a more positive and accepting light. Adolescence has created a space to step back and develop an

understanding of themselves and their position in society. The reframing of difference was not universal, but it was marked, especially as the participants moved from early to mid/late teens. Reframing 'weird' to 'quirky' is more than using a different word - it indicates that the participant's beliefs and assumptions about themselves have changed. The concept of cognitive reframing implies a change of conceptual viewpoint towards a situation or experience. It indicates a positivity and potential - a rejection of the model solely of deficit.

However, this study was in line with the findings of Lingam et al. (2014), in that there was no indication of an alternative DCD/Dyspraxia identity or self-advocacy movement. Neurodiversity movements, particularly referring to ASD, have challenged society's notion of 'dis-order' and pushed for greater acceptance of diverse experience, thinking and relating to the world (Kapp et al., 2013). Whilst there was some recognition of 'thinking differently', there was little challenge to the medical model of DCD as impairment. The fact that DCD is so little known among the general public - complicated by the use of a different names in the UK (dyspraxia) - and reportedly little understood by others, could be a factor limiting the development of neurodiversity language or awareness. Further complications are related to the diagnostic description of DCD that excludes executive functions, despite the fact that most of the participants in this research referred to problems with memory, processing and/or attention and that research indicates significant problems in this area (Kirby, Sugden, Beveridge, & Edwards, 2008; Purcell et al., 2015; Sumner et al., 2016; Zwicker et al., 2018). Developing an identity behind a concept that has little recognition, is often referred to by a different name and whose official diagnostic description does not reflect many of your difficulties may be problematic.

How participants felt about having a DCD was not simple to untangle and naturally was not uniform among the group - that the responses incorporated relief, shame

and ambivalence indicates the complexity. Taking a phenomenological approach allowed this research to explore complicated feelings that could be contradictory. Marks & Yardley (2004) make the analogy of quantitative studies being like a map that tells you where you are; whereas qualitative studies aim to explore and explain what it is like to be there. Stigma and shame were still very much evident in this research and are a barrier to open communication and understanding. According to Goffman's (1963) work on stigma, difference is only stigmatising if it is so considered by the social group. The initial feeling of relief at having a 'diagnosis' and appreciation of the utility of the label as an explanation was widespread. The sense of not in themselves being 'wrong' but of 'having something' again re-framed the stigma. However, a new type of stigma - that of having a 'disorder' was bestowed which resulted in the participants guarding to whom they revealed the condition and how much information they gave away. This is indicated by the fact that some participants were still not openly identifying as having DCD; and many were careful about who they shared this information with. Participants took steps to protect themselves from shame - whether that was the shame of having a 'disability'; the shame of not being good at sport and letting the team down; the shame of being clumsy and slow, and holding everyone up; of being laughed at or pitied. This shame could be compounded by casual remarks from teachers or hurtful comments from peers.

The impact of bullying has been well documented, and nearly all the participants reported incidents of bullying or social difficulties in primary school or early adolescence. Whilst none of the participants reported active bullying, many of the younger participants still felt excluded and uncertain within their social sphere. Jaspers (2012) found that within teenage years, exclusion was more likely to occur than blatant bullying, and that exclusion often leads to negative self-evaluation. Many of the participants were acutely aware of their lack of status in childhood and

adolescence- as being considered 'unpopular' or the 'middle' kid, who does not make a mark or excel. Particularly for the boys in this study the sense of not being 'sporty' was often explored and it was an often identity in itself; all three of the male participants expressed pride in being 'nerdy' - which typically involved gaming (one of them also claimed to be an excellent baker). In our increasingly technologically driven world, the words 'geek' or 'nerd' have become an alternative status symbol and gaming levelled the playing field for the male participants with DCD, as they felt able to compete at a similar level to their friends in the virtual realm, whereas in the physical realm this was described as difficult or they could be excluded. For the girls the techniques of finding status (something they regarded themselves as good at) were more diverse - ranging from creative writing, to extra-curricular activities such as climbing, running and swimming.

All the participants reported that they expected and needed a supportive structure, especially at school. They expressed frustration that this was often not realised and that, in line with previous studies, knowledge and support was often not evident (Camden, Wilson, Kirby, Sugden, & Missiuna, 2015). Passing the burden of repeatedly seeking help on to young students must be considered a failure of the system. Knowledge of DCD was disappointingly still reported as low. There was frustration that others did not understand their experience - that they could feel judged as 'lazy' or 'attention seeking'. This tallies with earlier findings that DCD is very much unknown or misunderstood among the general public and that responses from educational professions are considered poor (Novak et al., 2012). It is naturally disappointing that this situation is continuing. Although some of the participants identified exemplary teachers or support workers, many reported issues of a systematic failure of support that was seen as typical of their school experience, even involving head teachers. Many of the participants gave up seeking help out of frustration for this reason. Furthermore, many participants avoided discussing their

difficulties - claiming that their peers often did not understand or even could not believe that they struggled, which caused further frustration. Participants reported feelings of frustration and hopelessness due to repeatedly needing to ask for help or being promised help that does not then materialise. Miyahara & Piek's (2006) found that self-esteem was impacted to a greater degree among children with minor disabilities and hypothesised that this is in part due to the invisibility of the problems and hurdles faced influencing the lack of empathy and support received.

Developmental disorders are not simple concepts - understanding them and their impact on the child/adolescent takes effort - both on the part of the individual and the school - who need to implement and maintain adequate training of their staff. Furthermore, the impact of DCD is broad and varied. There is no one-size-fits-all solution and teachers and schools need to be up to the task of supporting students in the school environment. Sports lessons provide an ideal example of this complexity. For some participants, these lessons could be experienced as humiliating and shaming: and yet they were forced to take part at the same level as other children. It would be hard to imagine teachers treating a visually impaired child in the same way. However, the level of impairment with DCD is not always easy to determine, this is problematic for teachers to assess. In contrast, one or two of the participants enjoyed sports and most participants were of the opinion that it was important to 'give it a go' and not just give up. That it did not matter if you weren't any good at it, the important thing was to try. Here we see the complexity that dealing with DCD involves for professionals. On the one side there is the risk of shaming and humiliating an already fragile and disheartened child and on the other side there is the risk of teaching a child to give up and not participate.

Sport is significant in that has the potential to pose serious threat to the adolescents' status, particularly boys (Piek et al., 2006) and as it is a subject that may have an

impact on future physical health. Sports teachers bear a critical responsibility towards students with DCD and need to be supported in this by adequate training.

Adolescents are old enough to understand and discuss these issues. It is the adolescents themselves who understand more than anyone else where the boundary lies between 'giving up' and 'not being able to do it'. Historically, children and adolescents have been left out of the research (Magalhães. et al., 2011), however in this study most of the participants were clear about how having DCD impacted them and were more likely to express determination to 'give it a go' rather than to give up. Poorer levels of physical fitness and attitudes to sport have been noted in the literature (Cairney et al., 2005; Meek & Sugden, 1997) with Hands and Larkin (2006) arguing that educators and other health professionals needed to find ways to reach this group and develop physical fitness. However, in this research, disinclination towards sport as practised in school, was in the majority. This is a disappointing finding, considering this aforementioned research is between 10-20 years old - it seems that little has changed to impact the attitude of children and adolescents with DCD towards sport or that much effort or imagination has been put in place to consider how they may be involved in sport and encouraged to develop health-promoting activities.

As a qualitative study, results are not directly generalisable but do support previous findings - disappointingly in light of lack of knowledge and support - and illuminate the potential for further support in successfully re-framing DCD as a more positive facet of identity. Further limitations lie in the gender imbalance which disproportionately favoured females and which may have impacted responses and possibly in the supportive nature of the participant's homes (as all were recruited through the Dyspraxia Foundation) - which may be unrepresentative and unduly increased resilient responses. Whilst the age range from 11-18 represents a fuller picture of adolescence, it may impact the homogeneity of the findings.

Future research could consider ways of increasing societal knowledge and understanding of DCD, so that young people are not given the burden of explaining it to others; ways of encouraging a more collaborative approach between adolescents and schools regarding support; as well as further understanding the means by which some young people are able to develop resilience, whilst others struggle.

## **5. CONCLUSION**

This research provides a useful insight into the journey through adolescence for participants with DCD. Participants often understood themselves as different to peers; however, during adolescence many were able to re-frame difference in a positive light - seeing it in terms of uniqueness, creativity or defining themselves proudly as a 'nerd'. This highlights the importance of developing a positive alternative identity to that of impairment. The response to having DCD was complex and encompassed relief, shame and ambivalence. Most of the participants reported social difficulties in early life, including victimisation and exclusion. However, later in adolescence participants often expressed satisfaction in their social relationships and a heightened experience of the meaning of friendship and loyalty. The study highlights that adolescents with DCD feel their difficulties are often unrecognised and that there is a lack of knowledge regarding DCD within the general population, as well as within the school environment where support can be inconsistent.

Participation in sport was still a difficult issue for many of the participants and could be associated with humiliation and stigma. Although many of the findings were positive in terms of resilience and coping, the additional stress of managing the impact of DCD and the high incidence of previous bullying should stand as a warning of possible future difficulties; as studies have shown that victimisation may have long-term negative impact of emotional wellbeing.

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## **SECTION C: CLIENT STUDY / PROCESS REPORT**

Not being 'normal'

A clinical study using intersubjective psychotherapy with a male client experiencing shame.

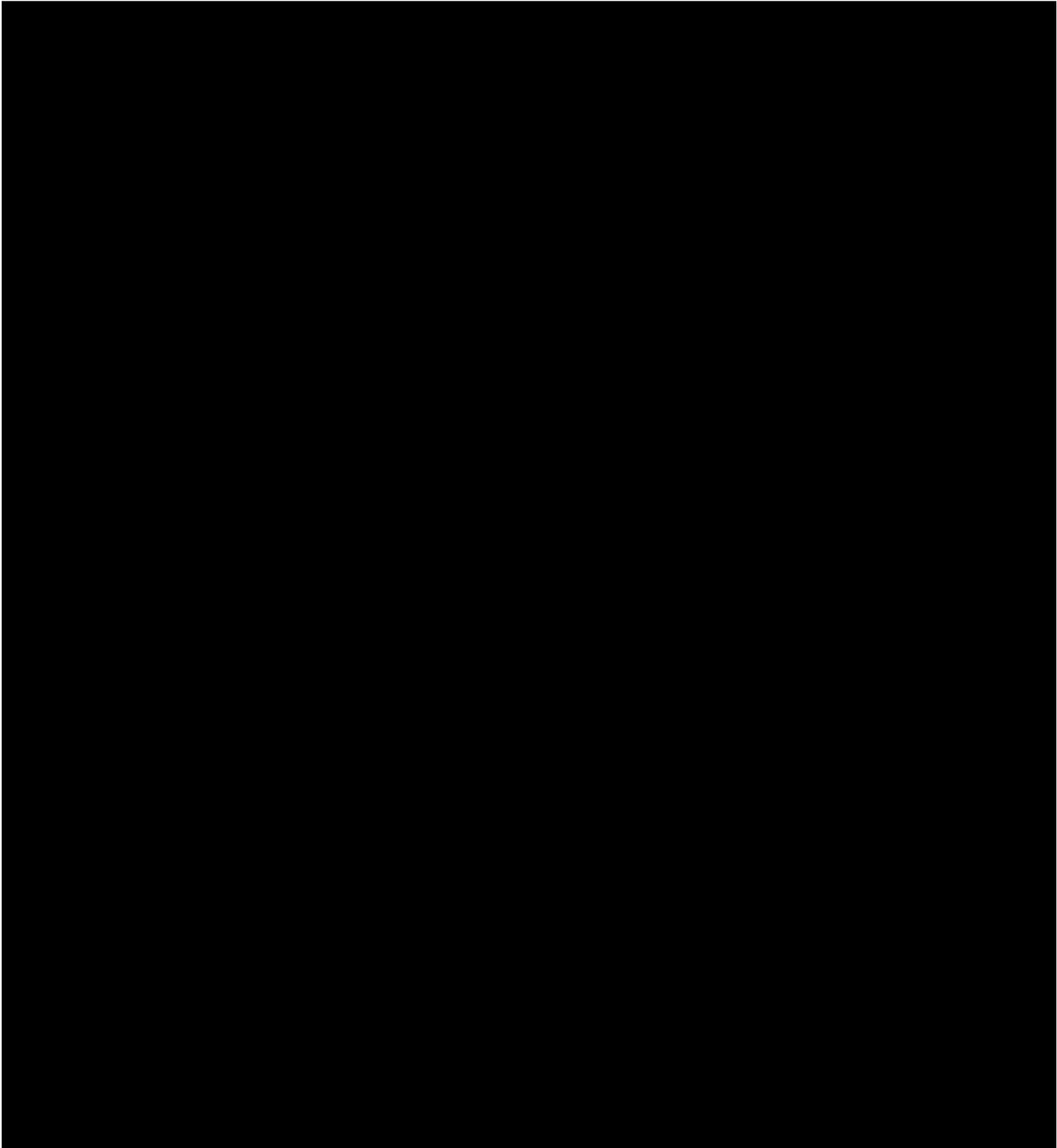
**THIS SECTION HAS BEEN REDACTED  
FOR REASONS OF CLIENT  
CONFIDENTIALITY**

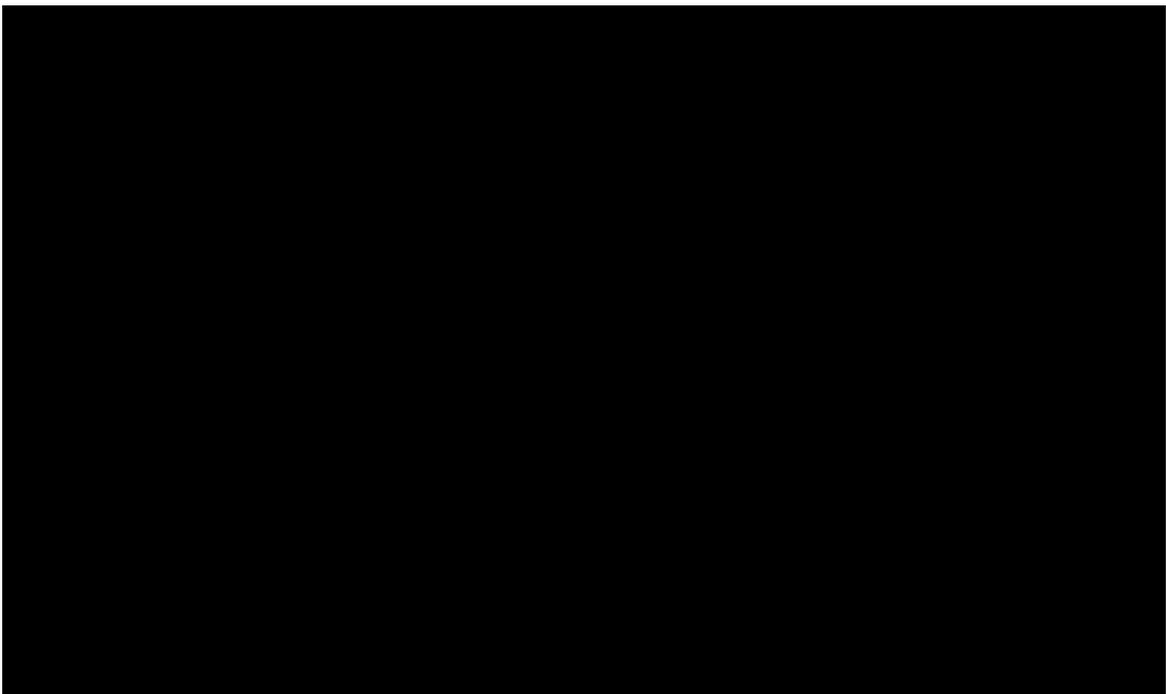
## CLIENT STUDY / PROCESS REPORT

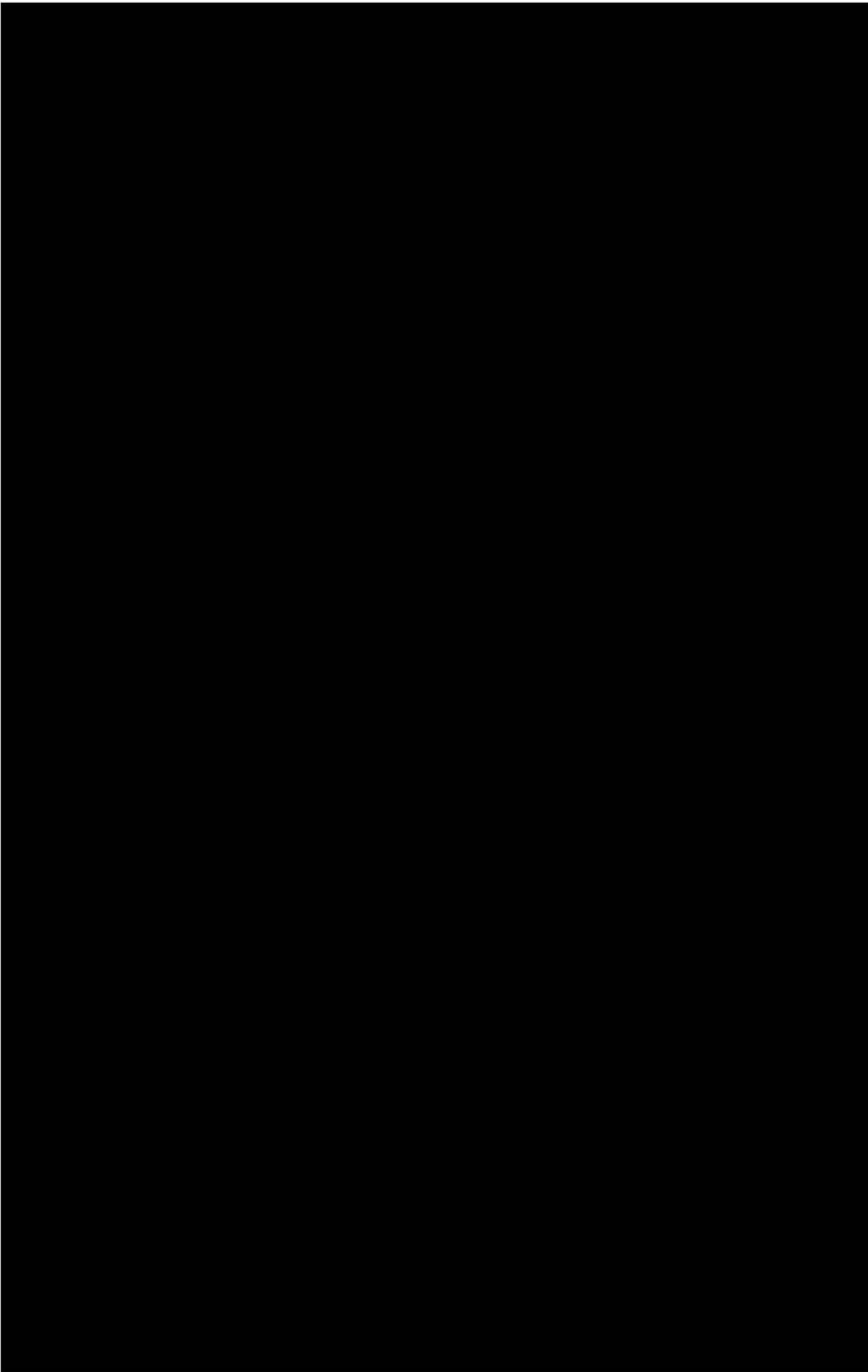
*(\*Identifying details have been changed to protect anonymity)*

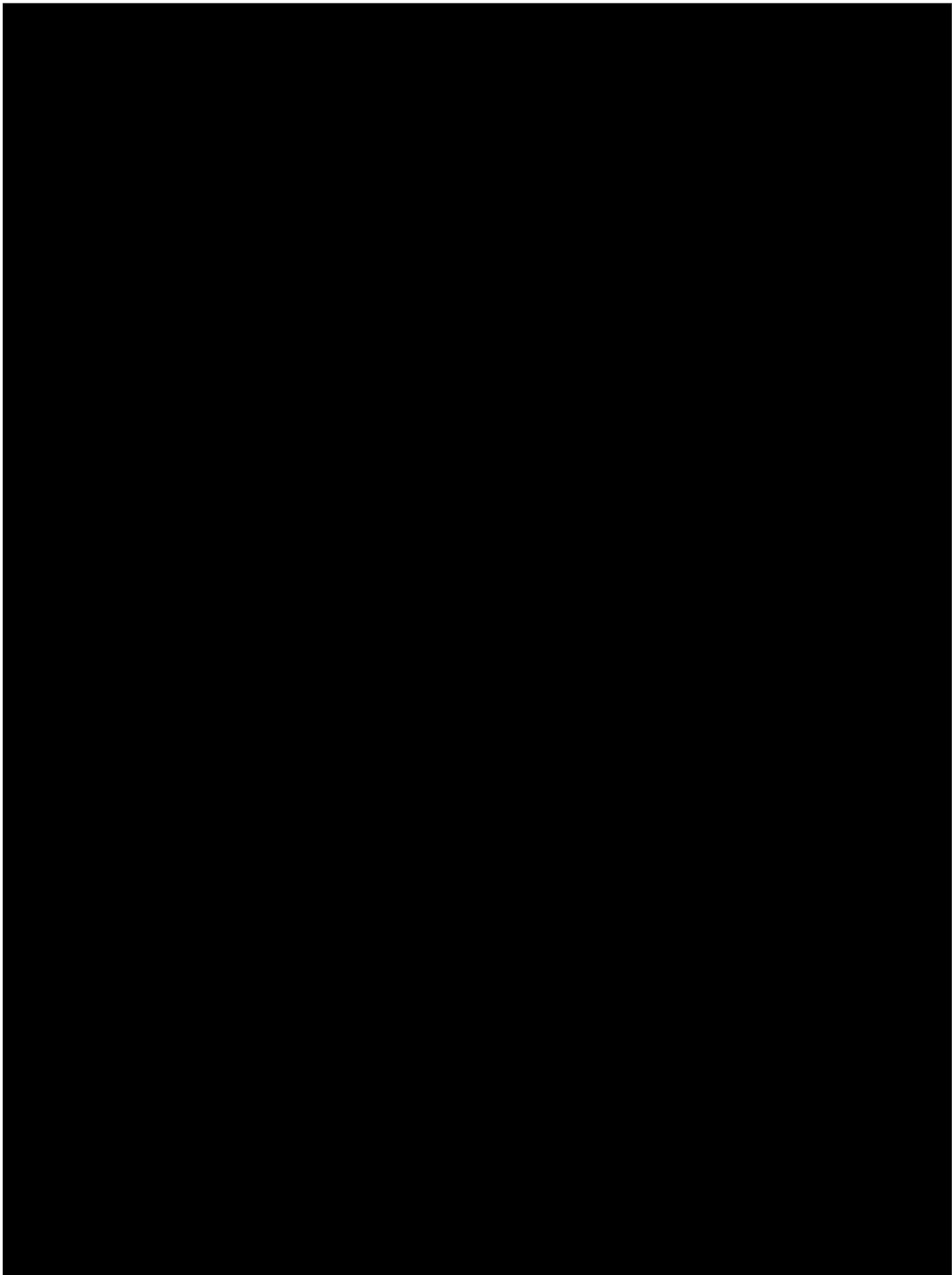
### **Introduction**

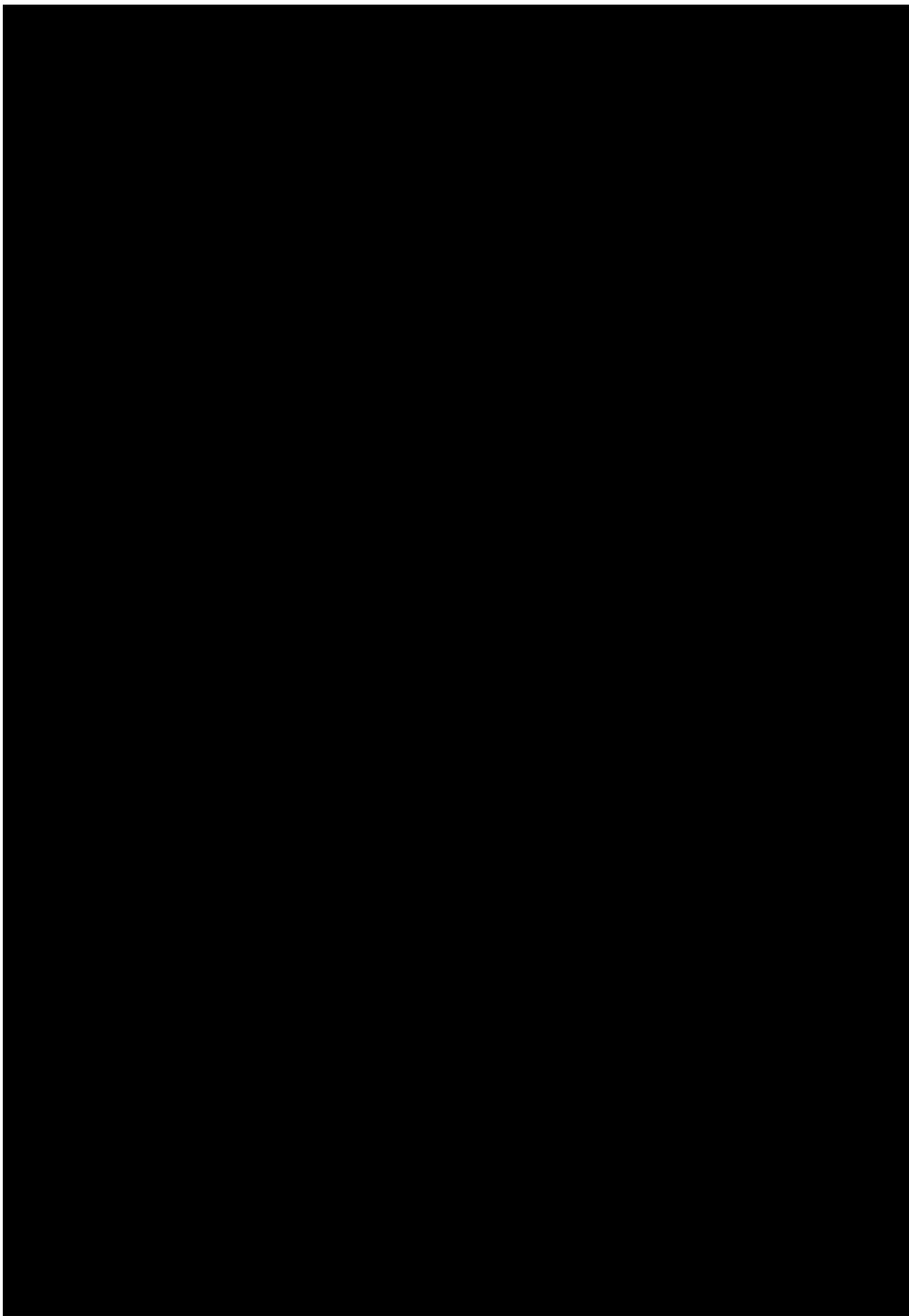
*Shame becomes inevitably bound up with the process of identity formation, which underlies man's striving for self, for valuing, and for meaning. The experience of shame is a fundamental sense of being defective as a person, accompanied by fear of exposure and self-protective rage. (p.568) (Kaufman, G., 1974)*

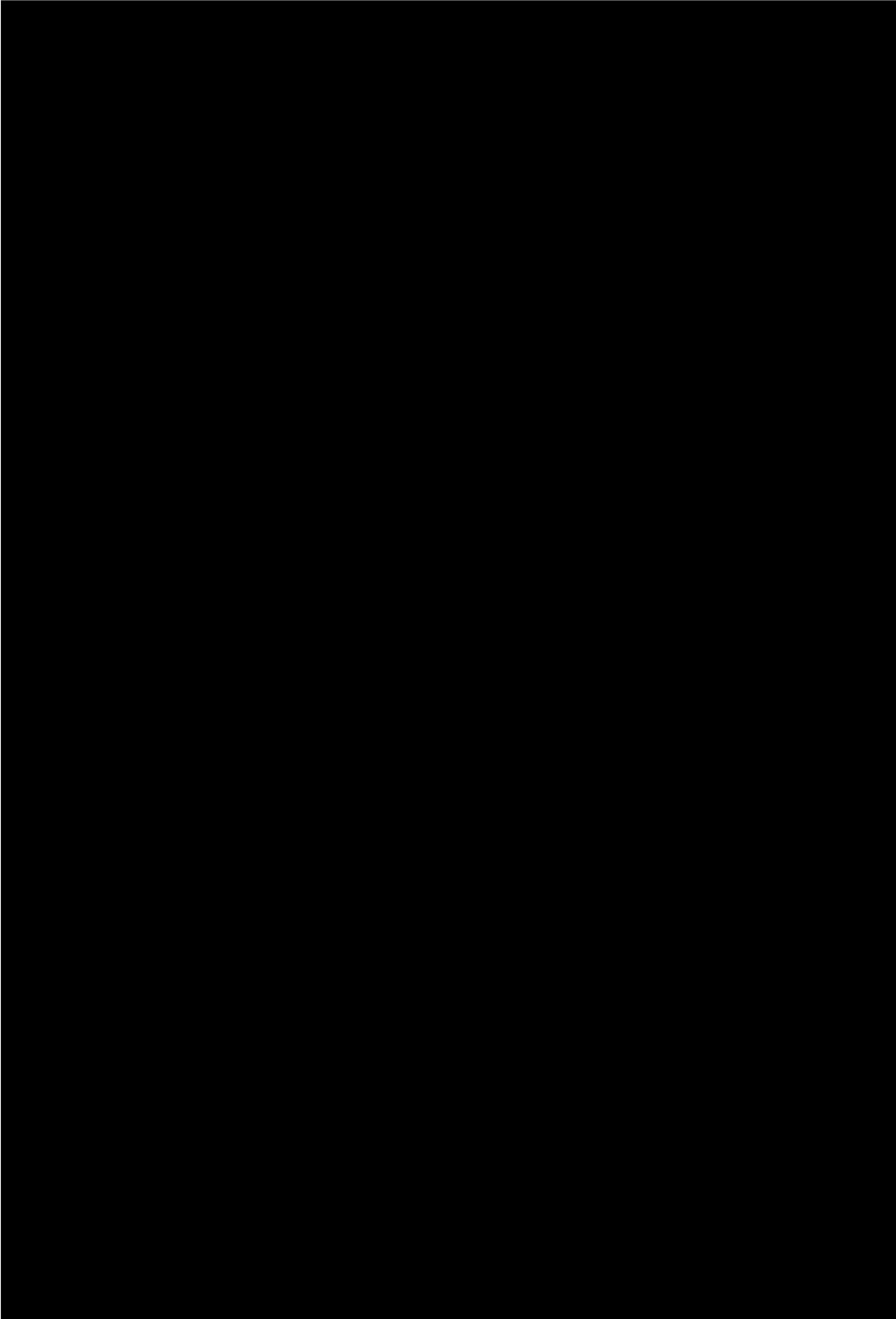


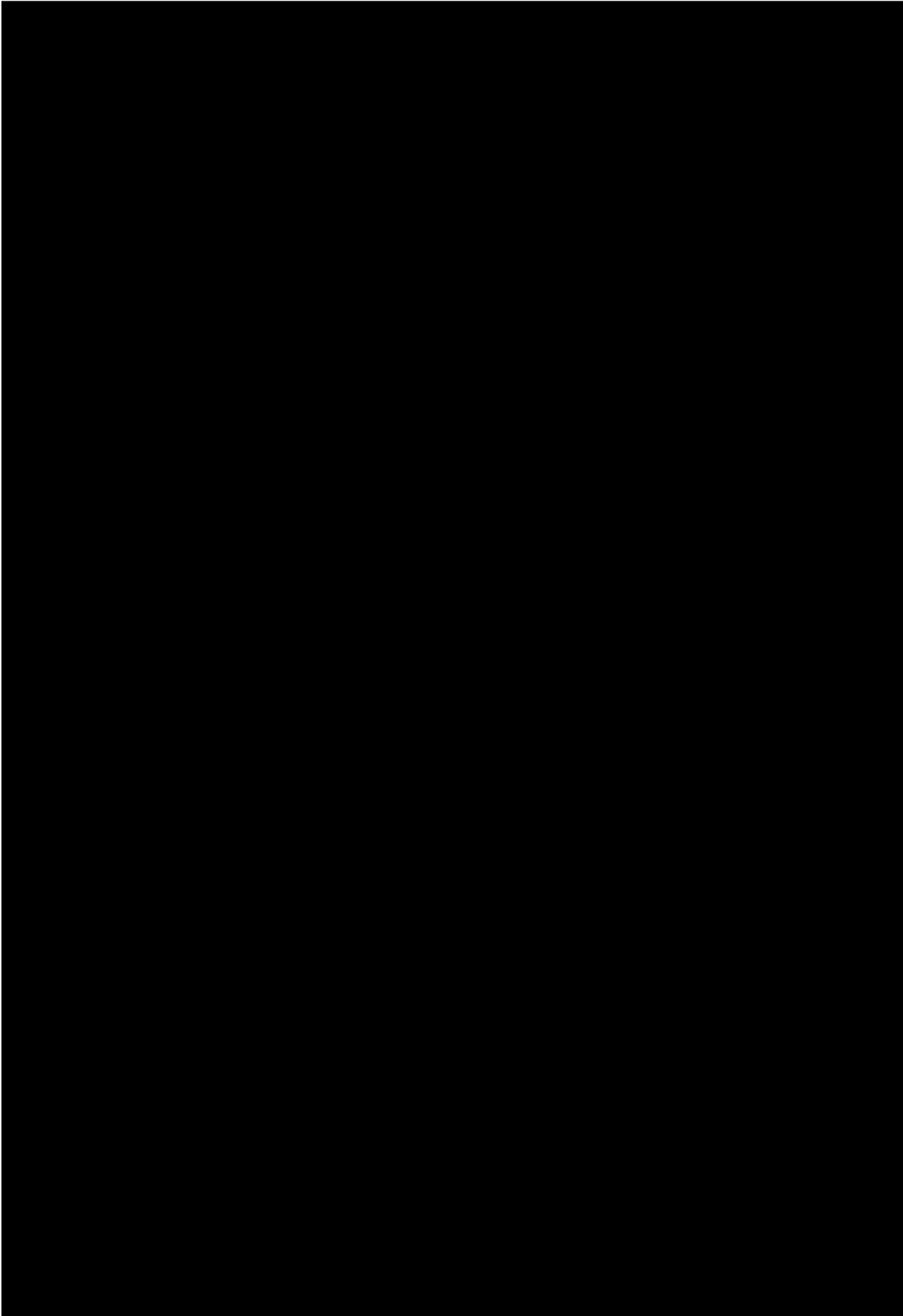




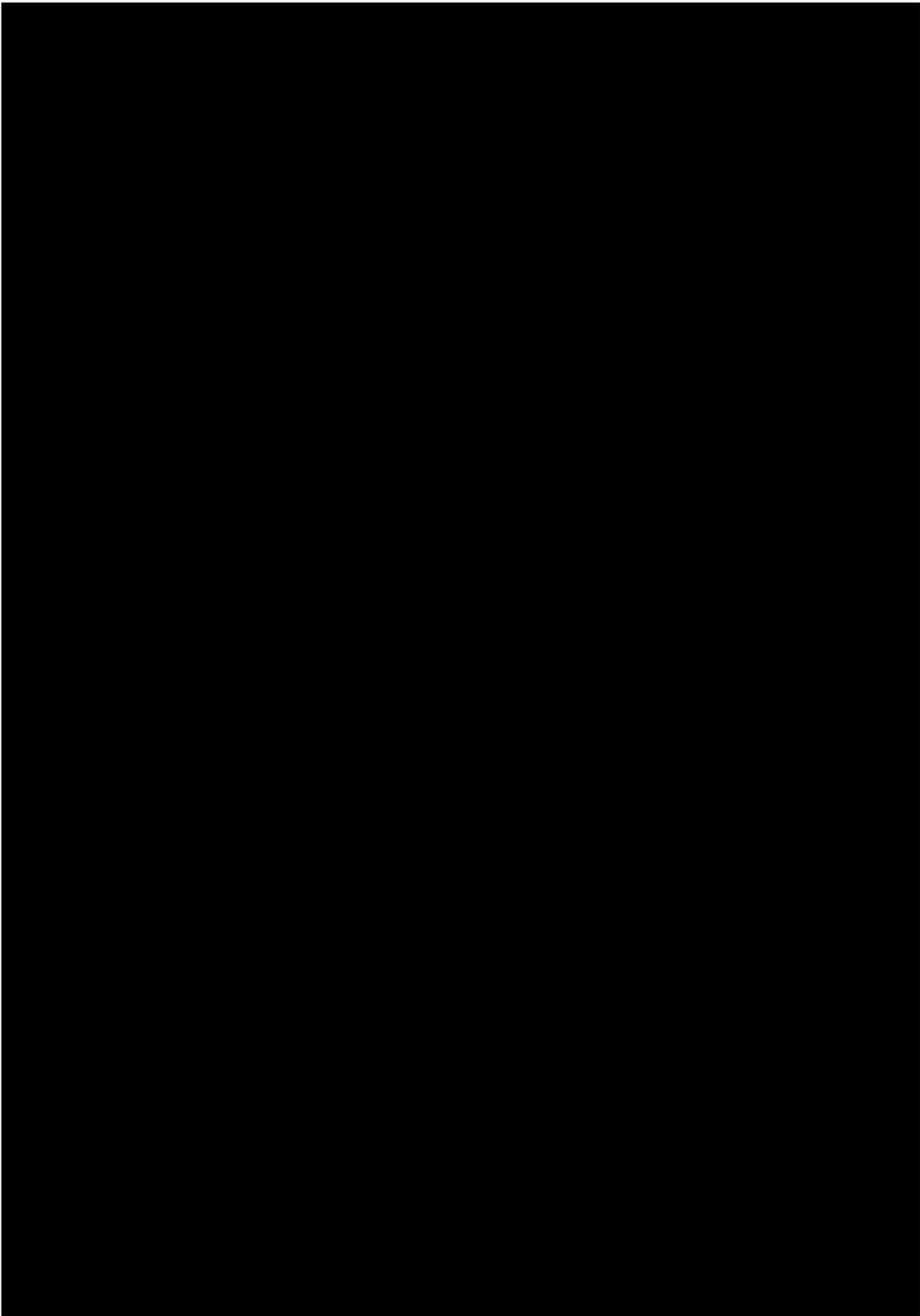


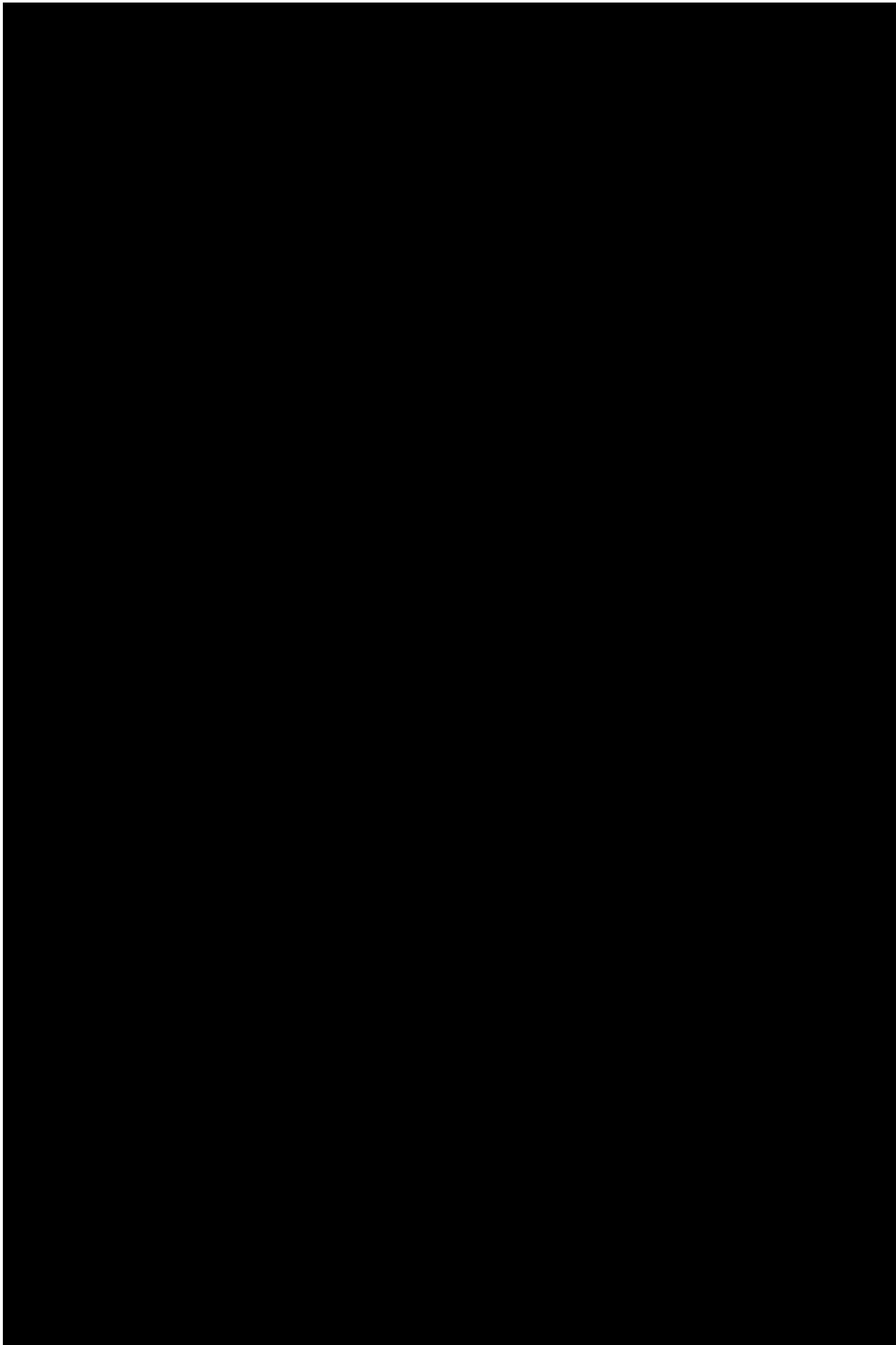


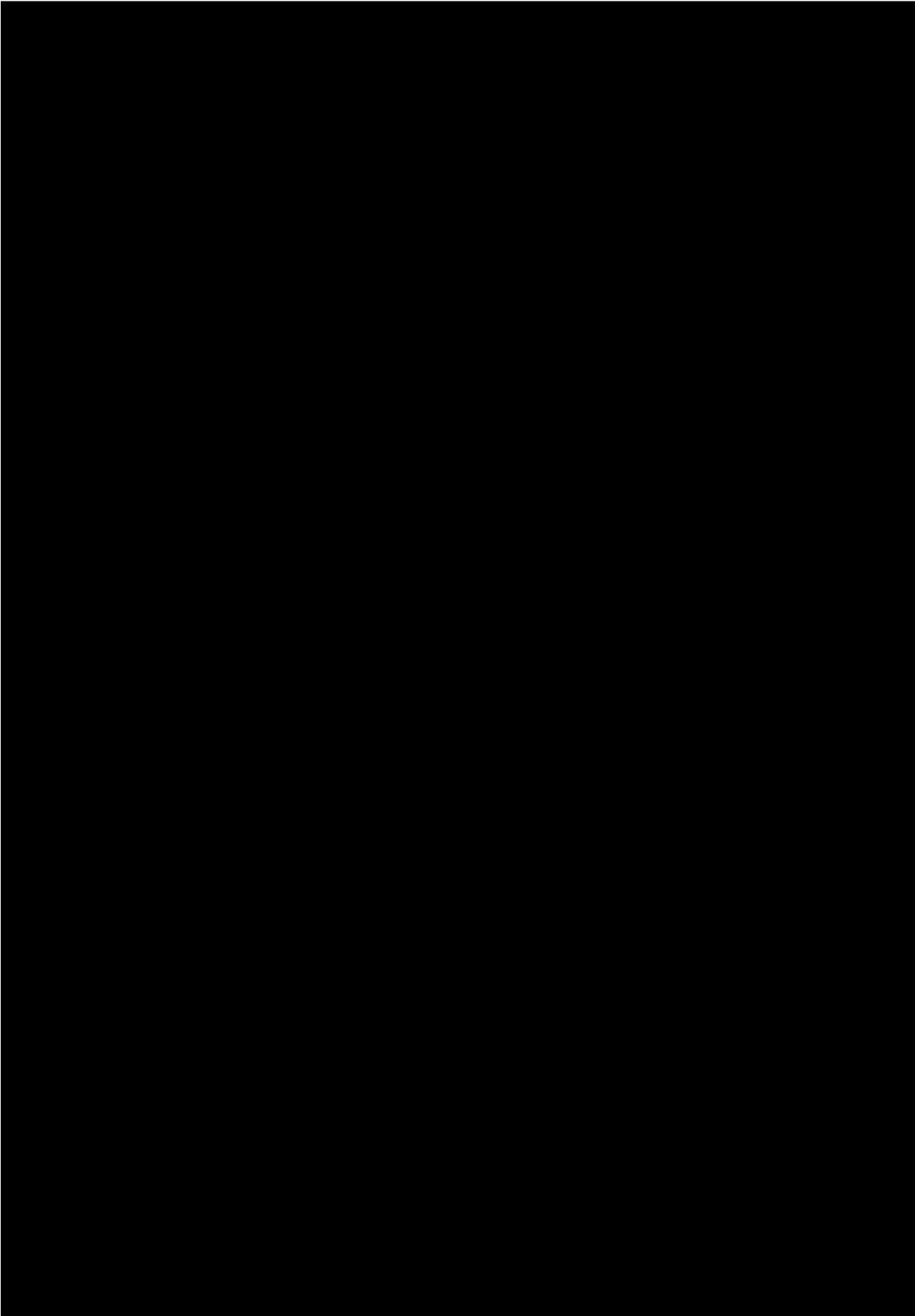


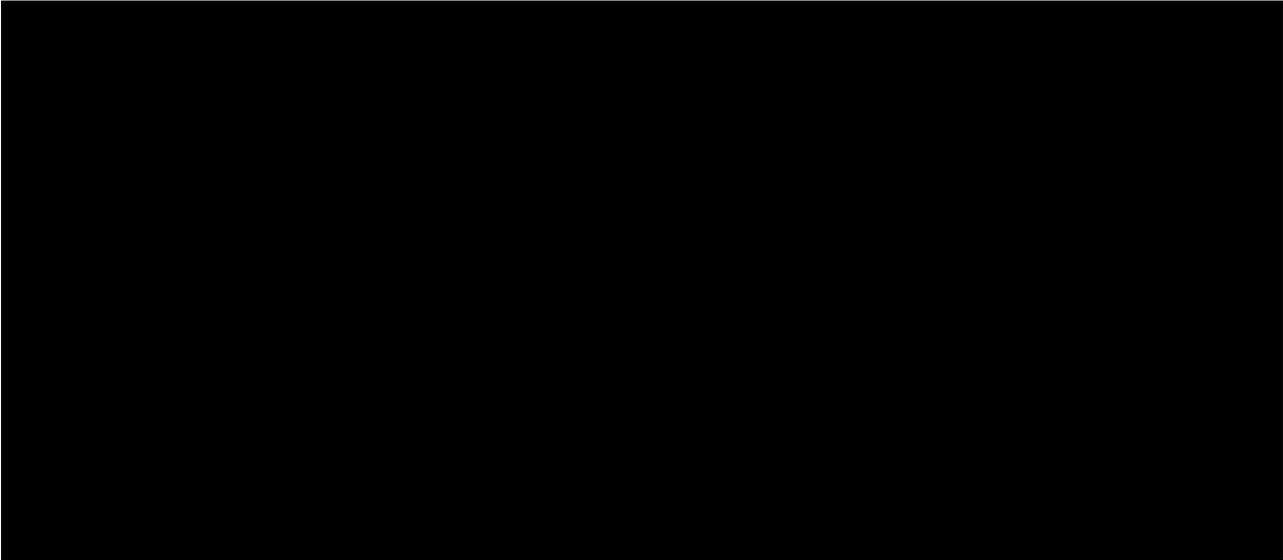


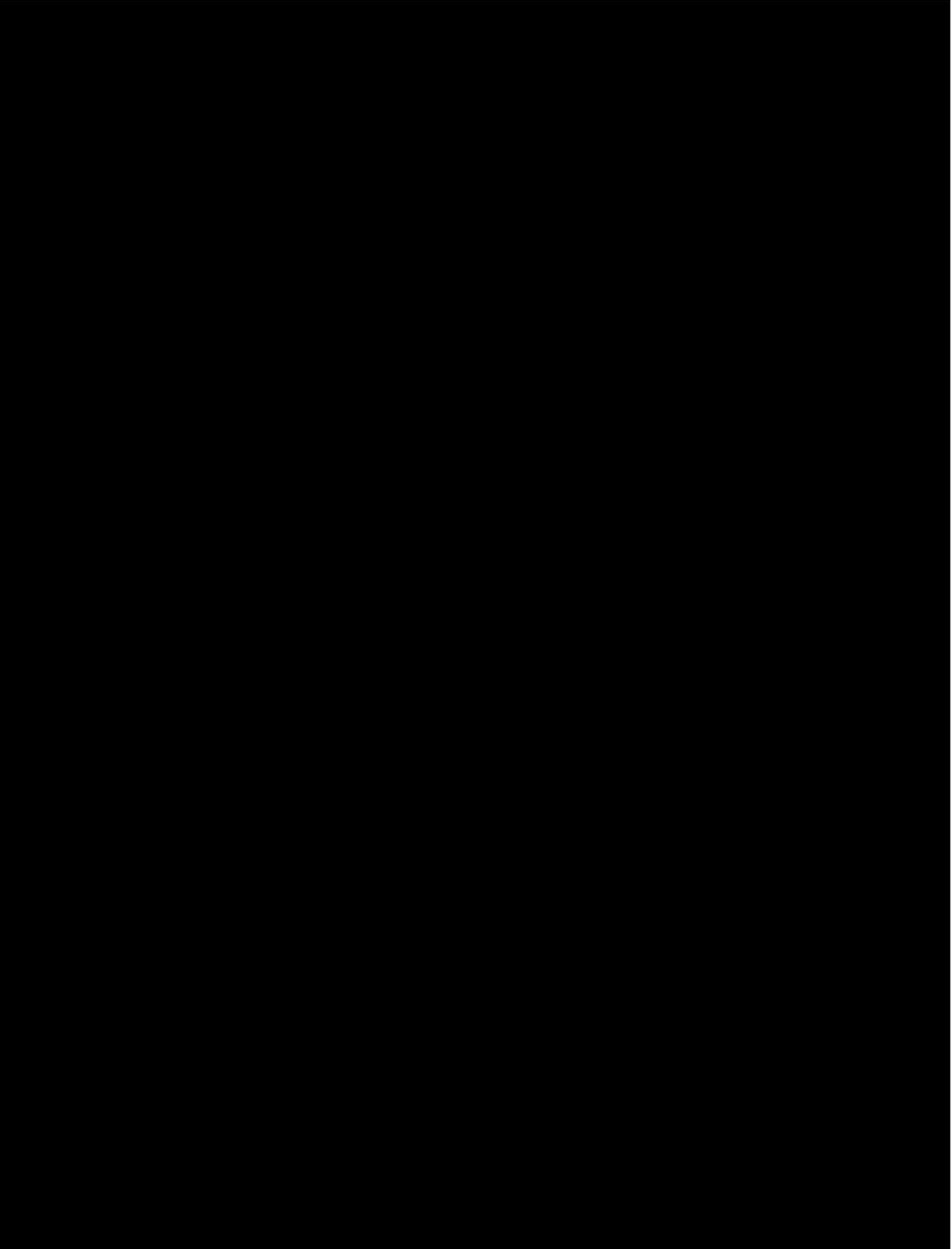


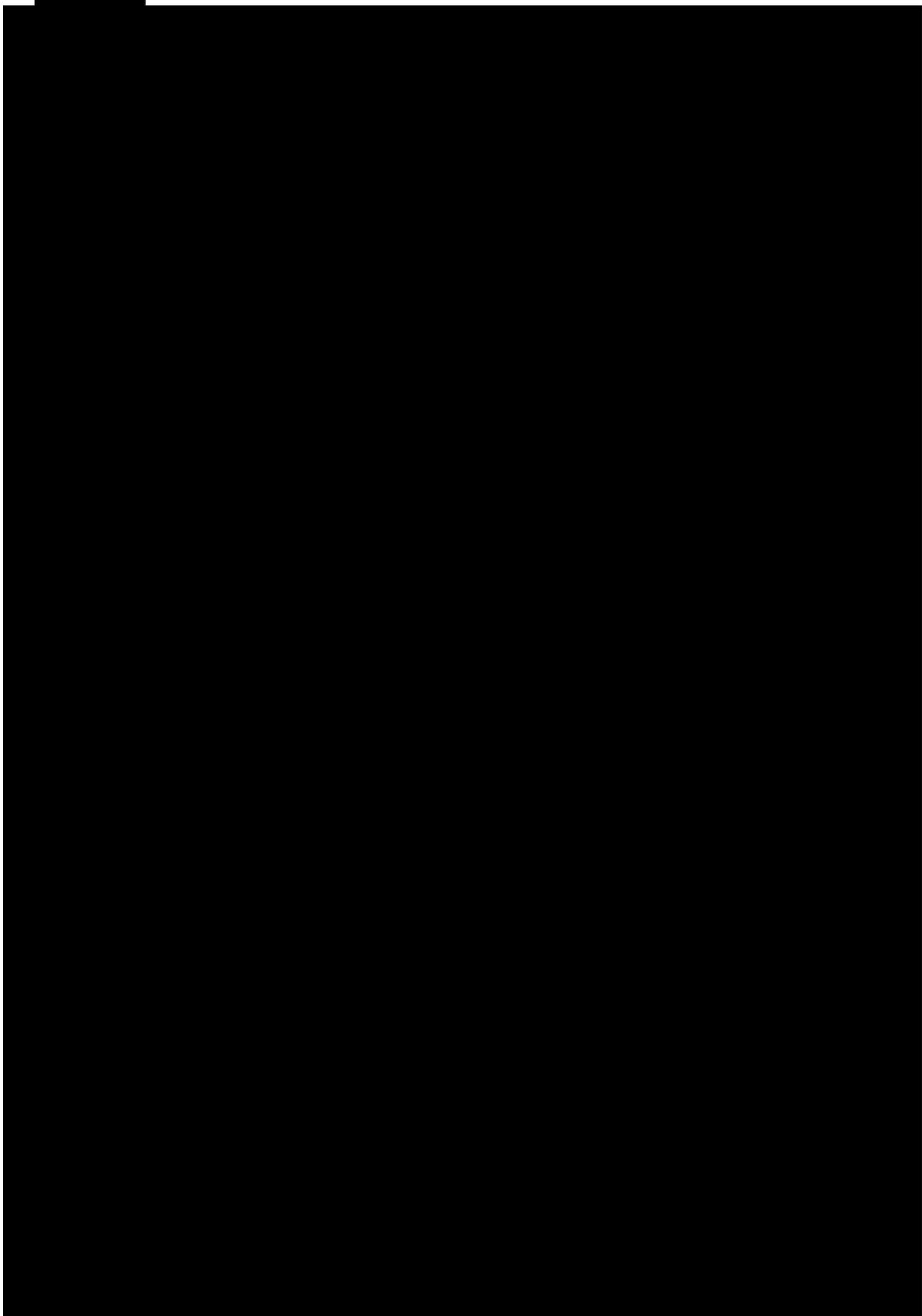


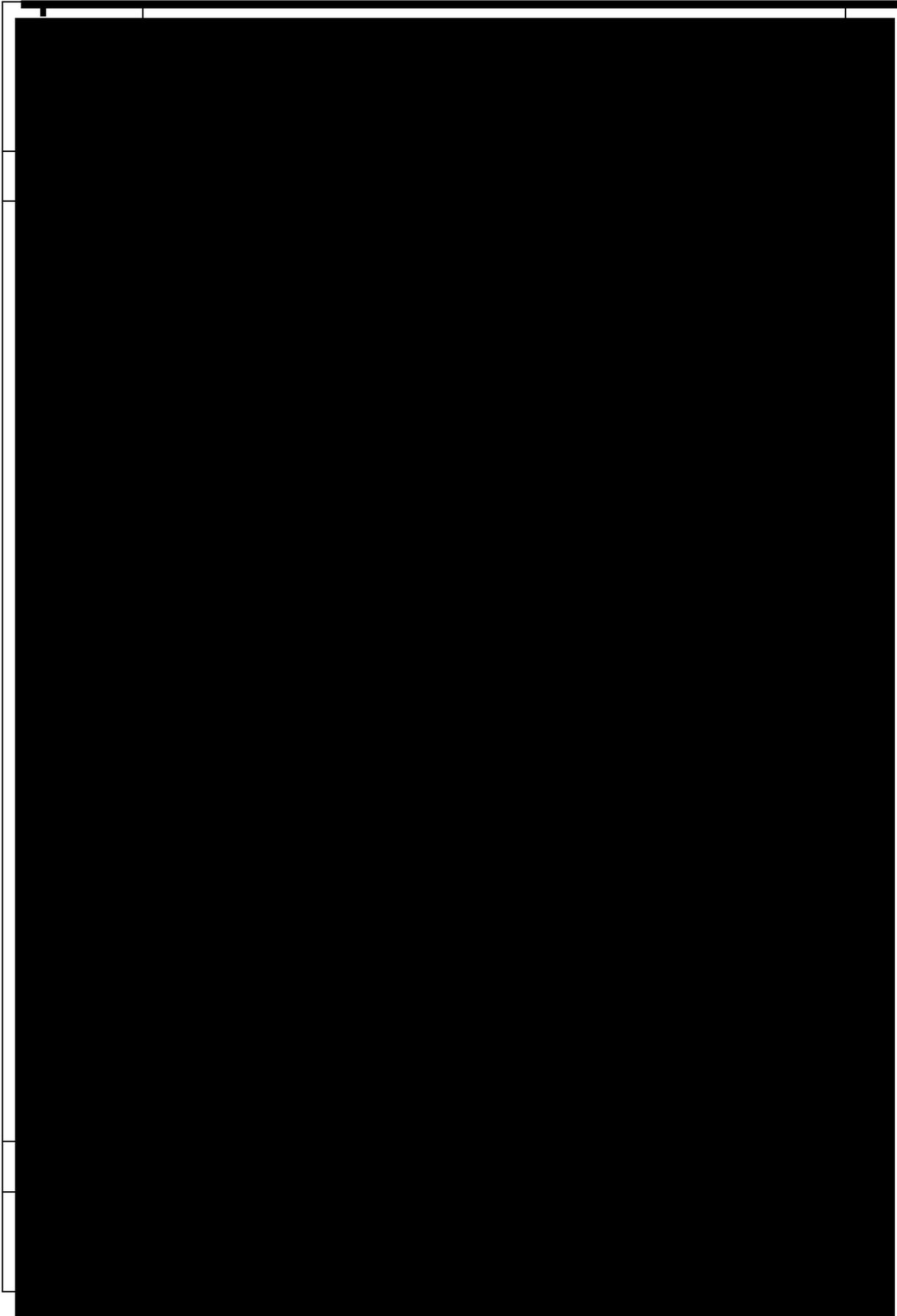


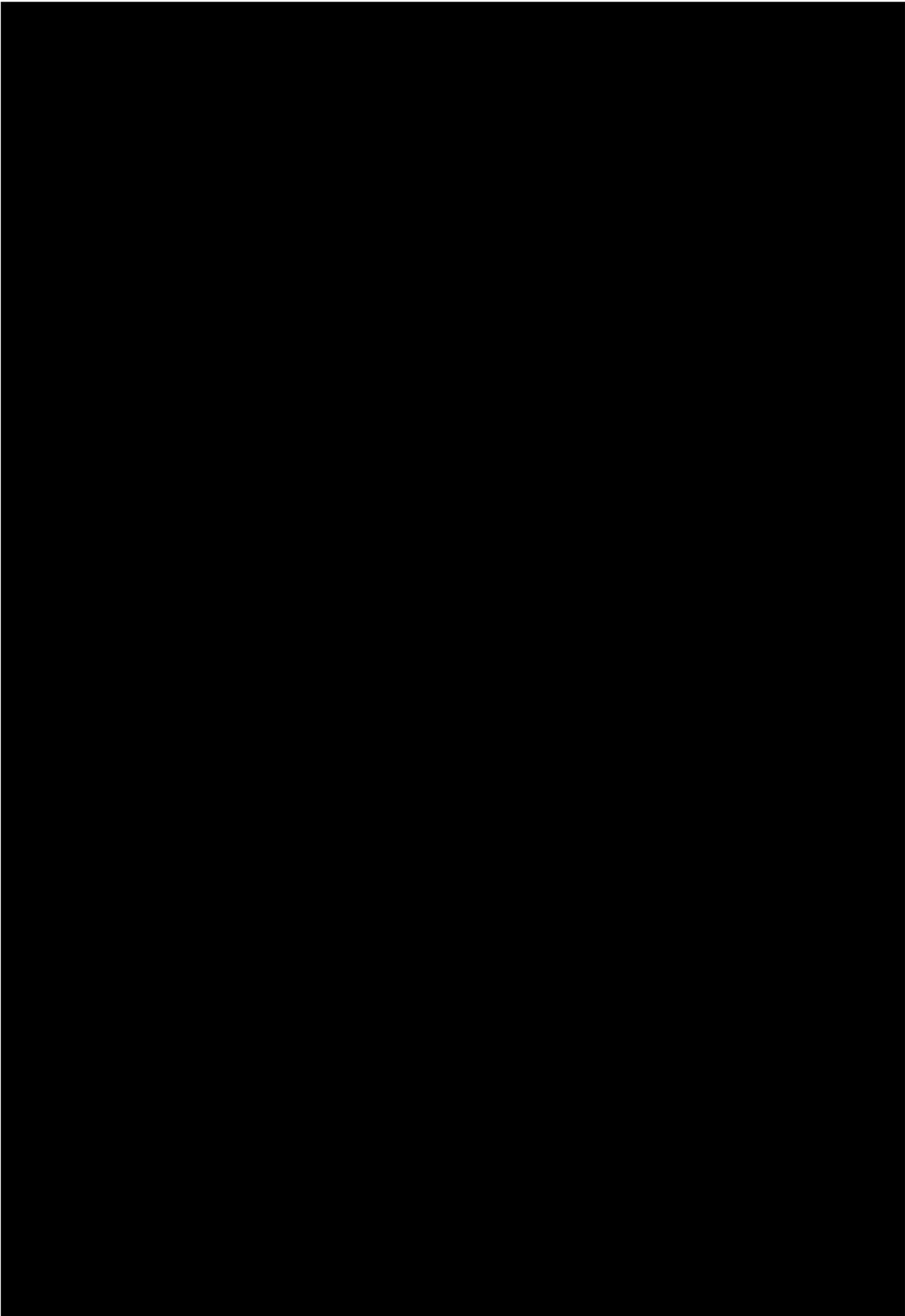


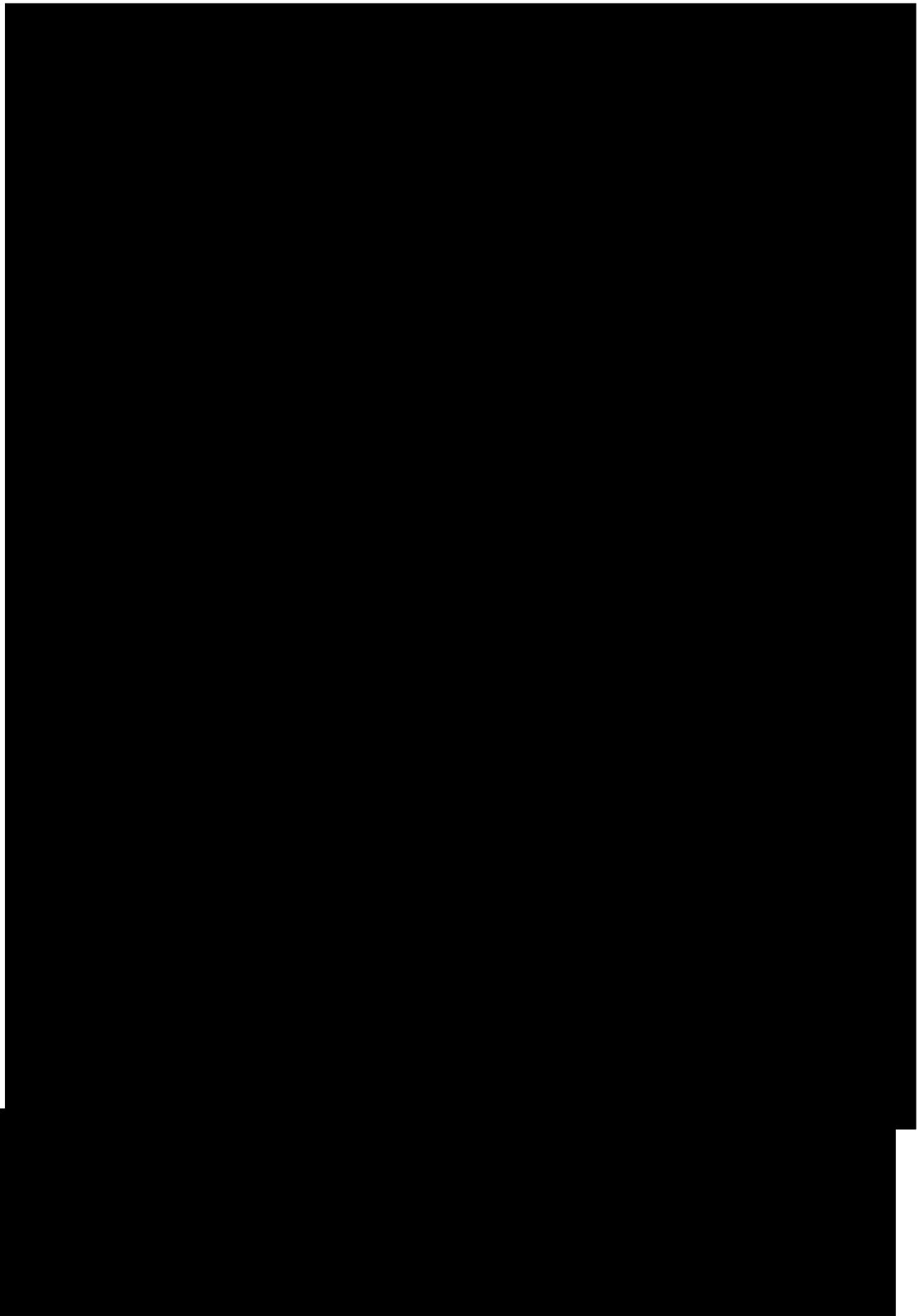


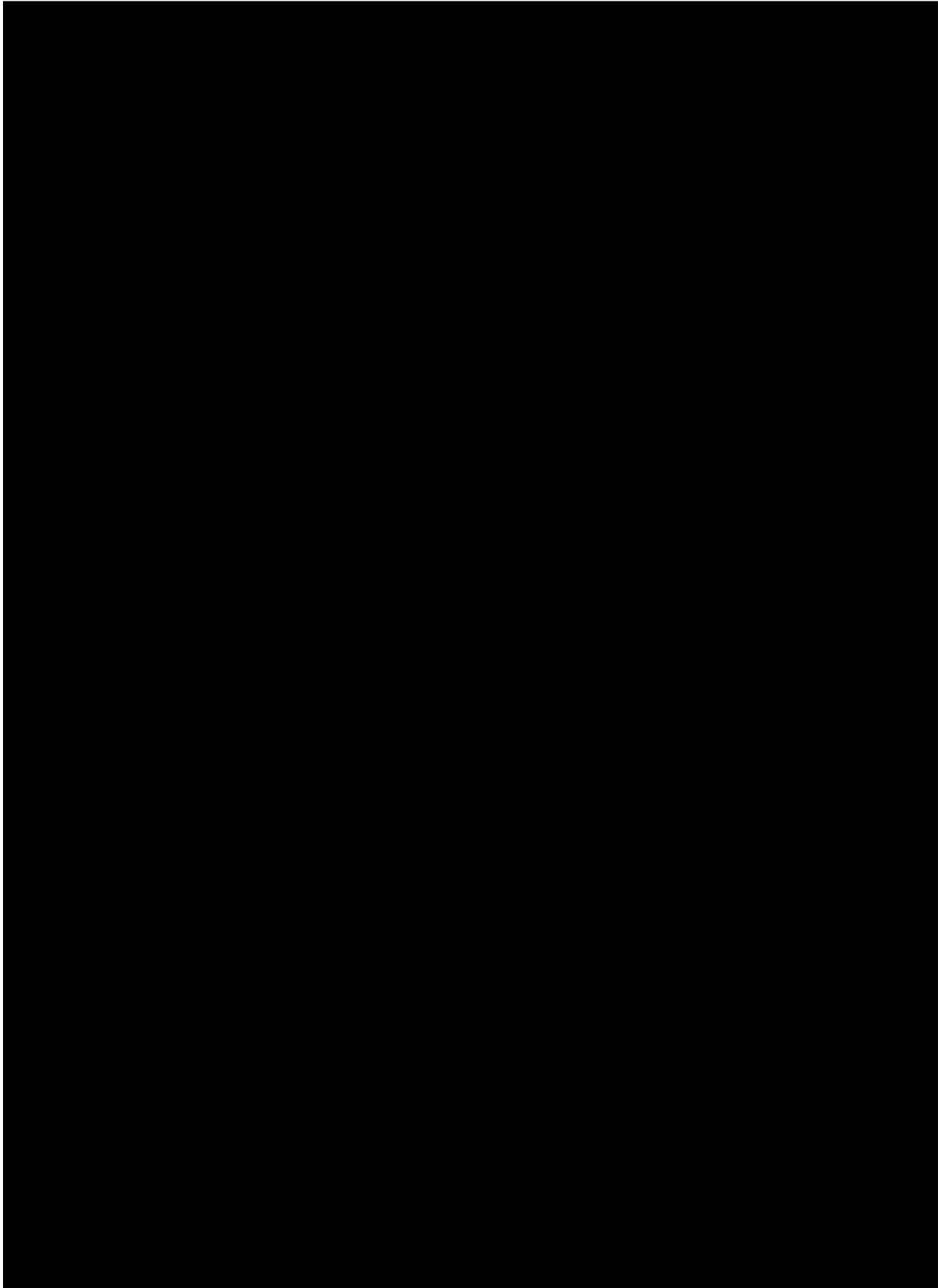


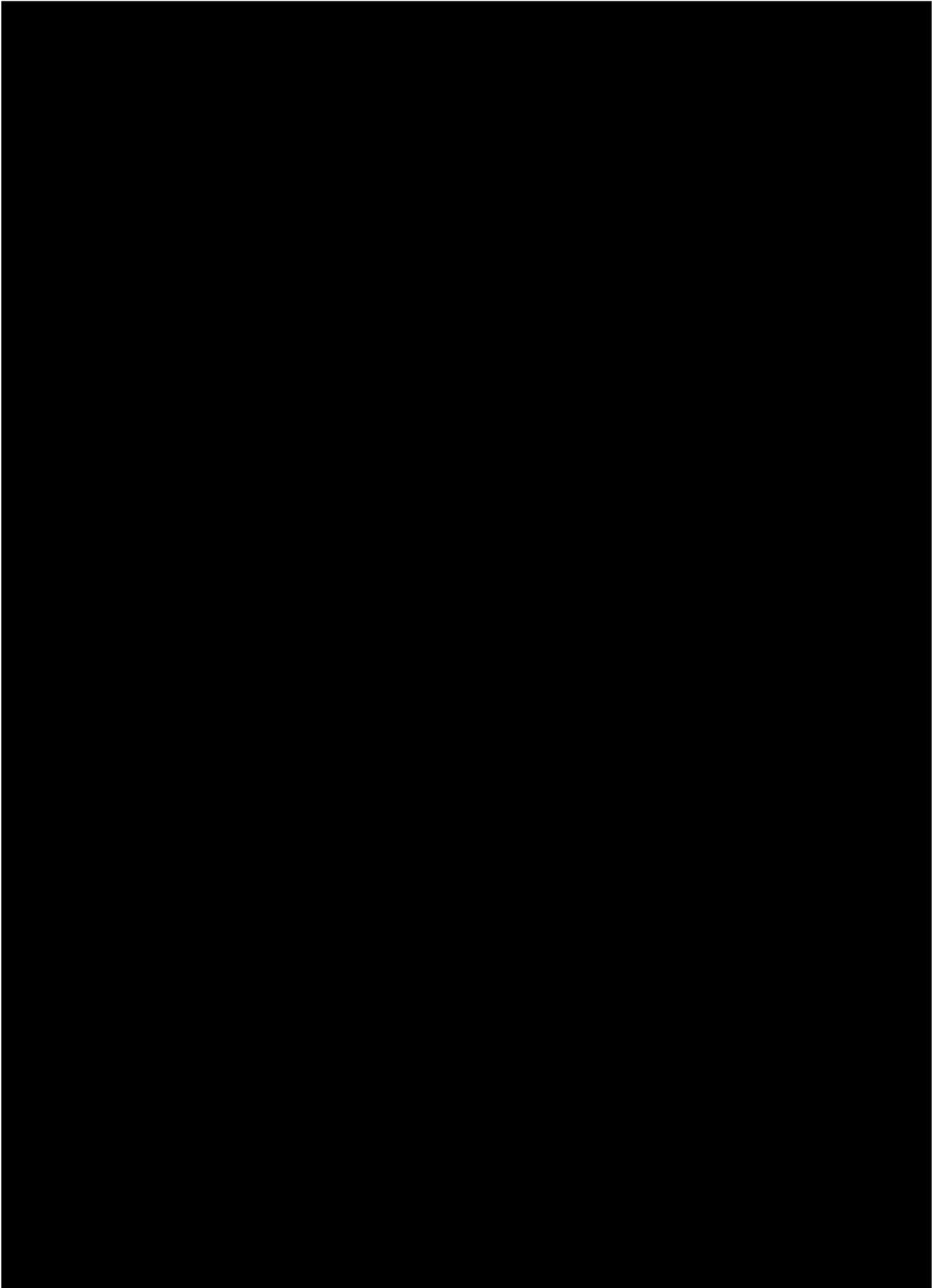


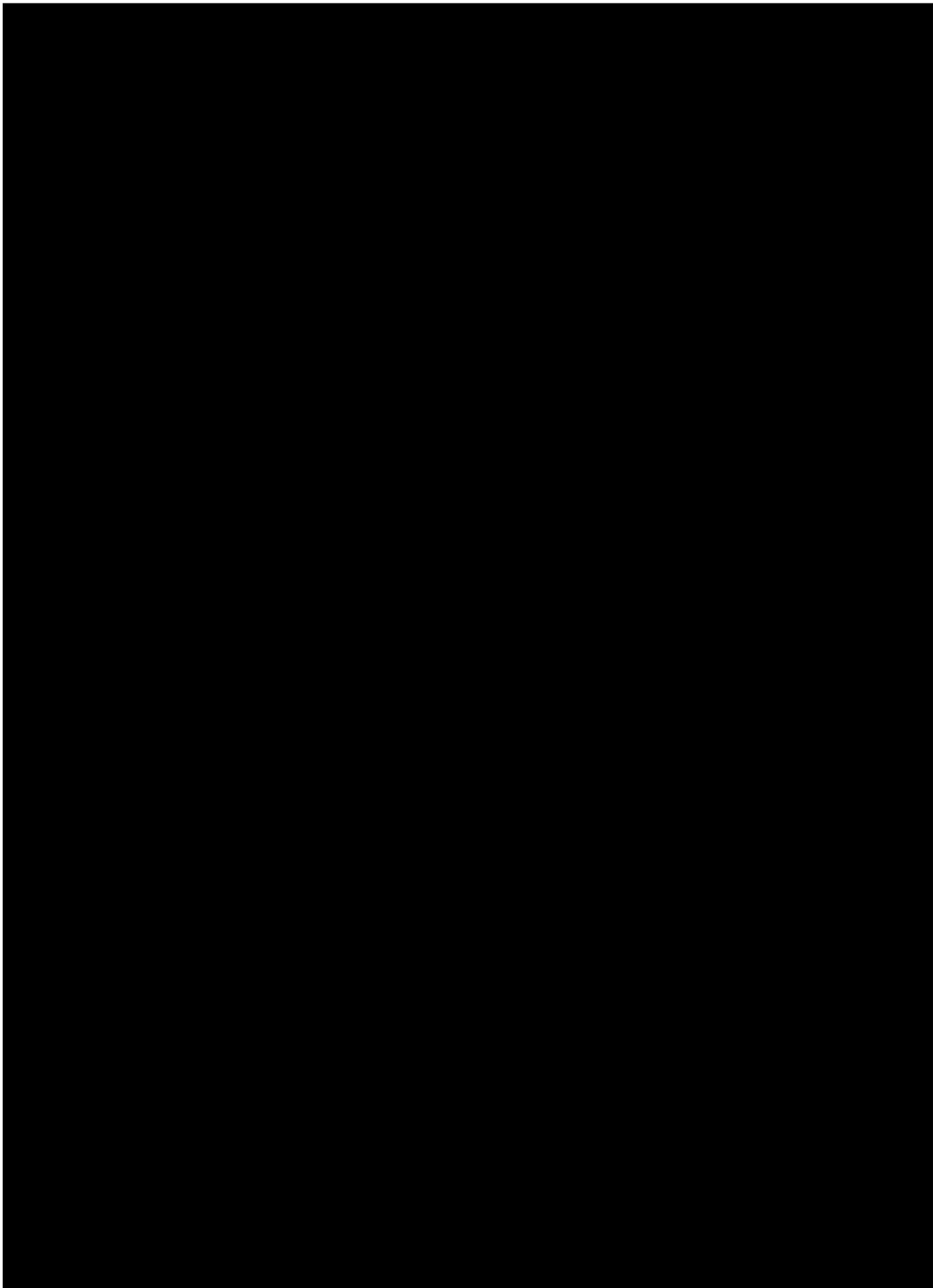


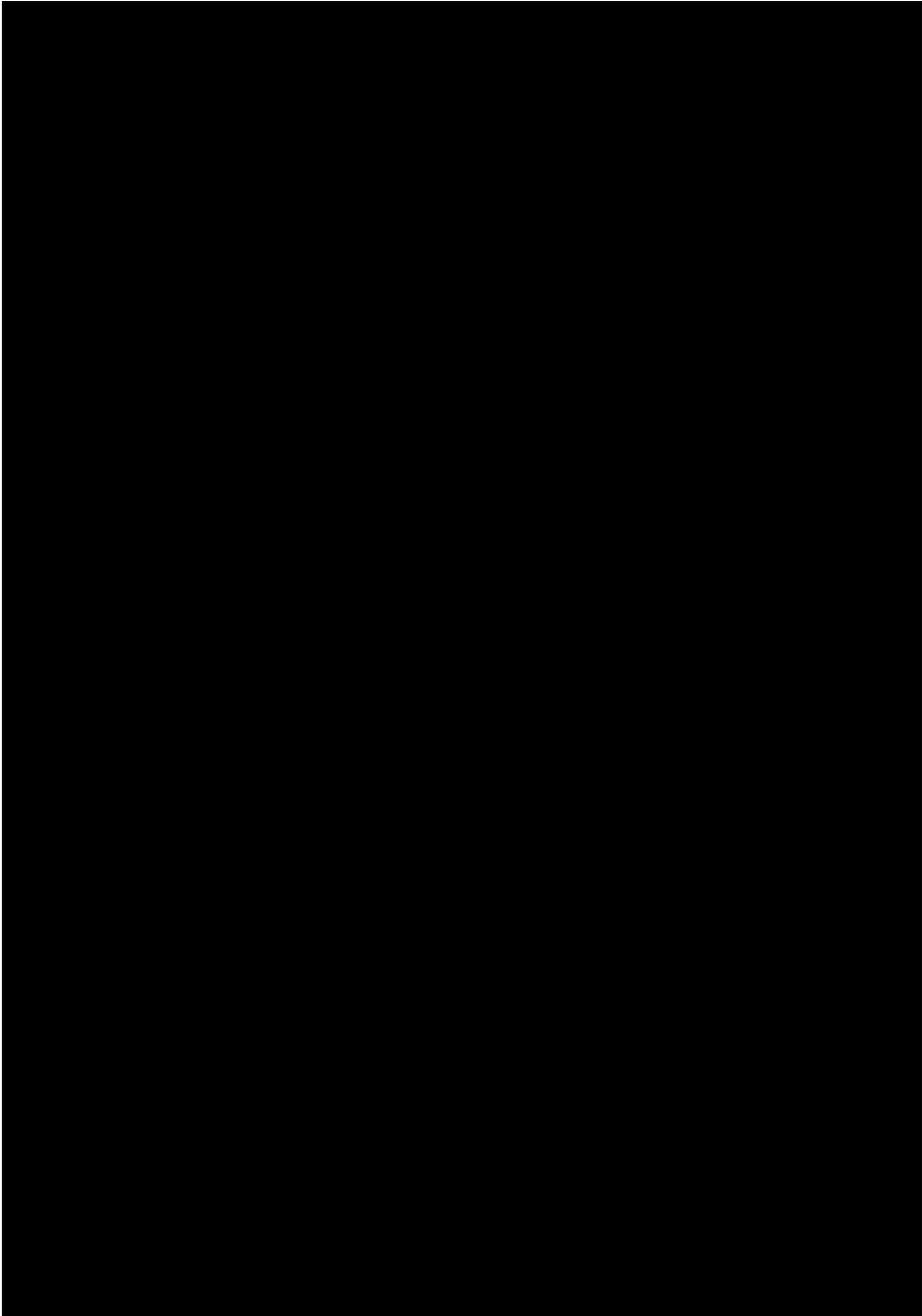


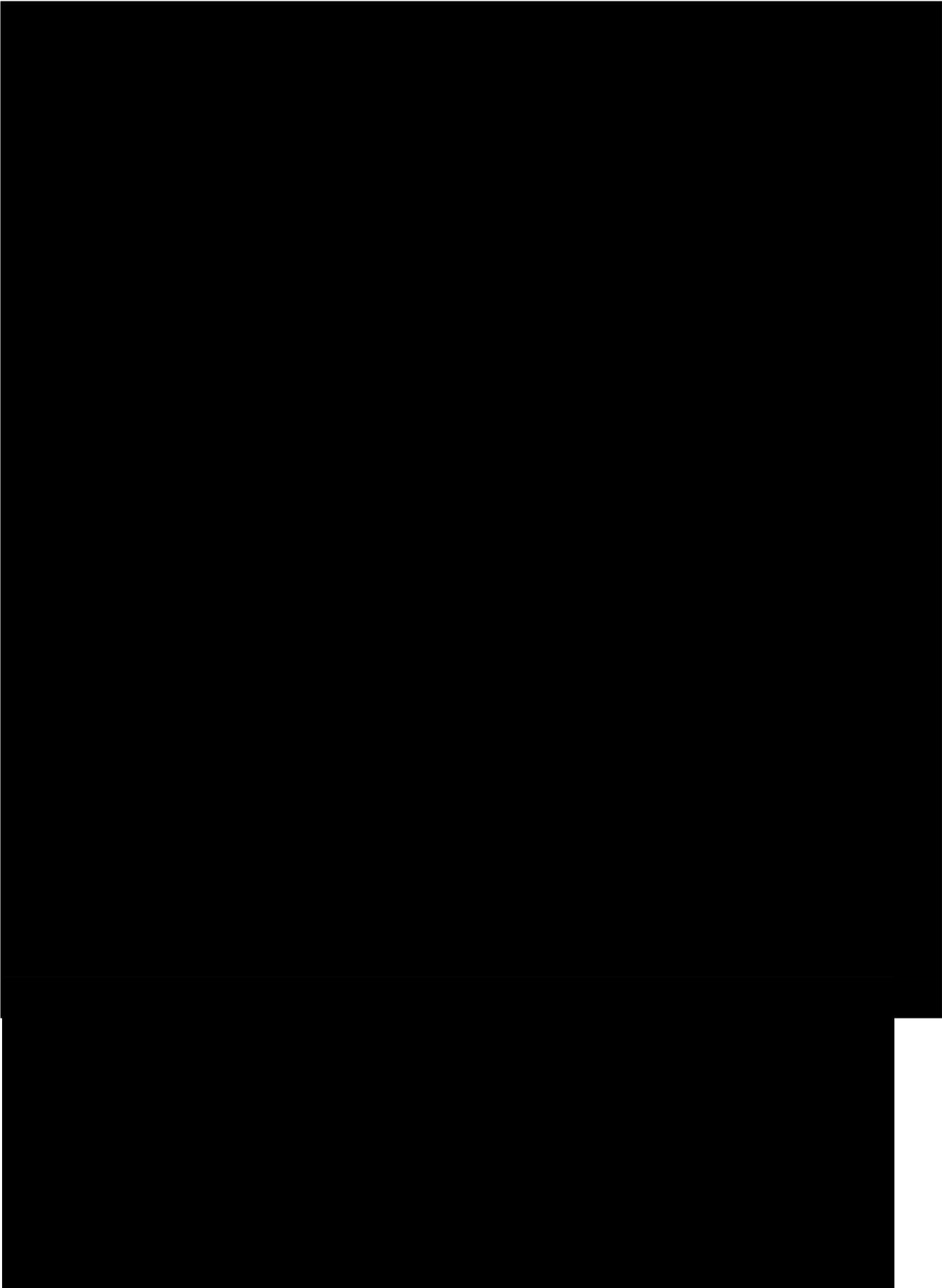


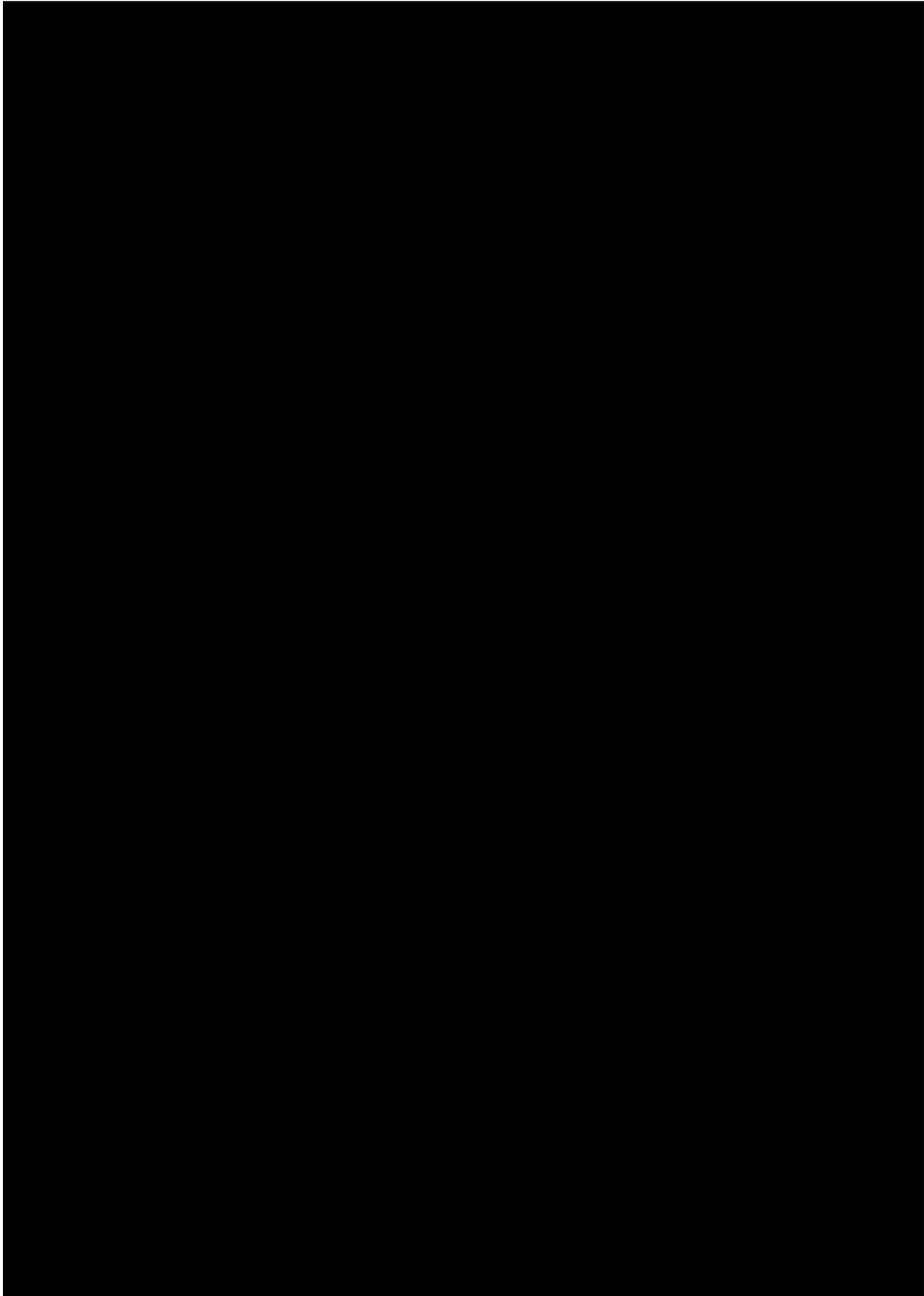




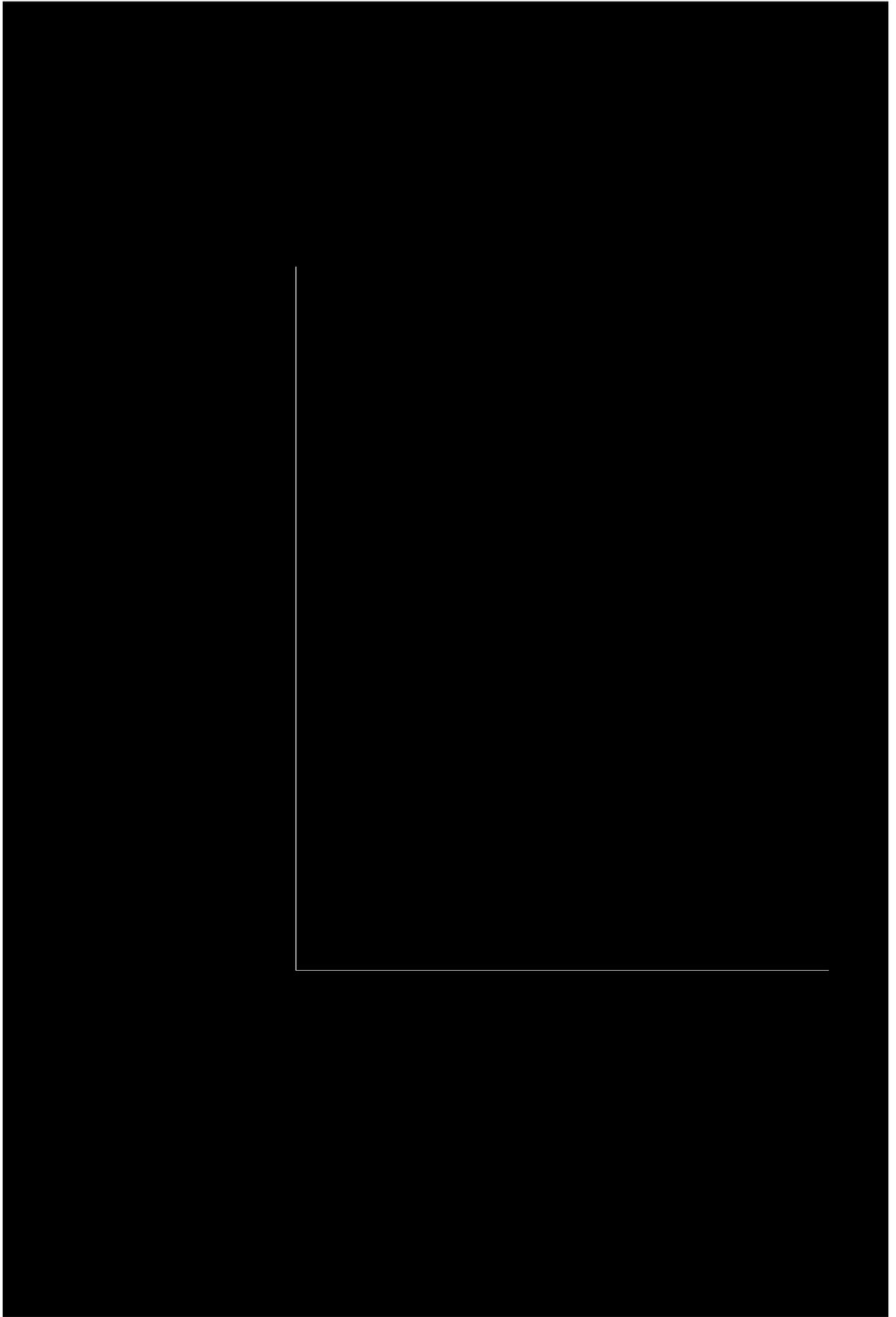


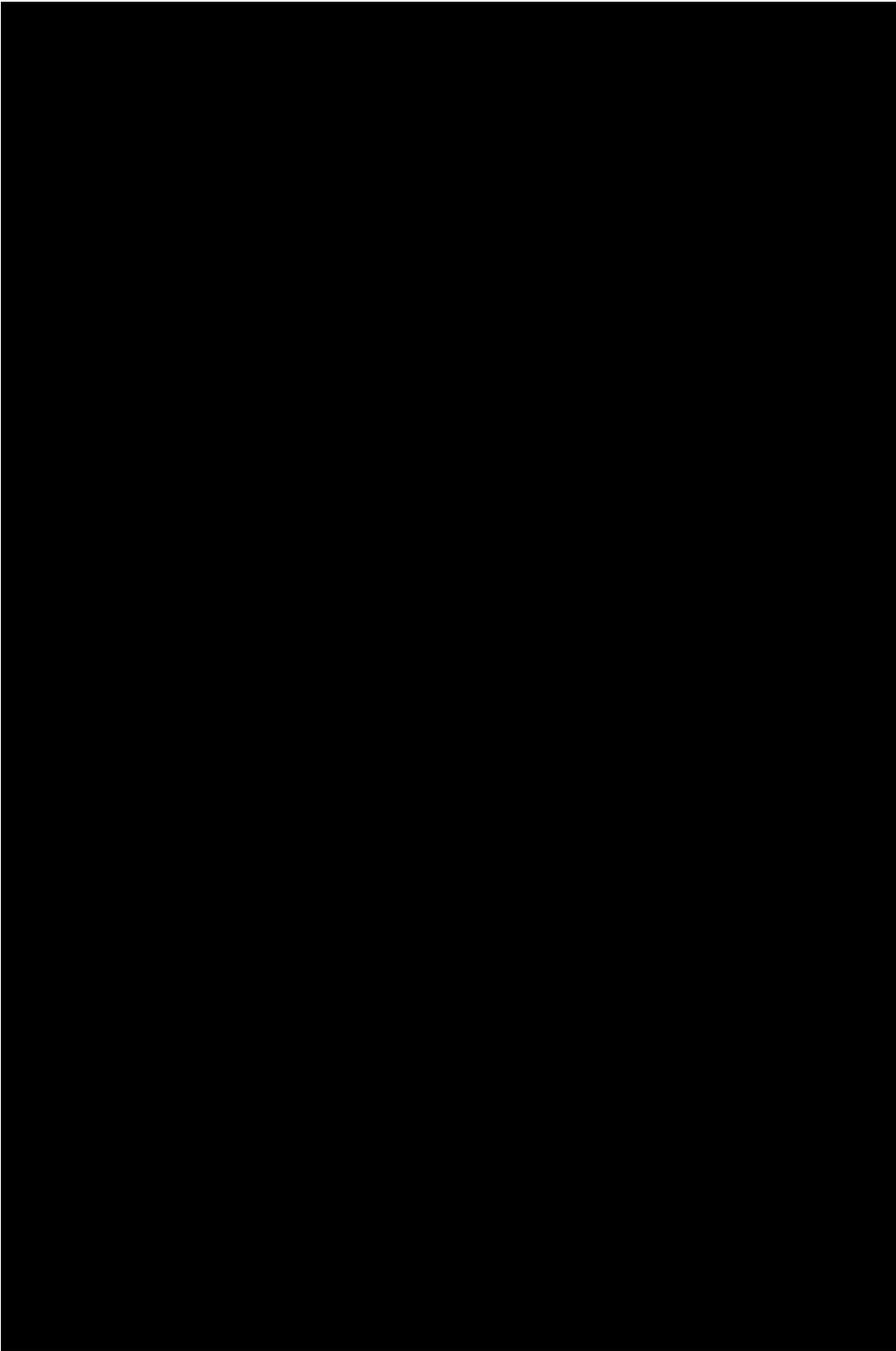


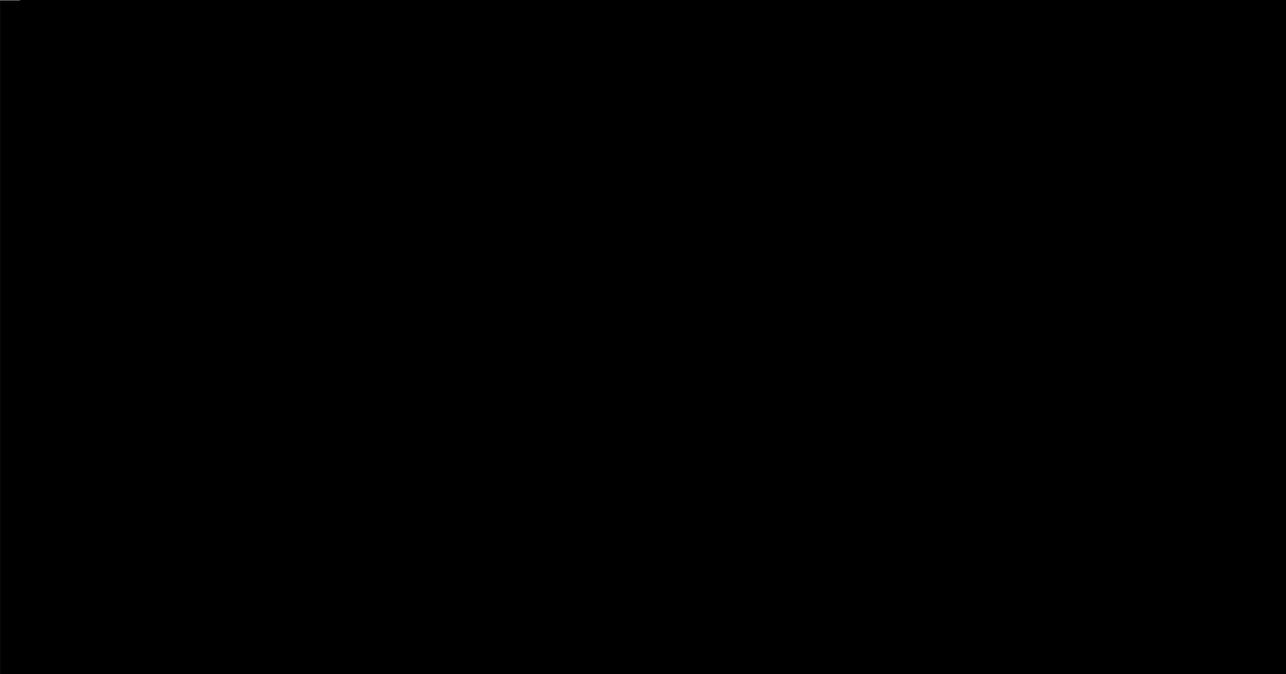
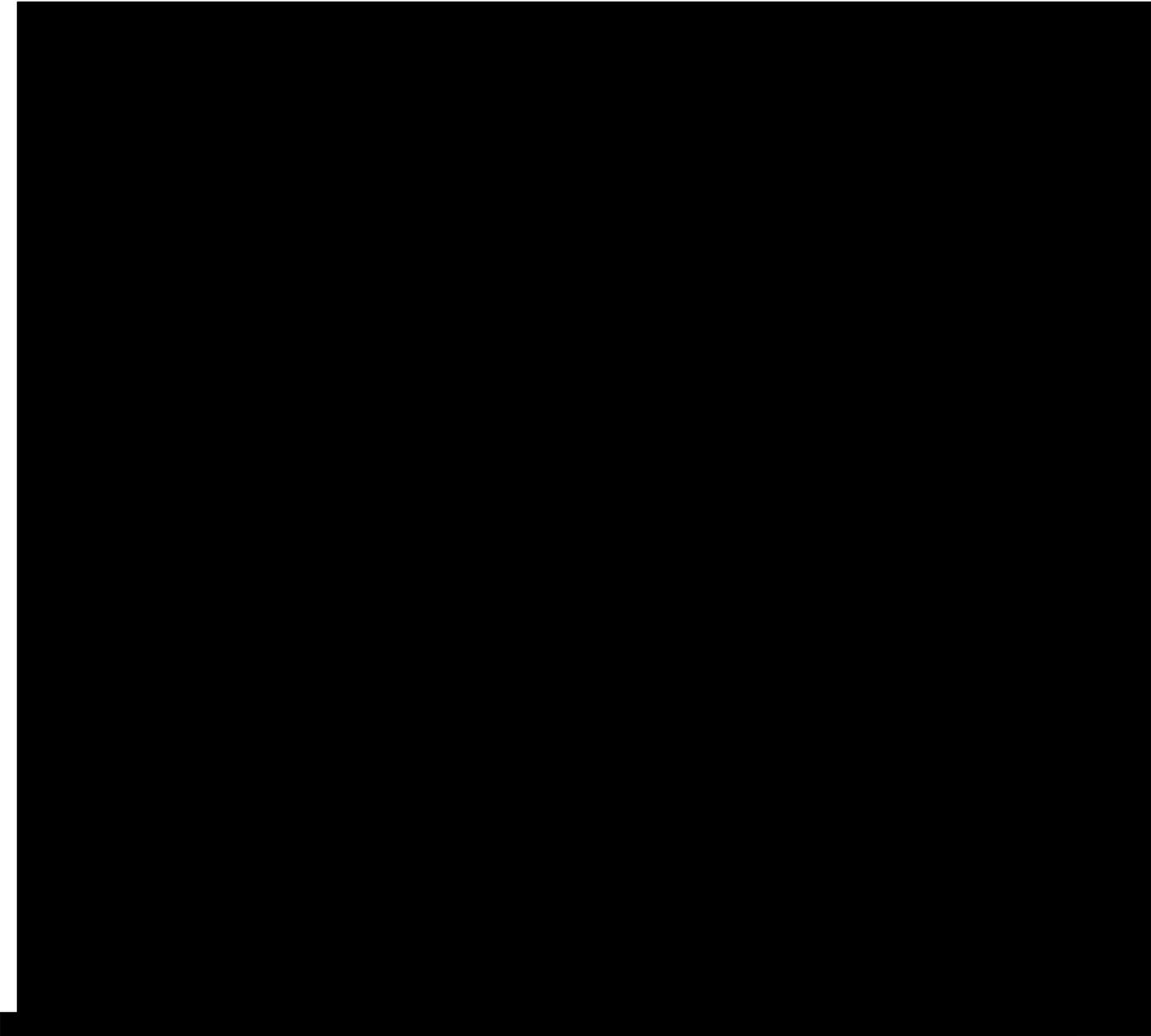


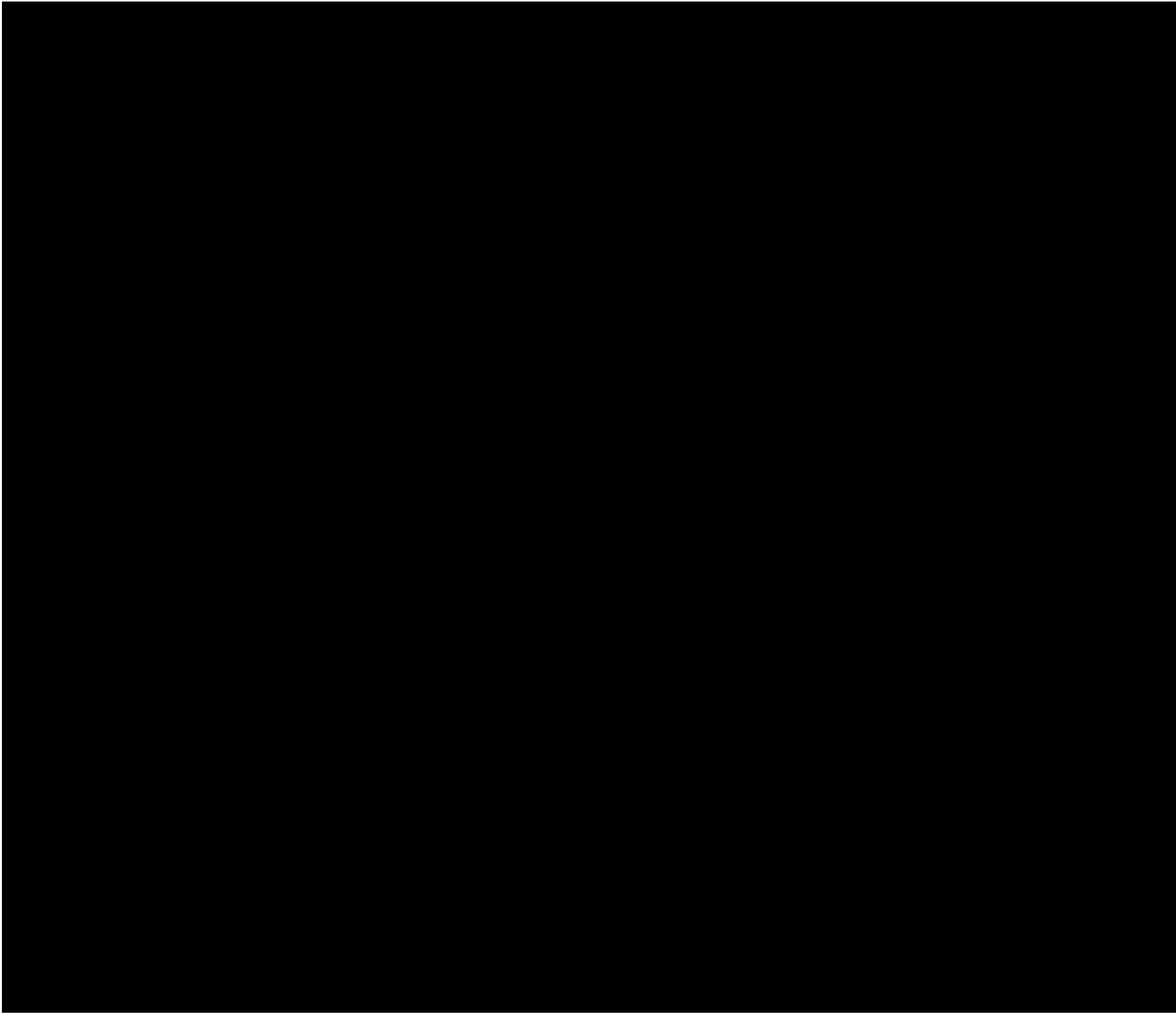












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