DUNDEE & ANGUS ADHD SUPPORT GROUP

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Research into Attention Deficit Hyperactivity Disorder [ADHD] Support needs in Dundee and Angus

FULL REPORT

Report prepared by the Dundee and Angus ADHD Support Group

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Thanks to the Dundee and Angus ADHD Support Group - to Alison Clink, Project Manager and to the staff, parents and children who so wholeheartedly embraced this study.

Thanks to all who participated and gave so freely of your views and ideas.

Let me take you deep inside
My complicated brain
A doctor said 'something's wrong'
But I can feel no pain.
My dopamine and serotonin levels
Are all wrong
My frontal lobes are smaller too
And yet I carry on
Mis-firing neuro-transmitters
That spark just out of time,
Stop me thinking before I act
And still I do just fine.
Nothing seems unusual
When you stand and stare at me
It's just the way I'm wired up
that makes me A.D.H.D

by Chris Traynor

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CHAPTER 1: INTRODUCTION

1.1 Introduction and background

The Dundee and Angus ADHD Support Group in November 2017 commissioned a small research team to complete a six month research study into the needs of those with the condition 'Attention Deficit Hyperactivity Disorder' [ADHD] and those interacting with them.

1.2 Local context

The Dundee and Angus ADHD Support Group was set up by a single mother after her son was diagnosed with ADHD – Attention Deficit Hyperactivity Disorder. She searched for support, guidance and advice and found it difficult to find so The Dundee and Angus ADHD Support Group was established to help support parents, families, children and young people (ranging from the age of diagnosis up to 18 years) suffering from the condition ADHD.

The group provides services to support and empower children, young people and parents/caregivers suffering from and affected by the medical condition Attention Deficit Hyperactive Disorder and through this aims to raise tolerance, awareness and acceptance of the condition.

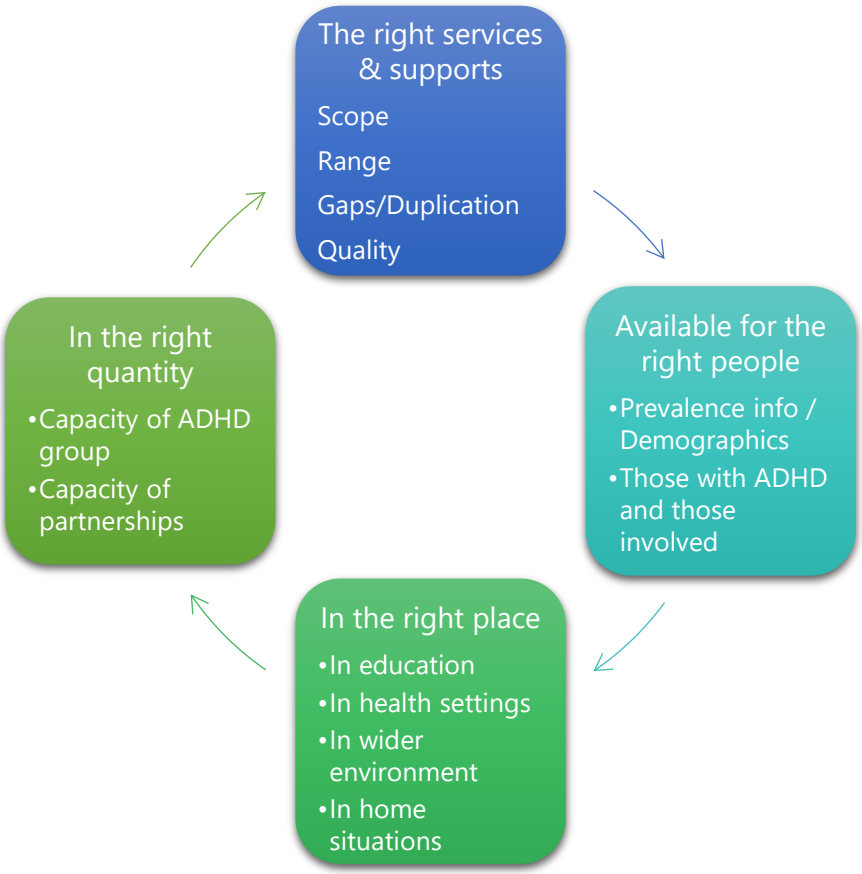
1.3 Purpose of the study

The purpose of the study was to (i) gather information on the needs of those with ADHD and those who are regularly involved with them, across the local authority areas of Dundee City Council (referred to in this report as Dundee City), and Angus Council (referred to in this report as Angus), and (ii) to use this information to determine in what way(s) for the Dundee and Angus ADHD Support Group might work (both seperatly and in partnership) to help meet these needs and to promote and implement positive change.

Fundamentally, this study sets out to answer whether in Dundee and Angus whether the right services and supports are available:

- for the right people;
- in the right quantity;
- in the right place; and
- at the right time.

Figure 1.1: Diagram of purpose of the research study



1.4 Objectives

The specific objectives of this study were:

- To set in context ADHD in society;
- To provide insight into the experiences of current service users and to use this to identify and promote improvements for change;
- To consult with professionals interacting with those with ADHD and with parent/caregivers;
- To consult with families including children and young people effected by ADHD and to consider their needs;
- To gather suggestions for improvement from professionals, parents/caregivers and those diagnosed with ADHD; and
- To provide the Dundee and Angus ADHD Support Group with recommended improvement actions within their current and potential capacity, both separately and in partnership with local and public sector organisations.

1.5 Scope of Study

This document presents the findings of the Needs Assessment within Dundee City and Angus. Evidence from the Needs Assessment will assist to:

- Provide evidence on the extent to which current services meet existing demand;
- Identify gaps in existing service provision;
- Suggest ways in which the Dundee and Angus ADHD Support Group and its partner agencies might extend/adapt services to meet needs; and
- Provide objective comment on the building of relationships between specialist mental health services, education, other community services, families and individuals to provide a system of care and support.

1.6 Stakeholders

It was considered essential to engage as broad a range of interests as possible as part of the Needs Assessment process.

The research was limited by time, the geography of the area and the broad societal range in its capacity to do this as comprehensively as needed. Due to these limitations the research team was unable to carry out detailed research into the needs of adults.

The research team sought the views of a range of different people including those with or involved with ADHD across services, organisations and locations within Dundee City and Angus. The qualitative element of the study in particular aimed to consult with staff from education and Child and Adolescent Mental Health Services (CAMHS) and with:

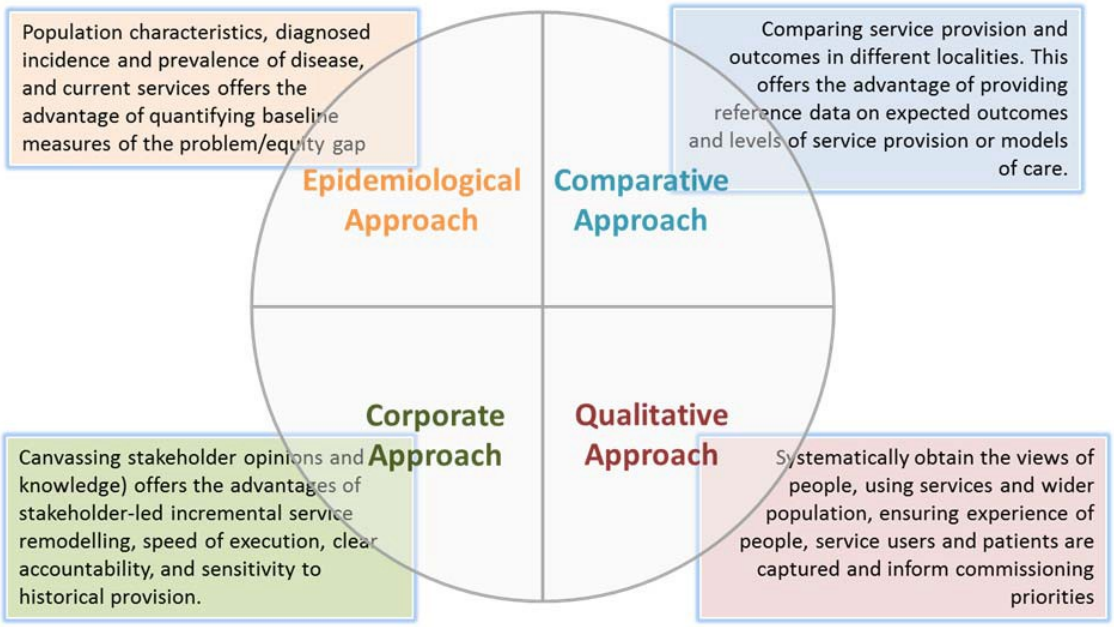
- Individuals with ADHD who are currently/recently engaged with local specialist services;
- Parents with dependent children who are currently engaged with local education and mental health services;
- Social Workers;
- Voluntary Sector providers;
- Police;
- Employers/employability organisations; and
- Others (e.g. Dundee Social Enterprise Network).

1.7 The Needs Assessment Process

The assessment process involved identifying need from four different perspectives (see Figure 1.2 below):

- **Epidemiological needs** – the use of health and social care information based on the population, including demographic trends, health status and risk, as well as evidence of clinical effectiveness of services and interventions.
- **Felt and expressed needs (Qualitative)** – the views of the public, from surveys, focus groups and the like, often using participatory appraisal methods.
- **Normative or expert needs (Corporate)** – as identified by professionals or experts.
- **Comparative needs** – the scope and nature of services available to the population and how these compare with services elsewhere.

Figure 1.2: Diagram of the needs assessment process



The study methods used in this Needs Assessment (outlined in section 1.8 below) were designed to capture each of these four different approaches/perspectives and are identified in Table 1.3 below.

1.8 Summary of Study Methods

The study was conducted in four stages. Each stage was tailored to the needs of the study, requiring a mix of data collection methods and sample populations. These are set out in Table 1.3 below.

Table 1.3: Summary of Data Collection Methods

Stage 1	**Method**		**Link to approaches / perspectives on need**
Review of Existing Datasets	Desk-based review of international, national and local datasets and any local specialist data available.		• Epidemiological • Comparative
Stage 2	**Method**	**Sample**	
Quantitative Survey	Online Surveys Focus Groups Interviews Questionnaires	• Service users • Professionals – Education, Health, Social Work • Carers, family members • Employers	• Normative/Expert (Corporate) • Comparative
Stage 3	**Method**	**Sample**	
Qualitative Surveys	Online and paper-based surveys Focus Groups Interviews Scottish Coalition Questionnaire	• Parents and Caregivers of ADHD • Young people with ADHD • Students	• Felt and Expressed (Qualitative)
Stage 4	**Method**	**Sample**	
Stakeholder Event / Working Group / Qualitative Interviews / Focus Groups	Stakeholder Events	• Key stakeholders invited to a half-day event in relation to ADHD – Health Professionals • Key stakeholders invited to education event in relation to ADHD – Parents/caregivers, professionals • Seminar for teachers and additional support staff • Awareness raising conference – Health professionals, Educators, Parents/Caregivers, Others	• Normative/Expert (Corporate) • Felt and Expressed (Qualitative)

	Semi-structured interviews	• Specialist services – CAMHS, Social Work • Education – Dundee and Angus Learning Support • Department of Work and Pensions • Discover Opportunities Dundee • Armistead • Criminal Justice Staff • Skills Development Scotland • WISE Group	• Normative/Expert (Corporate) • Felt and Expressed (Qualitative)
	Focus Groups	• ADHD Staff, volunteers and trustees • Service users (2) • Parents/Caregivers, family members (2) • Children and young people (4) • CAMHS • Community Mental Health Team • Angus Community Team • Social Workers • Occupational Therapists • Foster Parents • After School Clubs (2) • Armistead • Dundee Early Intervention Team	• Felt and Expressed (Qualitative)

The study used a range of quantitative and qualitative methods. Quantitative methods centred on a data analysis (local, national and international conference). Qualitative methods included one conference and 3 seminars (n=4), focus groups (n=19), interviews (n=10) and meetings with key Professional Advisers (n=2), service users (n=2) and questionnaires received as hard copy and online.

One conference and two seminars were held in Dundee City to raise awareness, collect data and qualitative information. Participants were targeted via contact lists from previous events, from Health Professionals, from Education Senior Staff and from other professional contacts and organisations. Events were co-facilitated by an experienced researcher, ADHD Support Group staff, Educational Psychologist, Education Staff and Specialist ADHD Trainers as appropriate. The conference was a

whole day event and the seminars half days. Notes were taken and question and answer sessions recorded to ensure accurate recall of information.

A number of focus groups were set up. Participants originated mainly from ADHD Support Group contacts and from other partner organisations (supplemented by 'word of mouth' referrals) through mail shots inviting engagement in the research, or through further interviews carried out by the Research Team. Each focus group meeting was chaired by a member of the Research Team and lasted approximately two hours. Each meeting was audio recorded and transcripts later produced to ensure accurate recall of the information. Hard copy questionnaires were also collected where applicable.

Semi-formal interviews were conducted by the lead researcher on a face to face basis. Each interview lasted approximately 60-90 minutes. A bespoke semi structured questionnaire was used to capture views based on the research objectives. Other professional stakeholders and parents/caregivers completed the questionnaire online, provided information by email and by telephone conversations.

With the permission of parents and caregivers a focus group was also held with children and young people with ADHD who were members of the ADHD Youth Groups. Bespoke methods were used to aid evidence gathering.

Respondents were provided with an information sheet which explained the research study. There were no complaints or adverse incidents or accidents throughout the study fieldwork.

In total, 800+ people took part in the research.

1.9 Terminology

When quoting individual respondents and when citing literature sources, the terms have been quoted literally for accuracy of representation. A Glossary of acronyms and abbreviations is in the appendices.

1.10 Considerations and limitations

There are a number of factors which should be taken into account when reading this report. These are:

- Due to the geographic and societal scope of the research and the limited time frame, sample sizes of groups were often small. This should not exclude their data from this regional study, as the research team collected information to inform the ADHD Support Group towards implementation of improvements of identified needs;
- The views of those interviewed and surveyed were taken and reported in good faith and are their own, not necessarily those of the Dundee and Angus Support Group, or the Research Team or the organisations they represent. It cannot be assumed that the views of the participants in

interviews, focus groups, stakeholder events or seminars are representative of all similar stakeholders; and

- In health care, need is commonly defined as 'the capacity to benefit'. If health needs are identified, then an effective intervention should be available to meet these needs and improve health. There will be no benefit from an intervention that is not effective or if there are no resources available.[1] The definition of need used in this study is 'the number of individuals in the general population with ADHD or involved or interacting with those with ADHD and who could benefit from intervention'. There are several challenges in estimating the prevalence of ADHD in the general population.

[1] Wright, J., Williams, R., & Wilkinson, J.R. (1998). Development and Importance of Health Needs Assessment. *British Medical Journal,* 316; 1310-1313.

CHAPTER 2: DEPRIVATION

2.1 Introduction

Deprivation is a fundamental consideration of this research. The Scottish Government's 'Aspiring Communities Fund', which funded this research, derives from the European Social Fund. It 'provides financial support to enable community bodies and third sector organisations in our most deprived and fragile communities to develop and deliver long-term local solutions that address local priorities and needs, increase active inclusion and build on the assets of local communities to reduce poverty and to enable inclusive growth.'[2]

Angus and Dundee City have distinct deprivation profiles, with the former experiencing high levels of 'Access' deprivation and the latter featuring areas of severe 'Income', 'Employment', 'Health', 'Education', 'Crime' and 'Housing' deprivation.

Rates of prescriptions for ADHD medication are considerably higher in the more deprived areas in Angus and Dundee City. Most of the individuals with ADHD (aged 16 and over) and their parents/caregivers living in Dundee City who participated in our research were found to live in the more deprived areas. The small number of participants in Angus predominantly lived in the less deprived areas.

2.2 Context

In the UK a significant association was found between socio-economic deprivation and the prevalence of ADHD in children and adolescents living in the North-West of England.[3]

A recent study of school children in Scotland found that 56.7% of those with ADHD compared to 42.6% of their non-ADHD peers, lived in the most-deprived datazones.

The study also found that, among children with ADHD, absences were more common for those in the most-deprived datazone (median: 12.0 days) than in the least-deprived datazone (6.5 days).

Deprivation had a clear impact on outcomes for children taking ADHD medication[4], with 33.3% of those in the most deprived data zone excluded, compared with 17.4% in the least deprived datazone.

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[2] The Aspiring Communities Fund is supported by the European Social Fund (ESF) and Scottish Government. It is delivered by Social Justice and Regeneration Division, Scottish Government as Lead Partner for the 2014-2020 ESF Programme. European Social Fund Aspiring Communities Fund Application for Funding - Guidelines

[3] Ogundele et al. (2012)

[4] *For this study the number of children taking ADHD medication was used as a proxy indicator of those with ADHD. This methodology will have meant that those with a diagnosis of ADHD but choosing not to take medication will not have been included in this sample.*

Deprivation was also a factor in exclusions among children who did not take ADHD medication, with 6.7% and 1.2% excluded in the most and least deprived datazone respectively.

The risk of unemployment was comparable between affluent children treated for ADHD and deprived children not receiving ADHD medication (16.1% vs 16.8%). Nonetheless, among children treated for ADHD the risk of unemployment was still higher for children in the most deprived datazone than in the least deprived datazone (27.7% vs 16.1%).[5]

2.3 Methodology

Throughout this Research many sample sizes are small. This was due to the time constraints, the societal and geographic spread of the research, self-selection of research participation and accessibility to children and young people within short time scale.

Although samples are small the information provided is relevant to the Dundee and Angus ADHD Support Group and important to the participating respondents whose voices are often not heard.

The following methods were used to gather information from literature and stakeholders:

- Interviews;
- Desk Research;
- Drop in sessions – Rural Angus;
- Hard Copies of Questionnaires distributed – Dundee City and Angus; and
- Online Questionnaires.

2.4 Angus and Dundee City deprivation profiles

This study focusses on two areas of extreme, but very different kinds of deprivation. The Scottish Index of Multiple Deprivation (SIMD) calculates deprivation according to a wide range of indicator scores within a particular datazone.[6] All the data in this section uses data from the most recent publication of SIMD data (2016).[7]

Whereas Dundee City ranks as the fifth-highest local authority in terms of the share of its datazones that are found in the 20% most deprived datazones in Scotland, Angus ranks twenty-second out of the thirty-two local authorities in Scotland (see Figure 2.1).

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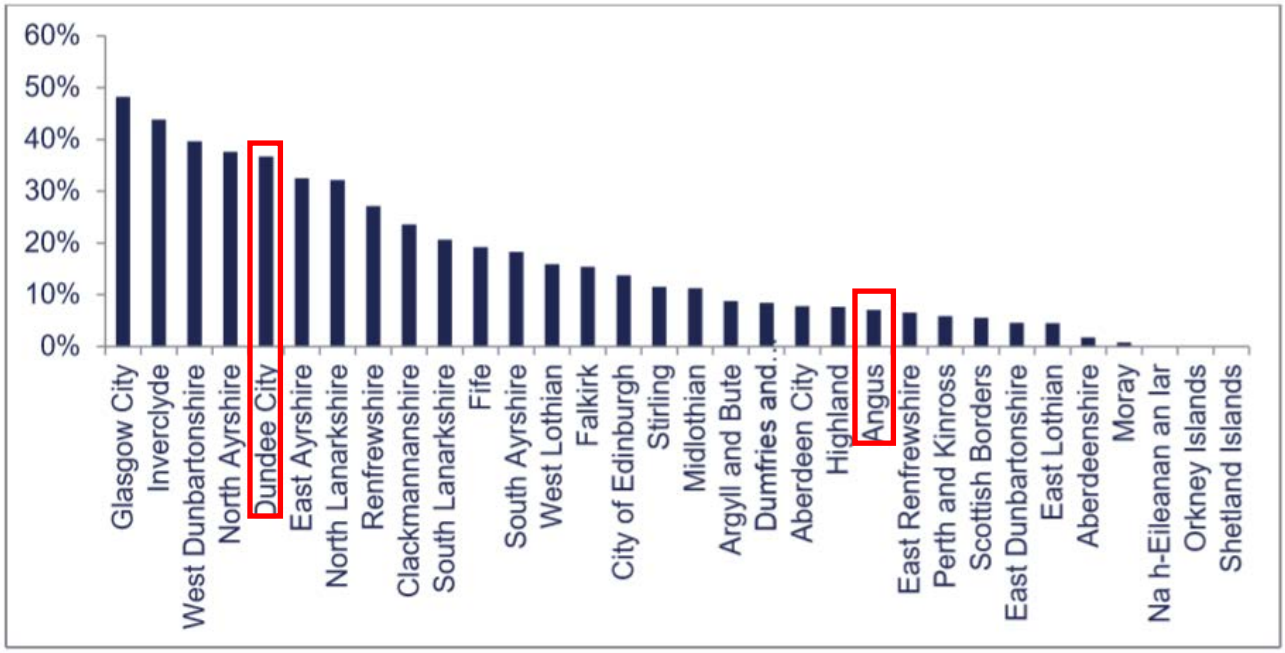
[5] *Fleming. (2017) Children treated for ADHD remained at a higher risk of unemployment after adjusting for absenteeism and omitting children with special educational needs*

[6] In the most recent SIMD (2016), Scotland was divided into 6,976 datazones http://www.gov.scot/Resource/0050/00504809.pdf.

[7] Source: http://www.gov.scot/Topics/Statistics/SIMD. For local authority area SIMD profiles, see http://www.gov.scot/Topics/Statistics/SIMD/analysis/councils

Figure 2.1: Local share of datazones in each council area that are found in the 20% most deprived datazones in Scotland (source: SIMD, 2016)



When viewed together (see Figures 2.2 and 2.3) in terms of an overall measure of deprivation, Dundee City faces far greater challenges than Angus. Whereas nine of the top ten most deprived datazones in Dundee City rank in the top 200 most deprived datazones in Scotland (the exception being S01007803: 'Linlathen and Midcraigie - 04', which ranks 201st), the highest-ranked datazone in terms of deprivation in Angus (S01007186: 'Arbroath Harbour - 03') sits 631st and is one of just two datazones in the whole local authority (the other being S01007186: 'Arbroath Warddykes - 03') which appears in the top 1000 most-deprived datazones in Scotland.

Figure 2.2: Angus by SIMD datazones (Overall deprivation; SIMD, 2016)

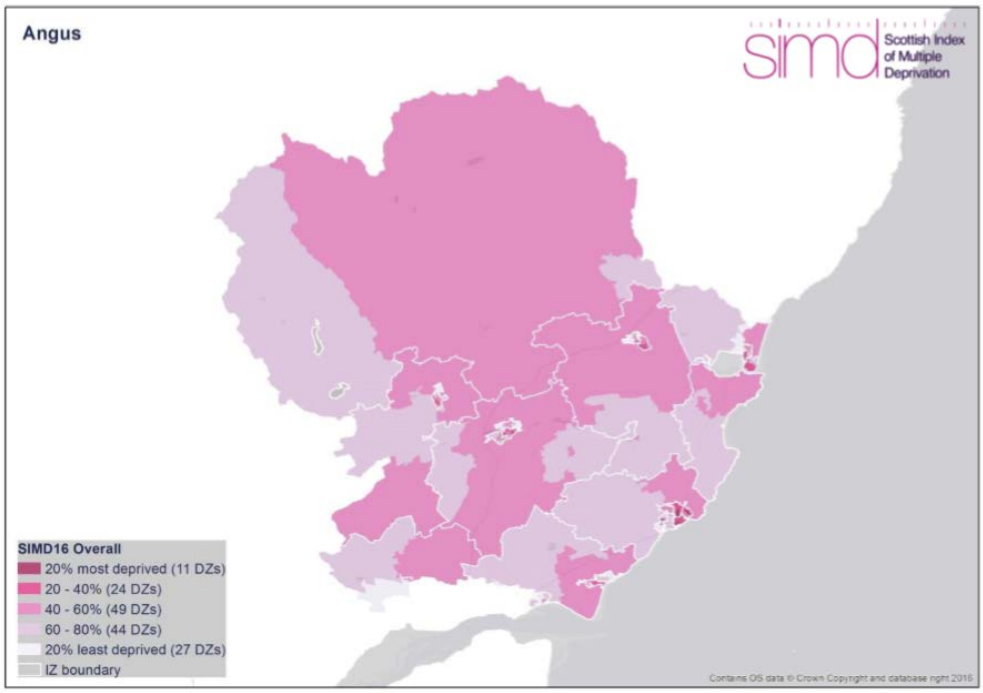
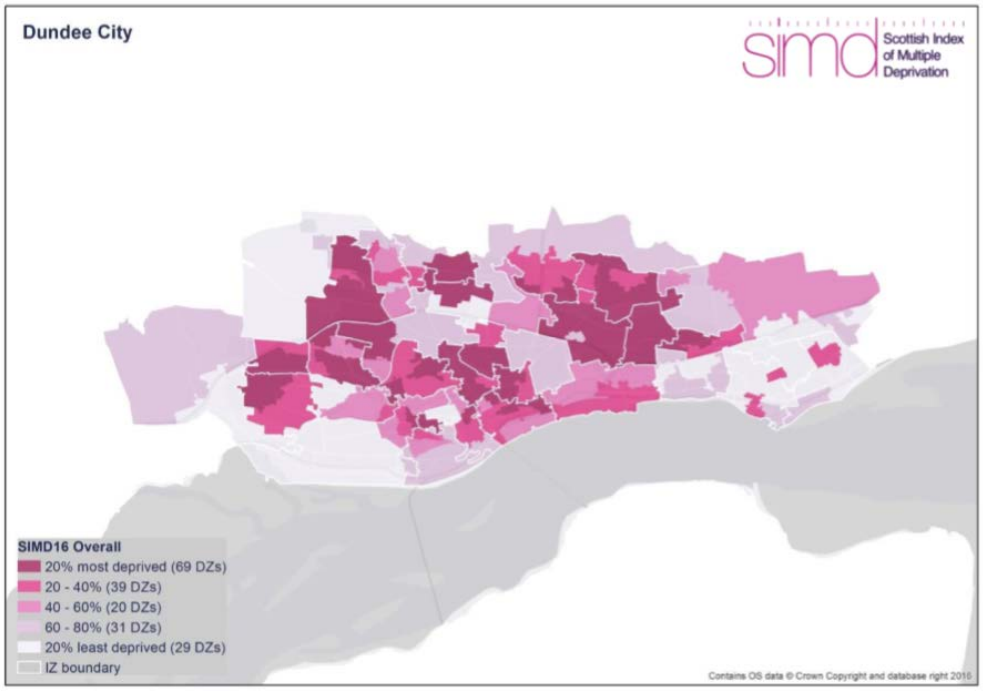


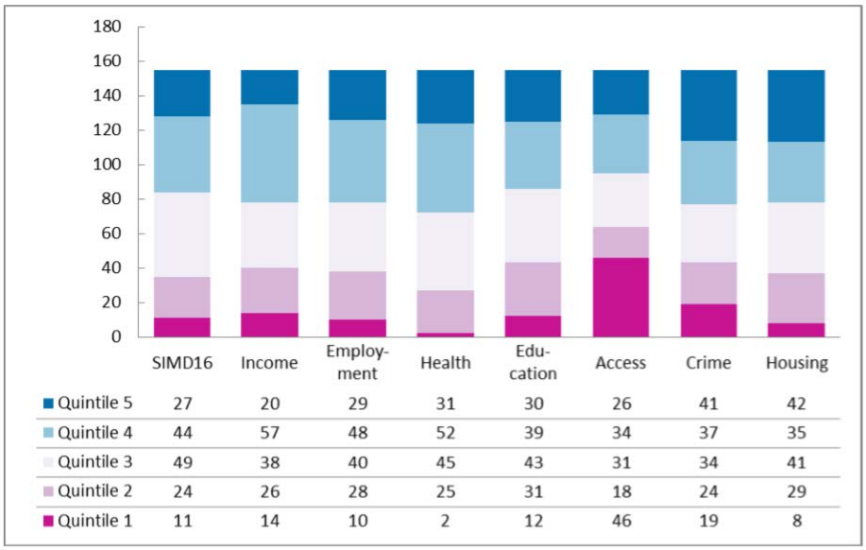
Figure 2.3: Dundee City by SIMD Datazones (Overall deprivation; SIMD, 2016)



Figures 2.4 and 2.5 (below) show the distribution of datazones (over the seven 'domains' used to calculate the SIMD) by SIMD deprivation quintile, where Quintile 1 is the most deprived and Quintile 5 is the least deprived.

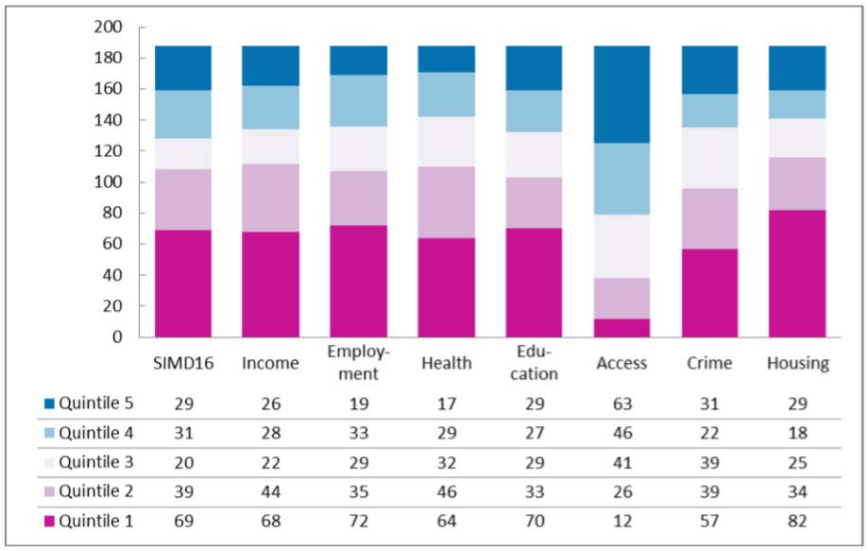
According to the SIMD definition of deprivation, a higher proportion of datazones in Angus suffer from the most extreme forms of access deprivation than for extreme forms of any other kind of deprivation, whereas Dundee City is faced with deprivation in many different forms, including income deprivation, employment deprivation, health deprivation, education deprivation, crime deprivation and housing deprivation.

Figure 2.4: Angus: Datazone distribution of quintiles by SIMD domain (source: SIMD, 2016)[8]



	SIMD16	Income	Employ-ment	Health	Edu-cation	Access	Crime	Housing
Quintile 5	27	20	29	31	30	26	41	42
Quintile 4	44	57	48	52	39	34	37	35
Quintile 3	49	38	40	45	43	31	34	41
Quintile 2	24	26	28	25	31	18	24	29
Quintile 1	11	14	10	2	12	46	19	8

Figure 2.5: Dundee CIty: Datazone distribution of quintiles by SIMD domain (source: SIMD, 2016)[9]



	SIMD16	Income	Employ-ment	Health	Edu-cation	Access	Crime	Housing
Quintile 5	29	26	19	17	29	63	31	29
Quintile 4	31	28	33	29	27	46	22	18
Quintile 3	20	22	29	32	29	41	39	25
Quintile 2	39	44	35	46	33	26	39	34
Quintile 1	69	68	72	64	70	12	57	82

[8] http://www.gov.scot/Topics/Statistics/SIMD/analysis/councils

[9] http://www.gov.scot/Topics/Statistics/SIMD/analysis/councils

2.5 ADHD Medication and Deprivation

The rates of prescriptions of ADHD medication in Angus and Dundee City are correlated with levels of deprivation in the area of residence, with particularly high rates found in the most deprived areas – see Figures 2.6 and 2.7 below.

Figure 2.6: Rate of prescriptions (per 100 population) by SIMD deprivation quintile – **Angus** (ISD, 2018)

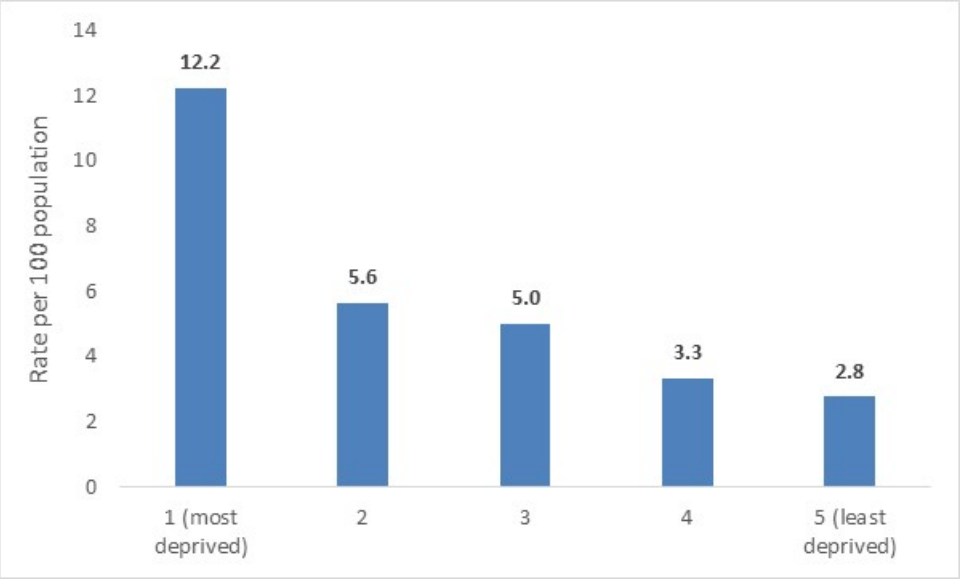
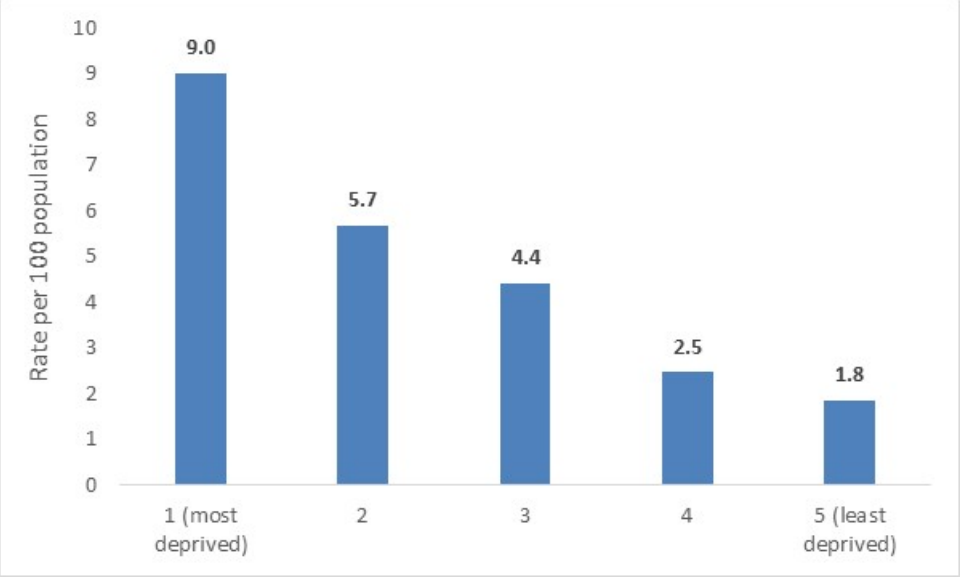


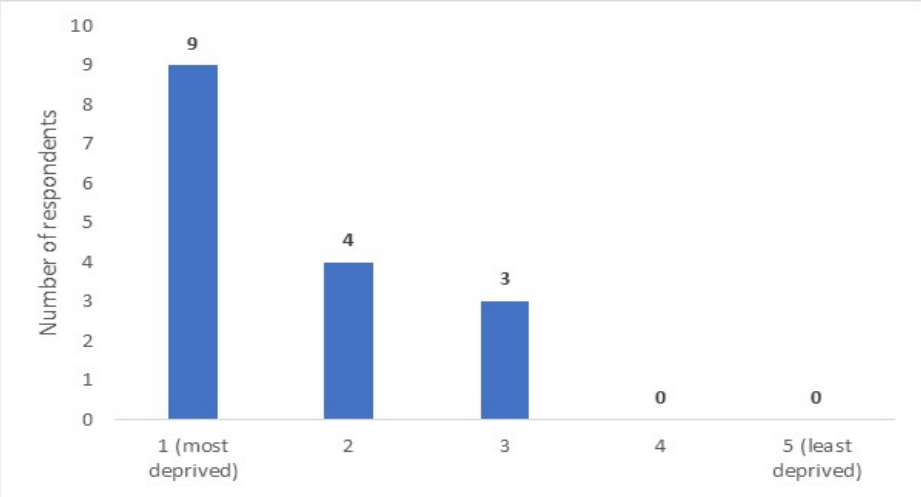
Figure 2.7: Rate of prescriptions (per 100 population) by SIMD deprivation quintile – **Dundee City** (Source: ISD, 2018)



We were able to match the postcodes of 16 out of the 25 individuals over the age of 16 (including students) who completed questionnaires. Over four fifths (81.3%) of respondents lived in areas

classed as 'deprived', while more than half of respondents lived in areas classed as 'most deprived'. All the respondents lived in Dundee City. See Figure 2.8 below.

Figure 2.8: Individuals (16+) and student participants, by SIMD quintile



There does not appear to be a correlation between the Urban Rural classification of the area of residence and the rates of prescriptions of ADHD medication in Angus - see table 2.9 below.[10]

Table 2.9: Prescriptions of ADHD medication in Angus by Urban Rural classification, by calendar year (ISD, 2018)

Calendar Year	Urban/Rural	Number of patients	Total population[11]	Rate per 100 population
2015	1 – Large Urban Areas	21	9,058	2.32
	2 – Other Urban Areas	245	62,796	3.90
	3 – Accessible Small Towns	34	13,595	2.50
	5 - Accessible Rural	77	29,698	2.59
	6 – Remote Rural	9	1,513	5.95
2016	1 – Large Urban Areas	23	9,058	2.54
	2 – Other Urban Areas	280	62,796	4.46

[10] Dundee City is much more homogenous in terms of its Urban Rural classification. The vast majority of those living in Dundee City live in areas classed as 'Large Urban Areas', while the numbers of those prescribed ADHD medications in 'Accessible Rural' areas within the Dundee City local authority area were too small (i.e. <5) to disclose.

[11] National Records of Scotland, 2016 mid-year population estimates. https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2016.

	3 – Accessible Small Towns	33	13,595	2.43
	5 - Accessible Rural	94	29,698	3.17
	6 – Remote Rural	10	1,513	6.61

Of those parents/caregivers who responded from Angus (and whose postcodes matched SIMD deprivation data (n=5)), none lived in areas classed as 'deprived'.[12]

Of those parents/caregivers who responded from Dundee City (and whose postcodes matched SIMD deprivation data (n=22), 10 (45.5%) lived in the most deprived areas.

See table 2.10 below.

Table 2.10: 2.10 Respondents who provided postcodes

SIMD Deprivation Quintile	Angus	Dundee City
1 (most deprived)	0	10
2	0	4
3	1	5
4	4	0
5 (least deprived)	0	3

2.6 Key Findings

- Rates of prescriptions in areas of most deprivation are higher than those in areas of least deprivation.
- In Dundee City rates of prescriptions are highest in the two most deprived quintiles.
- In Angus the rates of prescriptions are highest in the most deprived areas and then more evenly spread across areas of deprivation.

[12] For the full Urban Rural classifications, please see: http://www.gov.scot/Publications/2009/08/07115535/14.

CHAPTER 3: DIAGNOSIS AND TREATMENT

3.1 Introduction

Although ADHD disorder was not recognised as a valid disorder until 1990, it was being described in the latter part of the eighteenth century, when the Scot Sir Alexander Crichton published the article, 'Attention and its Diseases', where he linked problems with attention and restlessness to intense expressions of anger.[13]

The clinical definition of ADHD continues to evolve. The diagnostic criteria for both ADHD and Hyperkinetic Disorder (HKD) have changed with each revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD). Further revisions have been predicted in the future to address outstanding issues such as age of onset, subtypes of disorder, gender differences, and the extent to which the criteria can be applied across the lifespan.

Despite the continual evolution of the diagnostic criteria, the evidence to support the current clinical definitions of ADHD and HKD is substantial.

3.2 Context

Attention deficit hyperactivity disorder (ADHD) is an internationally recognised, clinically valid neurodevelopmental disorder with onset in early childhood, though it is believed to persist into adolescence and adulthood in roughly two thirds of cases. It is characterized by high levels of hyperactivity, impulsivity and inattention and ADHD does not manifest uniformly.

Three subtypes have been identified, of which the 'inattentive' type appears to be the most common (~50%), followed by the 'combined' type (~30%) and lastly the 'hyperactive' type (~20%). ADHD is highly heritable, however, like other common medical and psychiatric disorders, it is influenced by multiple genes, non-inherited factors, and an interplay between the two.

ADHD is also associated with a range of comorbidities, including related disorders, low self-esteem, substance abuse, and learning disabilities. As with most neurodevelopmental disorders it can frequently co-occur with other disorders. Between 30% and 50% of individuals with Autistic Spectrum Disorder (ASD) manifest ADHD symptoms, while according to one estimate, around two-thirds of individuals with ADHD show features of ASD.

ADHD is also highly comorbid with several disruptive behaviour disorders, including Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD). Some studies suggest as many as 50% of children with ADHD also display ODD or CD.

[13] Crichton. (1798)

Many children with ADHD also have a specific learning disorder, while Health Improvement Scotland (HIS) estimates that the majority (84%) of children and young people in Scotland with an ADHD diagnosis also have other behavioural difficulties (HIS, 2012). A recent study[14] of Scottish schoolchildren found that ADHD was associated with all of types of special educational needs identified in the study: mental health; social, emotional and behavioural; autistic spectrum disorder; learning disability; physical health; physical and motor impairment; learning difficulty; communication problems; and sensory impairment.

It would appear that the diagnosis of ADHD in adults falls some way short of the diagnosis in children and young people. A number of studies have found that fewer than 20% of adults with the condition are currently diagnosed and/or treated by psychiatrists.[15]

3.3 Methodology

Throughout this research many sample sizes are small. This was due to: the time constraints; the societal and geographic spread of the research; self-selection of research participation; and accessibility to children and young people within short time scale.

Although samples are small the information provided is relevant to the Dundee and Angus ADHD Support Group and important to the participating respondents whose voices are often not heard.

In gathering the views of a broad range of stakeholders in relation to diagnosis and treatment issues, the following methods were utilised:

- Focus Groups were held with:
    - Dundee and Angus ADHD Support Group – Parents and Caregivers;
    - Individuals with ADHD 16+;
    - CAMHS Staff;
    - Social Workers;
    - Foster parents;
    - Discover Opportunities Dundee; and
    - Occupational Therapy.
- Desk Research for background and context.
- Relevant responses from Scottish Coalition Survey 2018.
- Online and hard copy questionnaires.

[14] Fleming et al. (2007)

[15] Retz et al. (2011)

3.4 Prevalence

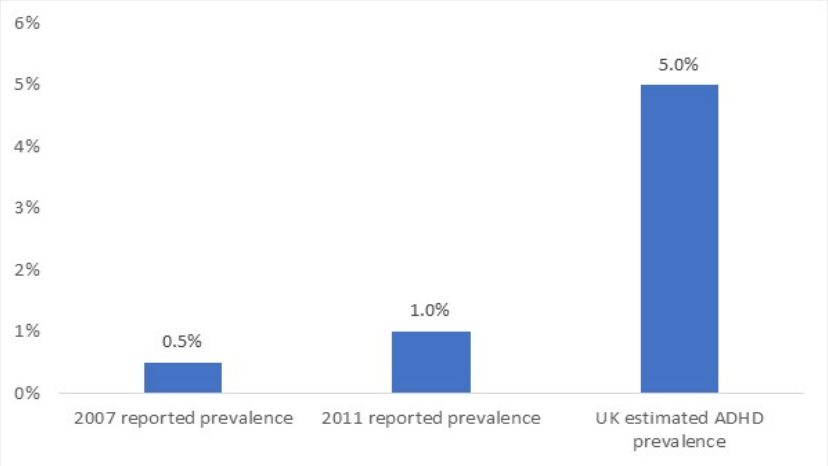
The lack of national-level investigations of child mental disorders which use population-based representative samples means that definitive data on the prevalence of ADHD is limited.[16] The international prevalence of ADHD has been estimated at 5.3% - 7.1% for children and adolescents, and 3.4% for adults.[17]

In 2008, Health Improvement Scotland (HIS) published part of a six-year review of ADHD services provided by each of the Health Boards in Scotland. They estimated that, in NHS Tayside, there were 3,955 children and young people (i.e. <18yrs) with ADHD and 1,187 with HKD.

At the time of the review there were approximately 400 children and young people under CAMHS care with a known diagnosis of ADHD in NHS Tayside, roughly 10% of the total number estimated to have the condition.

The bat chart below shows the 'reported prevalence' (i.e. the number of reported cases of ADHD as a percentage of the population) in Tayside in 2007 and 2011 (the last time data of this level of detail was collected in NHS Tayside), as compared with the estimated prevalence of ADHD in the UK. Figure 3.1 and Table 3.2 below show the data of the 'reported prevalence' figures in 2007 and 2011.

Figure 3.1: NHS Tayside reported prevalence of ADHD in 2007 and 2011, as compared with the UK estimated prevalence of ADHD in the UK[18]



[16] Rowland A.S. et al (2008)

[17] While there is no global consensus (due to methodological differences between studies), meta-regression analyses have estimated the worldwide prevalence of ADHD (including hyperkinetic disorder (HKD) at between 5.3% (Polanczyk et al., 2007) and 7.1% (Wilcutt, 2012) in children and adolescents. The worldwide prevalence for adults is estimated to be 3.4% (with a range of 1.2-7.3%), while prevalence estimates for very young children or adults over the age of 44 are much harder to come by Fayyad et al. (2007). The prevalence of ADHD in the male population is generally reported to be higher than its prevalence in the female population Wilcutt, (2012); Novik et al., (2006); Biederman et al. (2004).

[18] *(HIS, 2012; page 95)*

Table 3.2: NHS Tayside background data for reported prevalence of ADHD in 2007 and 2011[19]

2007 data	2011 data
407 reported cases (0.5% of <18 population)	743 reported cases (1.0% of <18 population)
Boys 85%, Girls 15% (of caseload) (Ratio 6:1)	Boys 80%, Girls 20% (of caseload) (Ratio 4:1)

In relation to Adults with ADHD in Scotland, in 2012 Health Improvement Scotland (HIS) reported that, 'During the regional sessions, staff reported concerns that colleagues in adult mental health services may not recognise previously undiagnosed ADHD in adults. This could be due to a lack of knowledge around the condition, or a lack of belief that the condition persists into adulthood. Training and capacity issues within the adult mental health service workforce were identified as barriers to successful transition from CAMHS or paediatric services.'[20]

3.5 Diagnosis

Roughly 37,000 children and young people in Scotland may be affected and need access to ADHD support and services; however, just 4,539 (~12%) have a diagnosis of ADHD and are in contact with specialist services (HIS, 2012).

ADHD management for those up to the age of 18 in the UK is the responsibility primarily of specialists working within either paediatric departments or Child and Adolescent Mental Health Services. The CAMHS Centre for Child Health at Dudhope (Dundee) involves a multidisciplinary team of consultant psychiatrists, paediatricians, nurses, clinical psychologists, speech and language therapists and occupational therapists.

With an increase in recent years in the acceptance and awareness of ADHD, management of the condition has now become a major part of the work of these services.

Several studies have found that fewer than 20% of adults with the condition are currently diagnosed and/or treated by psychiatrists. Across Europe there are still many professionals who remain unsure of the diagnosis and appropriate use of ADHD medication in adult mental health. There remains an observable gulf between attitudes and practices relating to ADHD in child/adolescent and adult mental health services.

[19] (HIS, 2012; page 95)

[20] (HIS, 2012; page 23).

In the Scottish ADHD Coalition Parent Survey (Angus and Dundee City results; 2018), 39 out of the 40 parents/caregivers who responded to the question, 'Who diagnosed your child with ADHD?' said that the diagnosis was carried out by CAMHS, a psychiatrist, or a specialist ADHD team.

Table 3.3 below shows the responses of 40 parents/caregivers to the question posed by the Scottish ADHD Coalition's Parent Survey (Angus and Dundee City results; 2018):

Table 3.3: Responses to 'Thinking back to when your child was diagnosed with ADHD, what do you think about the time this took?'

Response choices	Numbers
'Long wait to see CAMHS / ADHD team after we were referred'	18
'Delay in school recognising and acting on difficulties'	9
'Assessment and decision-making process took too long'	8
'Delay in us as parents / carers recognising that our child had a problem'	3
'Delay in GP making a referral'	2

3.6 Methods of Diagnosis

3.6.1 The Diagnostic and Statistical Manual of Mental Disorders – 5th edition (DSM-5™)

DSM-5™, used for the formal diagnosis of attention-deficit hyperactivity disorder (ADHD), was released by the American Psychiatric Association in 2013 and replaces the previous version (4th edition [DSM-IV]).[21],[22]

DSM-5™ identifies three subtypes of ADHD: predominantly inattentive type (which features inattention but not hyperactivity/impulsivity); predominantly hyperactive-impulsive type (which features hyperactivity/impulsivity but not inattention) and combined type (which features signs of inattention and hyperactivity/impulsivity).

[21] American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. 2013

[22] American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. Washington, DC: American Psychiatric Association, 2004.

3.6.2 The International Classification of Mental and Behavioural Disorders 10th revision (ICD-10)

The ICD-10 medical classification system was published by the World Health Organization (WHO) in 1992.[23]

The ICD-10 diagnostic criteria refers to ADHD as 'HKD', or 'hyperkinetic disorder' (sometimes referred to as 'severe ADHD'). 'HKD characterises more severe disturbance with significant hyperactivity included as a criterion for diagnosis. DSM and ICD are categorical models and minimum thresholds of presenting symptoms must be present to achieve diagnosis. Children and young people failing to meet the defined criteria of ADHD/HKD may nevertheless be experiencing significant difficulties in day to day life.'[24]

3.6.3 Overview of the DSM-5 medical classification system for ADHD

A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development:

- For children, 6 or more of the symptoms (Table 3.4 below) have persisted for at least 6 months to a degree that is inconsistent with developmental level, and that negatively impacts directly on social and academic/occupational activities;
- Please note: the symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility or failure to understand tasks or instructions; and[19]
- For older adolescents and adults (age 17 and older), 5 or more symptoms are required (Table 3.4 below).

Table 3.4: Symptoms used in the DSM-5 medical classification system for ADHD

Symptoms of inattention	Symptoms of hyperactivity and impulsivity
Often fails to give close attention to detail or makes mistakes	Often fidgets with or taps hands and feet, or squirms in seat
Often has difficulty sustaining attention in tasks or activities	Often leaves seat in situations when remaining seated is expected
Often does not seem to listen when spoken to directly	Often runs or climbs in situations where it is inappropriate

[23] World Health Organization. The ICD-10 Classification of Mental and Behavioural Disorders. Available at: www.who.int/entity/classifications/icd/en/bluebook.pdf. Last updated 1993; 1: 1-263.

[24] http://www.sign.ac.uk/assets/sign112.pdf

Often does not follow through on instructions and fails to finish schoolwork or workplace duties	Often unable to play in leisure activities quietly
Often has difficulty organising tasks and activities	Is often 'on the go', acting as if 'driven by a motor'
Often avoids, dislikes or is reluctant to engage in tasks that require sustained mental effort	Often talks excessively

3.6.4 Overview of the ICD-10 medical classification system for ADHD[21]

ICD-10 refers to attention-deficit hyperactivity disorder (ADHD) as hyperkinetic disorder (HKD).

This classification system defines HKD as a persistent and severe impairment of psychological development, characterised by 'early onset; a combination of overactive, poorly modulated behaviour with marked inattention and lack of persistent task involvement; and pervasiveness, over situations and persistence over time of these behavioural characteristics'.[21]

The main symptoms of HKD are impaired attention and overactivity. Both are necessary for diagnosis.

- Impaired attention – manifested by a lack of persistent task involvement and tendency to move from one activity to another without completion;
- Overactivity – characterised by restlessness, talkativeness, noisiness and fidgeting, particularly in situations requiring calm; and
- Early onset – behavioural symptoms present prior to 6 years of age, and of long duration.

Impairment must be present in two or more settings (e.g. home, classroom, clinic).

Diagnosis of anxiety disorders, mood affective disorders, pervasive developmental disorders and schizophrenia must be excluded.

3.6.5 Adult diagnosis

Diagnosis of HKD may also be made in adult life using the same criteria; however, attention and activity must be judged with reference to developmentally appropriate norms.

Both the current DSM-5 and ICD-10 require that symptoms are present in several settings, such as school or work, home life, and leisure activities; that symptoms are evidenced in early life[25]; and that

[25] The more stringent ICD-10 requires evident symptoms by the age of seven, while the DSM-5 requires evident symptoms by the age of twelve.

functional impairment due to symptoms of ADHD must be observed in the individual's life, with the symptoms adversely affecting psychological, social and/or educational/occupational functioning.[26]

3.6.6 DIVA – Diagnostic Interview for ADHD in Adults

The Diagnostic Interview for ADHD in Adults (DIVA) questionnaire[27] is the most widely used adult diagnostic tool in the UK and is based on the criteria for ADHD in DSM-IV.[28]

DIVA 2.0 asks about the presence of ADHD symptoms in adulthood as well as childhood, chronicity of these symptoms, and significant clinical or psychosocial impairments due to these symptoms.

DIVA was developed in Dutch and translated in many different languages, because there is a need for a structured diagnostic instrument in the field that is easily available at low costs for research and clinical assessment purposes.

The main requirements for the diagnosis are that the onset of ADHD symptoms occurred during childhood and that this was followed by a lifelong persistence of the characteristic symptoms to the time of the current evaluation. The symptoms need to be associated with significant clinical or psychosocial impairments that affect the individual in two or more life situations.

To simplify the evaluation of each of the 18 symptom criteria for ADHD, in childhood and adulthood, the interview provides a list of concrete and realistic examples, for both current and retrospective (childhood) behaviour. The examples are based on the common descriptions provided by adult patients in clinical practice. Examples are also provided of the types of impairments that are commonly associated with the symptoms in five areas of everyday life: work and education; relationships and family life; social contacts; free time and hobbies; self-confidence and self-image.

3.7 Treatment

There is evidence for the positive impacts of a multimodal[29] approach to treatment, including a combination of pharmacological treatment and intensive behavioural therapy. In 2012, Health Improvement Scotland (HIS) reported that while 76% of cases 'were receiving other interventions in addition to medication', behavioural parent programmes offered were often unavailable in hard-to-reach areas, 'generic in nature', and not engaged-with by parents of children with ADHD.

[26] National Institute of Clinical Excellence (NICE. 2018)

[27] Kooij and Francken (2010)

[28] rcpsych.ac.uk/pdf/ADHD_in_AdultsFINAL_GUIDELINES_JUNE2017

[29] See https://www.nimh.nih.gov/funding/clinical-research/practical/mta/multimodal-treatment-of-attention-deficit-hyperactivity-disorder-mta-study.shtml

HIS cited anecdotal evidence that programmes specifically targeted at parents or carers of children with ADHD were more beneficial 'as they allow parents/caregivers to benefit from peer support and focus on behaviour problems in the context of an ADHD diagnosis'.[30]

Medication has been found to be the most powerful treatment for core ADHD and HKD symptoms, while those receiving a combination of medication and intensive behavioural therapy have been shown to experience significantly greater improvements than those receiving behaviour therapy alone.[31] If school children attending CAMHS cease taking medication they will no longer receive CAMHS support unless there are other comorbidities or areas of concern[32] but as soon as a diagnosis of ADHD is made medication may be offered.

There are five types of medication licensed for the treatment of ADHD[33]:

- Methylphenidate;
- Dexamfetamine;
- Lisdexamfetamine;
- Atomoxetine; and
- Guanfacine.

These medications are not a permanent cure for ADHD but may help someone with the condition concentrate better, be less impulsive, feel calmer, and learn and practise new skills.

The most commonly prescribed ADHD medication today, methylphenidate, was licensed by the US Food and Drug Administration (FDA) in 1955[34] and became medically available to treat hyperactivity and behavioural disorders in children from 1960 onwards.

Long-acting stimulants and non-stimulant medication were developed in the 2000s and by 2004 a marked increase had been observed in the prescribing of psychostimulant medications for children and young people with ADHD.

Prescriptions for methylphenidate alone had increased from 69 prescriptions per 10,000 population in 1996 to 603/10,000 in 2003.[35] Prescribing rates have continued to rise since, with an increase of 7.1% between 2010-2011 and 2011-2012.[36]

See Figure 3.5 below: for diagnostic rates 2007/2008 and 2011/2012:

[30] Health Improvement Scotland. 2012, page 17

[31] SIGN, 2009; pages 25-6

[32] (IGTFOISA4544) Freedom of Information Appendix 1

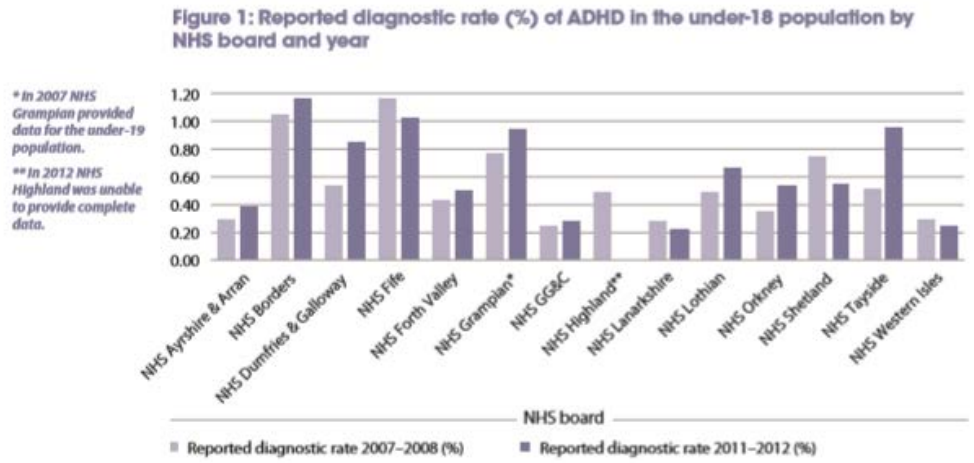
[33] www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/treatment/3

[34] Methylphenidate was initially approved by the FDA to treat depression and narcolepsy.

[35] NHS Quality Improvement Scotland. (2004).

[36] National Services Scotland, Information Services Division. (2012)

Figure 3.5: Reported diagnostis rate (%) of ADHD in the under-18 population by NHS Board and year



Dundee City does not record the numbers of people living within its boundaries who have prescriptions for medication used to treat ADHD. The same is true for Angus, although it is able to provide the number of children who have to take medication for ADHD during school hours, as there are 'agreed individual protocols' in place for this (i.e. 67, out of the 179 children and young people in the Angus education system with a diagnosis of ADHD).[37]

Prescription data can be used as a rough measure to identify the number of population who have a diagnosis of ADHD and who are in contact with mental health services, although there will be individuals with ADHD receiving support from mental health services who do not take medication for their ADHD. For those aged 0-19 at least, both the number of prescribed items and prescribing rates[38] for ADHD medications vary enormously between NHS Health Boards (see Table 3.5 above) and indeed have increased in all but one NHS Health Board since 2009/10 - the recent increase in prescribing rate in NHS Tayside is second only, in Scotland, to NHS Borders.

Tables 3.6 and 3.7 below show the numbers of prescribed ADHD medication by age and gender over the years 2015 – 2017 in Dundee City and Angus.

[37] FOI (20180131011) Freedom of Information Appendix 2

[38] 'Defined Daily Doses' (DDDs) are a measure developed by the World Health Organisation (WHO). They are derived from data on the international use of the substance in question. The WHO defines DDDs as, 'the assumed average maintenance dose per day used on its main indication in adults'. The caveat included with this measure is that, 'the daily dose is a unit of measurement and does not necessarily reflect the recommended or Prescribed Daily Dose'. The ISD add that, 'By providing a fixed unit of measurement, they allow the trend of drug consumption over time or for other regions or countries to be compared. Occasionally the WHO recommended DDD for a drug will change. The data in this [Medicines for Mental Health 2016/17 Publication Report] are presented by current DDD for all years in order to allow meaningful trend analysis.' https://isdscotland.scot.nhs.uk/Health-Topics/Prescribing-and-Medicines/Publications/2016-10-04/2016-10-04-PrescribingMentalHealth-Report.pdf (accessed, 14/04/2018)

Table 3.6: Dundee City- Number of individuals prescribed ADHD medications by age band, sex and calendar year (ISD, 2018)

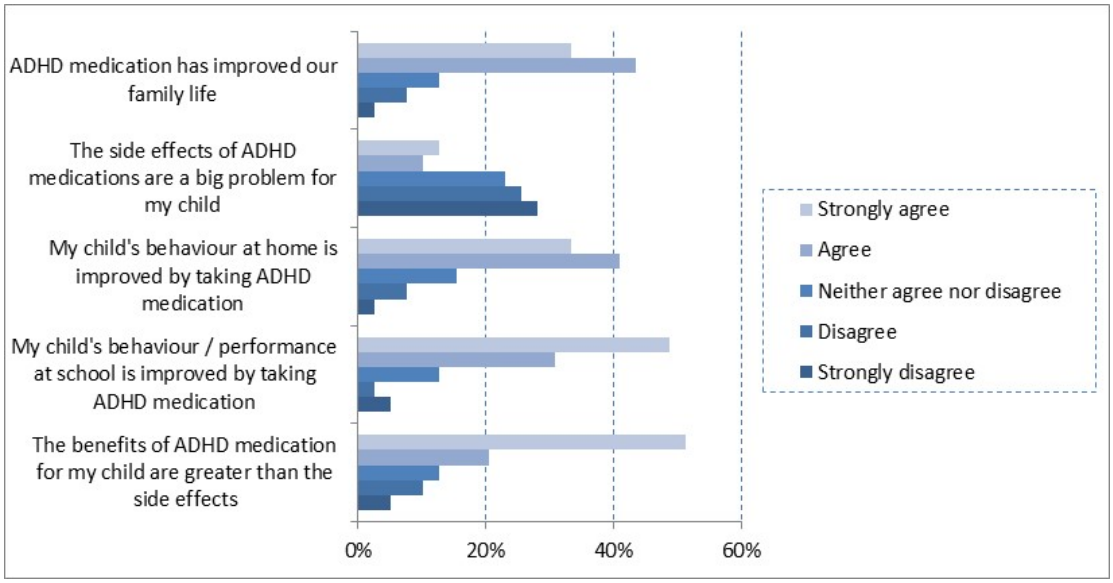
	5-15		16-30		31-40		41+	
	Males	Females	Males	Females	Males	Females	Males	Females
2015	337	81	164	44	12	*	*	5
2016	387	94	179	49	18	*	6	7
2017	408	107	185	54	22	*	8	10

Table 3.7: Angus - Number of individuals prescribed ADHD medications by age band, sex and calendar year (ISD, 2018)

	5-15		16-30		31-40		41+	
	Males	Females	Males	Females	Males	Females	Males	Females
2015	175	31	88	41	16	8	9	12
2016	198	39	114	42	15	10	6	11
2017	235	58	135	46	19	12	6	13

The Angus and Dundee City local results in the ADHD Coalition Parent Survey (2018), was that most parents viewed medication in a positive light. The responses are shown in the Figure 3.8 below:

Figure 3.8: Parental views regarding medication



3.8 Health Professionals Feedback

3.8.1 General Health Professionals

At a seminar with Health Professionals the following questions were asked:

1. Have you participated in any staff development related to ADHD?

2. What are the biggest challenges those with ADHD and their parents/caregivers face?

3. If an Information Pack was to be developed by the Dundee and Angus Support Group for Health Professionals, what would you like to see in it?

4. What other resources would most help you to support those with ADHD?

Table 3.9 below shows the collated responses from Health Professionals who responded:

Table 3.9: Health Professional views

Questions asked	Responses	Nursing Staff	Psychologists /Psychiatrists	Other Health Professionals	Totals
1. Participated in Training	Yes	5	2	1	8
	No	2	2	1	5
2. Challenges	Lack of resources and Support	9	6	2	17
	Understanding of ADHD	5	5	1	11
	School	3	-	-	3
	Waiting Times	4	-	-	4
3. Information Pack for you	Diagnosis information	7	4	-	11
	Training Opportunities	6	2	1	9
	Advice and Guidance	6	-	2	8
	Signposting to resources/services	2	6	-	8
	Transition from CAMHS to GAP	1	-	-	1

4. Other Resources	Training	7	5	1	13
	Support at School	3	1	1	5
	Communication - between services	2	1	1	4
	Adults service	-	1	-	1
	Leaflets/support groups etc.	3	-	-	3

At a seminar with both Health Professionals and Parents/Caregivers the following questions were asked:

1. *What advice and information do you think that individuals with ADHD require?*
2. *What do you know about the diagnostic process?*

Responses to questions 1 and 2 are shown below:

Table 3.10: Question 1 - Required advice and information – Health Professionals and Parents/Caregivers responses

Responses received	Number of responses
Information on support – where to find it	8
Validation of ADHD as genuine condition	5
Counselling/mentoring	2
Employment advice	2

Table 3.11: Question 2 - Diagnostic process – Health Professionals and Parents/Caregivers responses

Responses received	Number of responses
Need for early diagnosis	5
Need for support during the process	3
Helpline needed	2
Teachers diagnosis training needed	1

Other general comments were received as shown below:

- Lack of attention to comorbidities;
- There is a struggle to access local services;
- Lack of information on medication and diagnosis for parents; and
- Need for more support groups.

3.8.2 CAMHS – Child and Adolescent Mental Health Services

CAMHS Staff were asked:

1. What improvements could be made to the referrals process? and

2. What other options would you like to see over and above what is currently offered in terms of treatment?

The responses are shown below for question 1:

• Whole team collaboration.
• Information for school and home at point of referral.
• More robust.
• Better liaison in general.
• Better links with 3rd Sector.

The responses are shown below for question 2:

• Consultation with Support Groups.
• Use of APPs to communicate data.
• Easy to access parents' support groups to include support for:

o Life and Social Skills;
o Parenting;
o Behavioural strategies;
o Sleep and anxiety; and
o Teaching strategies and support in school.

3.8.3 Community Mental Health Team

Community Mental Health Staff (n=12) were asked:

> *What support would most help you to support individuals with ADHD?*

The responses are shown in Table 3.12 below:

Table 3.12: Supporting individuals with ADHD – CMHT staff responses

Responses received	Number of responses
Training including practical and management strategies	7
Support groups	3
Better education/understanding in Schools	1
Online Resources	1

Both CAMHS Staff (n=8) and Community Mental Health Nurses (n=12) provided responses as to 'Co-morbidities' with those shown below as the main responses received:

- Autistic Spectrum Disorder (ASD) 10
- Anxiety and mental health 12
- Oppositional Defiant Disorder (ODD) 7
- Learning difficulties 6

3.8.4 Occupational Therapy Staff

Occupational Therapy Staff (n=11) were asked:

> *What are the biggest challenges those with ADHD and their parents, caregivers and families face?*

The responses are shown in Table 3.13 below:

Table 3.13: Biggest challenges for those with ADHD and their parents/caregivers,families – view of Occupational Health staff

Responses received	Number of responses
Everyday life- employment, housing, finances, isolation etc.	12
Accessing support	9
Diagnosis and referrals process	8
Lack of understanding/knowledge	5
Lack of integration	1

* Respondents were able to give multiple responses.

Occupational Therapy Staff (n=11) were asked:

'What support would most help you to support individuals with ADHD?'

The responses are shown in Table 3.14 below:

Table 3.14: Support that would most help me in my role – views of Occupational Health staff

Responses received	Number of responses
Support from other services and more support groups	10
Training	7
Pathways for parents/caregivers	3
Funding	1

* Respondents were able to give multiple responses.

Occupational Therapy Staff (n=11) were asked:

What information would you like to see in a pack to help professionals support individuals with ADHD and their parents/caregivers?

The responses are shown in Table 3.15 below:

Table 3.15: Information packs – views of Occupational Health staff

Responses received	Number of responses
Signposting	10
Impact of ADHD and practical strategies	9
Roles of different Health Professionals	3
Information on diagnosis process	3

* Respondents were able to give multiple responses.

3.8.5 Experiences of CAMHS and General Adult Psychiatry (GAP) services by individuals with ADHD

Individuals with ADHD were asked:

What was your experience with CAMHS/GAP? (as applicable)

The responses are shown in Table 3.16 below:

Table 3.16: Experience of CAMHS/GAP - by individuals with ADHD

Responses received	CAMHS (10)	GAP (9)
Positive	3	2
Mixed	5	4
Not good	2	3

Individuals with ADHD (n=6) were asked:

Have you been offered support during the transition from CAMHS to Adult Psychiatry Services?

The responses are shown in Table 3.17 below:

Table 3.17: Support offered during transition from CAMHS to Adult Psychiatry - by individuals with ADHD

Responses received	Individuals with ADHD
Offered transition support	2
Not offered transition support	4

3.8.6 Experiences of CAMHS from Parents/Caregivers

Parents/Caregivers (n=19) were asked

What services or resources have been of most help to you?

The responses are shown in Table 3.18 below:

Table 3.18: Most helpful services or resources – views of parents/caregivers

Responses received	Number of responses
CAMHS	8
Dundee and Angus ADHD Support Group	5
Speaking to other parents	5
Internet information	1

Parents/Caregivers (n=44) were asked:

What was your experience with CAMHS?

The responses are shown in Table 3.19 below:

Table 3.19: Experience of CAMHS – views of parents/ caregivers

Responses received	Number of responses
Positive	9
Mixed	24
Not Good	8
I have had no experience of CAMHS	3

Parents/Caregivers (n=44) were asked:

What was your experience of the support given to you DURING the diagnosis process?

What was your experience of the support given to you AFTER the diagnosis process?

The responses are shown in Table 3.20 below:

Table 3.20: Experiences of parents/caregivers during and after the ADHD diagnosis process

Responses received	**DURING** Diagnosis	**AFTER** Diagnosis
Positive	11	13
Mixed	13	14
Not Good	8	6
Did not receive any support	10	9
I have not had a diagnosis	2	2

The Scottish ADHD Coalition (Angus and Dundee City Results; 2018) posed the following question in relation to support:

> *Please tell us about what support was offered to you by the health team that diagnosed your child.*

The responses are shown in Table 3.21 below:

Table 3.21: Support received from health teams – views of parents/caregivers

Support services	**We received / used this**	**We were offered this but chose not to use it**	**We were not offered this**
Parent training specifically for ADHD	8	3	29
Referral to general parent training	5	1	34
Regular follow up review appointments with a specialist health professional	35	0	5
Psychology / counselling / CBT / other therapy for your child	6	0	34
Health team communicating with your child's school so they were aware of the diagnosis	19	0	21
Written information about ADHD for us as parents/caregivers	26	0	14
Written information about ADHD aimed at our child	8	1	31
Information about where to find more information (e.g. list of books / websites)	11	1	28

The Scottish ADHD Coalition Parent Survey (Angus and Dundee City local results; 2018) posed the following question to parents and caregivers:

> *What would you most like to see improve in health services to support you and your child better?*

The responses are shown in Table 3.22 below:

Table 3.22: Preferred health service improvements – views of parents/caregivers

Responses received	Number of responses
Waiting times reduced	11
Interactions with School	8
Parents Support	6
Whole Family Support	5
Information	5
Information for children	4
Other non-medication treatments	3
Larger CAMHS team	2

The Scottish ADHD Coalition Parent Survey (Angus and Dundee City local results; 2018) posed the following question to parents and caregivers:

> *Is there anything that the health team has done particularly well in diagnosing and treating your child's ADHD? What have you valued the most?*

The responses are shown in Table 3.23 below:

Table 3.23: Best practice in diagnosis and treatment – views of parents/caregivers

Responses received	Number of responses
Support from Nurses/Doctor	6
Nothing	5
Medication issues	4

3.8.7 Experiences of CAMHS from other professionals

Several professional groups were asked about their experiences of working with CAMHS. Responses are presented below (by professional group category).

Social Workers

Social workers (n=19) were asked:

> *When encountering an individual with ADHD or other additional support needs, do you have any dialogue with CAMHS? If applicable, please explain your answer to the previous question.*

The responses are shown in Table 3.24 below:

Table 3.24: Do you have dialogue with CAMHS?– views of Social Workers

Responses received	**Number of responses**
Yes	9
Depends on Additional Support Needs	5
No	5
Reasons for the responses received	**Number of responses**
CAMHS already involved beforehand	5
I would go for advice	4
CAMHS are too stretched/long wait time	3

Foster Parents/Caregivers

Foster Parents/Caregivers (n=4) were asked:

> *When encountering an individual with ADHD or other additional support needs, do you have any dialogue with CAMHS?*

Responses: 2 respondents said they would have dialogue with CAMHS

> 2 respondents said they would not have any diaglogue with CAMHS, one of whom gave the reason that 'support was not available at the time'.

Discover Opportunities Centre

Discover Opportunities Dundee is an organisation which supports Dundee-based young people aged 16-19 who are not in full-time education or employment to get a job. In a discussion with staff feedback included:

> *'That the long wait for transition from CAMHS to adult psychological services was a major impediment to many of the young people they support.'*
>
> *'[We need] a better service than waiting two years before moving from CAMHS to adult services.'*

Angus Communities Team

In a meeting with the Angus Communities Team[39], staff spoke at length about the current provision of mental health services for young people.

> *'Services are totally stretched – now to get to CAMHS you have to be in crisis.'*
>
> *'I don't think you can ask anyone to wait 18 months for support'.*

University of Dundee Support Staff

In a meeting with University Support Staff they spoke about the:

> *'Increase in the number of students looking for support and guidance with how to get a (ADHD) diagnosis.'*

3.9 Key Findings

- Sufficient resources and support are lacking in the provision of information, support and training.
- Experiences of those engaged with CAMHS were mainly positive or mixed.
- Waiting times for diagnosis and treatment were found to be too long.
- A mix of medication and non-pharmacological treatments was acknowledged as best practice.
- Communications and interactions between health and school could be improved.
- Although there is work being done on a Pathway from CAMHS to Adult Mental Health Services the research team was unable to ascertain its current stage of development.
- An Information Pack created by the Dundee and Angus ADHD Support Group should include in its contents:

- Signposting to services;
- Advice on diagnosis;
- Parenting and Life and Social Skills classes;
- Training information and opportunities; and
- Where to access local information and advice.

CHAPTER 4: EDUCATION

4.1 Introduction

Teachers are often the first to identify ADHD-type behaviours, and the diagnostic process often begins with a referral from the individual's classroom teacher.[40,41]

Education staff's perceptions, knowledge, strategies and relationships with other pertinent professionals supporting the child or adolescent, are important to the child or adolescent's outcomes, as well as to diagnostic considerations and in the treatment decisions.[42]

4.2 Context

This section provides a review of key literature and data associated with ADHD and Education. It is constructed under the following five headings:

- Literature – academic performance.
- Literature – social issues and stigma.
- Literature – professional perceptions and knowledge.
- National guidance – summary.
- Data/Desk Research to provide context of ADHD within local, national and international settings.

4.2.1 Literature – academic performance

A recent study of schoolchildren in Scotland corroborated existing literature on ADHD and education. Those treated for ADHD were at higher risk of low academic attainment compared to their peers, left school at an earlier age, took more unauthorised absences, were more likely to be excluded from school, were at a higher risk of having special educational needs and had poorer performance in examinations. Academic attainment was worse even among children treated for ADHD who did not have special educational needs, while poorer academic attainment and therefore a higher risk of unemployment later in life were not simply due to absenteeism, which was controlled for in the study.[43]

[40] Norvilitis J.and Fang P. (2005)

[41] Mynors G. (2017) In a recent Master's thesis on education professionals' attitudes and the impact on referrals from education in Greater Glasgow and Clyde, Mynors notes that, 'a number of conditions need to be in place for that specialist referral to be made. First, someone in close contact with that child, typically a parent or teacher, needs to recognise that the child's experience or behaviour represents a problem, outside the normal range. They then need to be willing to raise the issue and seek help…They then need to be both willing and able to refer the child or to signpost the parents to a specialist health professional for further assessment.' page 95.

[42] Vereb R.L. and DiPerna J.C.. (2004)

[43] Fleming M. et al. (2017)

4.2.2 Literature – social issues and stigma

Beyond academic performance, there is considerable evidence of children and adolescents with ADHD experiencing social issues at school.[44,45] A large number of studies internationally have found that young people with ADHD and their parents may experience stigma in the form of being stereotyped as having an 'anger problem', and being exposed to discriminatory behaviour, and that this can detrimentally affect that young person's self-esteem and treatment receptivity, as well as leaving them socially isolated and rejected.[46,47,48,49] A study in Ireland of children's and adolescent's explicit and implicit stigma towards peers with ADHD, depression and other issues found that adolescents were less accepting and more prejudiced towards both ADHD and depression than children were. Adolescents also reported significantly stronger feelings of anger and wanted greater social distance towards the peer with ADHD than the peer with depression. The peer with ADHD was discriminated against more and seen as more personally responsible for their difficulties, than the peer with depression.[50]

4.2.3 Literature – professional perceptions and knowledge

Through their likely exposure to numerous sources of inconsistent information about the condition (from training courses, the media, interactions with children, and personal experiences), teachers are often faced with a confusing and contradictory picture of ADHD. This can lead to ambivalent and occasionally prejudicial attitudes[51] together with a lower level of willingness to consider certain educational[52] and treatment options.[53]

A number of studies of teachers have found that a greater knowledge of ADHD tends to lead to more positive attitudes[54,55], while there is evidence that attitudes towards (and beliefs about) teaching children and young people with ADHD can affect the behavioural management strategies

[44] Grygiel P. et al. (2014)

[45] Diamantopoulou S.,Henricsson L. and Rydell A-M. (2005)

[46] Koro-Ljungberg M. and Bussing R. (2009)

[47] Bussing R. et al. (2011)

[48] Singh I. (2012)

[49] dosReis S. et al. (2010)

[50] O'Driscoll C. et al. (2012)

[51] Anderson D.L., Wat S.E. and Shanley D.C. (2017)

[52] Bussing R. et al. (2012)

[53] Moldavsky M. and Sayal K. (2013)

[54] Bekle B. (2004)

[55] Nur N. and Kavakci O. (2010)

employed by teachers.[56] These can in turn affect the engagement with school[57] behaviour and well-being of students with ADHD.[58]

4.2.4 National guidance

The recent (March 2018) National Institute for Health and Care Excellence (NICE) guideline [NG87][59] provides clear guidance on involving schools, colleges and universities in improving the experience of care for those with ADHD and their parents/carergivers. The guidance states:

> *'When ADHD is diagnosed, when symptoms change, and when there is transition between schools or from school to college or college to university, obtain consent and then contact the school, college or university to explain:*
>
> - *the validity of a diagnosis of ADHD and how symptoms are likely to affect school, college or university life;*
> - *other coexisting conditions (for example, learning disabilities) are distinct from ADHD and may need different adjustments;*
> - *the treatment plan and identified special educational needs, including advice for reasonable adjustments and environmental modifications within the educational placement; and*
> - *the value of feedback from schools, colleges and universities to people with ADHD and their healthcare professionals.'*

4.2.5 Data and Desk Research to provide context of ADHD within local, national and international settings

The annual pupil census for publicly-funded schools in Scotland identifies pupils with special needs but does not identify ADHD specifically.[60] The census data can be linked with other sources of information, such as:

- School Leaver Attainment and Destinations Statistics (National Statistics Publication for Scotland, Scottish Government);[61]

[56] Blotnicky-Gallant P. et al. (2014)

[57] Stiener N.J. et al. (2014)

[58] Rush C. and Harrison P. (2008)

[59] NICE (2018). Nice Guideline NG87: Attention deficit hyperactivity disorder: diagnosis and management.

[60] The categories for 'special need' in the Pupils in Scotland census include two specific conditions (dyslexia and autistic spectrum disorder) and can be viewed here: http://www.gov.scot/Topics/Statistics/ScotXed/SchoolEducation/SchoolPupilCensus/SurveyDocumentation

[61] https://beta.gov.scot/news/school-leaver-attainment-and-destinations/

- The Pupil Attendance and Absence in Scottish Schools Survey[62]; and
- The Summary Statistics for Schools in Scotland (which includes exclusions data).[63]

There is a lack of a specific ADHD delineation within the category of 'special need' in the census. Education Scotland does not collect accessible information on the number of pupils in Scottish schools with a diagnosis of ADHD, at either a local authority or a national level, nor does it collect accessible information on the academic performance, leaving age, attendance rates and exclusion rates (both temporary and permanent) of pupils with ADHD. Education Scotland has not published policies or guidance on the education of children with ADHD. However, Education Scotland has continued to support professional learning activities and resources on topics such as Getting It Right For Every Child (GIRFEC) self-evaluation, personalised learning, and supporting learners through Nurturing Approaches.[64]

At a local level, Dundee City Council does not record the number of children and adolescents living within its boundaries who have a diagnosis of ADHD.[65] Dundee City Council does not hold information for the number of children and adolescents in the education system who have ADHD and who are provided with alternative or off-site provision.

Angus Council do record the number of children and young people recorded in the school system with a diagnosis of ADHD (n=179).[66] In 2017, 3.4% of males (n=235) and 0.9% of females (n=58) aged 5-15 were prescribed ADHD medication, for which a diagnosis of ADHD is a prerequisite.[67,68] The available statistics appear to show an inconsistency in the recording of the number of children with a diagnosis of ADHD on school information systems across Angus.

Both Dundee City and Angus Councils were unable to confirm the levels of attainment for pupils with ADHD in S4, S5 and S6, or how they compared with their peers.[69]

Both local authorities were asked the following questions:

> *1. What arrangements are made for children and adolescents with additional support needs when transitioning between schools?*
>
> *2. Are any arrangements made for children and adolescents with ADHD? If so, what are they?*

[62] http://www.gov.scot/Topics/Statistics/Browse/School-Education/PubAttendanceAbsence

[63] http://www.gov.scot/Topics/Statistics/Browse/School-Education/Summarystatsforschools

[64] FOI Freedom of Information Appendix 3

[65] FOI Freedom of Information Appendix 3

[66] FOI Freedom of Information Appendix 3

[67] Number of males and females aged 5-15 in Angus: 6,900 and 6,753 (https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates (accessed: 01/01/2018)).

[68] FOI Freedom of Information Appendix 3

[69] FOI Freedom of Information Appendix 3 and 4

Dundee City referred to their Children and Families Service 'Transition Guidance for Young People with Additional Support Needs (including LAAC) Leaving School'.

Angus holds 'Transition Conferences' to facilitate the sharing of information between agencies to help with this transition. While children and young people with 'significant' additional support needs in Angus are provided with 'enhanced transition' between primary and secondary school, no specific provision is provided for those with ADHD, meaning it is likely to be only those with HKD ('severe ADHD') or ADHD with comorbidities who can take full advantage of this support.

4.3 Methodology

A mixed-methods approach was adopted to gather views and data from education stakeholders. The main methods utilised were:

- Contacts with those in Dundee City and Angus Local Authorities - questionnaires were distributed to teachers, education support staff, and other staff in a range of services relating to childcare and education.
- A conference was held for all those interested in ADHD to raise awareness of the research.
- A series of freedom-of-information requests were given to both local authorities to determine the extent to which they provided ADHD information or ADHD training to education staff.
- Online questionnaires were created for the following groups and then advertised on Wave 102 Radio, through word-of-mouth and on the group's Facebook page:
    - Parents/Caregivers of those with ADHD;
    - Individuals with ADHD (one questionnaire for those under 16 years of age and another for those 16 years and over); and
    - Students with ADHD.
- A seminar of teachers and additional support staff was held in partnership with Dundee's Education department.
- A seminar was held for those interested in adults with ADHD.
- Focus groups were held in Dundee City and Angus with the following groups:
    - After School Clubs – Monifieth and Dundee City Schools;
    - Angus Carers Team;
    - Further Education/Higher Education students (University of Dundee);
    - Dundee and Angus ADHD Support Group (Trustees and all Support Group workers); and
    - Additionally, questionnaires were distributed to a selection of Dundee and Angus Nurseries.

- Interview sessions were held with staff within Education and other services e.g. employability organisations, Dundee Social Enterprise Network [DSEN].
- Local area results from the Parent Survey circulated contemporaneously by the ADHD Coalition are included (of which the Dundee & Angus ADHD Support Group is a founding member).
- Input from CAMHS included (distributed by email through contacts within the CAMHS service).
- Desk Research was undertaken to provide background and context.

4.4 Limitations and assumptions

Throughout this research many sample sizes are small. This was due to the time constraints, the societal and geographic spread of the research, self-selection of research participation and accessibility to children and young people within short time scale.

Numbers of responses can vary considerably to individual questions posed as respondents self selected which questions to answer.

Although samples are small the information provided is relevant to the Dundee and Angus ADHD Support Group and important to the participating respondents whose voices are often not heard.

4.5 Results - Teachers and Education Support Staff

The evidence collected in relation to education staff has been structured under the following 7 sections:

1. Communication and information - from schools and between services;
2. Staff strategies;
3. Training;
4. Resources;
5. Perceptions;
6. Identification of ADHD traits; and
7. Difficulties, challenges and barriers to learning.

4.5.1 Communication from schools and between services

Questions were posed to a wide group of stakeholders to gather views on the effectiveness of communication from schools and between services. Responses from each stakeholder group are presented below.

Teachers

Teachers (n=60) across Dundee City and Angus were asked two questions in relation to communication from schools and between services. The two questions asked are detailed below:

1. What do you think about the nature of communication between education and other organisations, such as health and social work?

The responses are shown in table 4.1 below.

Table 4.1: The nature of communication between education and other services

Response options	Numbers (n=60)
Poor / slow / could be better / not enough face to face	39
Good / beneficial / improved / improving	13
No information or involvement	8

2. How can communication between services be improved?

Teachers provided a range of valuable suggestions of how communication between services could be improved, which are presented below:

'Needs to be honest, upfront and benefit the child.'
'Need joined up thinking and sharing of appropriate information.'
'[We] should receive full details of a child's conditions.'
'Everyone turning up to meeting. Social work meeting[s] are during the week and inconvenient.'
'Observation of child in school setting.'
'Open communication.'
'Information should be shared.'
'Links should be easier.'
'Building better relationships.'
'I think there is good communication when required between CAMHS and social work. I feel there are closer links with DEPS (Dundee Education Psychology Service) and the allied services like OT who provide practical advice and support when needed.'
'I think CAMHS do offer some support but this can be limited without the support of the families.'
'Allowing everyone an input.'

Additionally, there were four respondents who highlighted the need for training and sessions with 'experts'.

Parents/Caregivers

The Scottish ADHD Coalition Parent Survey 2018[70] asked respondents to rate the extent to which they agreed with the statement that the school communicates effectively with them about how well their child is managing at school.

The responses are shown in table 4.2 below:

Table 4.2: Effectiveness of communication between schools and caregivers – by caregiver rating

Response options	Numbers (n=40)
Strongly agree	5
Agree	9
Neither agree nor disagree	9
Disagree	9
Strongly disagree	8

Parents/caregivers were asked (via online questionnaires, the ADHD Support Group Facebook Page and a Parents Support Group meeting) the following question:

> *'If you have had interaction with social work and/or CAMHS regarding your child's ADHD, how well co-ordinated do you feel that these services have been with each other and with education?'*

The responses are shown in table 4.3 below:

Table 4.3: Coordination of services – caregivers responses

Response options	Numbers (n=21)
Poor	15
Uncoordinated	5
Not enough	1

[70] Scottish ADHD Coalition (2018), *Attending to Parents: Children's ADHD Services in Scotland 2018. Results of a Parents Survey by the Scottish ADHD Coalition.* Available at: https://www.scottishadhdcoalition.org/wp-content/uploads/2018/04/SAC-parent-survey-17.4.2018.pdf

CAMHS

Communication improvements suggested by CAMHS included two respondents suggesting joint training sessions involving multiple disciplines. One stated that 'pressure means communication turns into emails', and the other stated that 'perhaps presence at the ADHD support group, tutorials [would be beneficial]'.

4.5.2 Staff strategies

Teachers were asked:

> *When you are supporting/teaching a child with ADHD, what strategies work well?*

The responses received gave evidence of imaginative, flexible and sympathetic teaching strategies used by teachers across Dundee City and Angus.

Table 4.4 below shows a number of consistent themes that were mentioned by at least 1 in 5 respondents. Other responses included 'Fidget toys', 'routines' and one individual stated that their best responses came from 'treating them, as much as possible, in the same way that every other child is treated i.e. with care and respect.'

Table 4.4: Teacher responses to the question, 'When you are supporting/teaching a child with ADHD, what strategies work well?'

Consistent response themes	Numbers (n=90)
Splitting lessons into short chunks	36
Positive reinforcement / check-ins	24
Use of visuals / different planning formats	17
Regular 'Brain-breaks'	13

*Please note that respondents were able to mention more than one strategy.

One response was received from a Principal Teacher for Supporting Learners at a Primary School:

> *'[I make] sure that the strategies and supports are tailored to the individual child […] Some of the strategies I have used are: Movement break before teaching input; use of fidget toy during teaching input; instructions are short, sharp and repeated with use of visuals when required; visual timetable; emotions chart – use of lanyard when child is struggling to express or communicate fully; brain breaks built in throughout the day with targeted movement or high impact exercise; [and] differentiated tasks'.*

A similar question was asked to education support staff:

Do you support individuals with ADHD or have you supported individuals with ADHD in the past? If so, which strategies for supporting this individual have worked well for:

(a) overcoming barriers to learning?

(b) de-escalating challenging behaviours?

The responses are shown in Tables 4.5 and 4.6 below:

Overcoming barriers to learning

Table 4.5: Education support staff responses to a question about overcoming barriers to learning

Consistent response themes	Numbers (n=47)
Short and precise instructions	12
Regular short breaks	10
Quiet/calm environment	10
One-to-one support	7
Patience	4
Achievable targets	4

*Please note that respondents were able to mention more than one barrier to learning.

Table 4.6: Education support staff responses to a question about de-escalating challenging behaviours

Consistent response themes	Numbers (n=45)
Voice and environment calm	17
Distractions	13
Removing from heightened situation	7
Encouraging breathing	5
Spotting triggers early	3

*Please note that respondents were able to mention more than one de-escalation technique.

4.5.3 Training

A total of 139 teachers responded through the teachers' survey to a question about whether they had participated in any staff development or training specifically related to ADHD.

The responses are shown in table 4.7 below:

Table 4.7: Teacher response to the question, 'Have you participated in any staff development or training (CLPL)[71] specifically related to ADHD?'

Responses received	Angus/Dundee City	Total figures
Yes, within the last year	28	28
Yes, within the last two years	24	24
Yes, within the last five years	30	30
Yes, but it was more than five years ago	17	17
No, never	32	32
Don't know	8	8
TOTAL	**139**	**139**

A total of 48 teachers also reported that they had carried out personal research. Of these, 40 said they had used online materials, while eight said they had done other reading on the subject.

The same question was distributed to education support staff across Dundee City and Angus and the responses [n=229].

The responses are shown in table 4.8 below:

Table 4.8: Education support staff response to the question, 'Have you participated in any staff development or training (CLPL) specifically related to ADHD?'

Response options	**Number who responded**		
	Angus	**Dundee City**	**Total**
Yes, within the last year	16	27	42
Yes, within the last two years	12	10	22
Yes, within the last five years	17	11	28
Yes, but it was more than five years ago	21	12	33
No, never	57	37	94
Don't know	6	3	9
TOTAL	**129**	**100**	**229**

[71] Career Long Professional Learning

4.5.4 Resources

Teachers and education support staff were asked the question:

> *The Dundee & Angus ADHD Support Group is considering putting together an information pack to help professionals supporting individuals with ADHD. What information would you like to see in this information pack?*

The responses are shown in Table 4.9 below. Also included are responses from other support staff in childcare (e.g. nursery staff and student support staff).

Table 4.9: What information should be included in an information pack for professionals supporting individuals with ADHD?

Responses	Teachers	Education support staff	General support staff	Student support staff
Practical strategies / Whole class Strategies / Training / How to support	57	34	18	9
Basic Information / including for families, parents etc	20	18	5	6
Traits and identifying characteristics	16	15	8	2
Case studies /stories	6	1		
Resources / Guide / ADHD Dictionary	6	2		3
Help with referrals / better health communication	4	1	3	
TOTAL	**109**	**71**	**34**	**20**

Teachers and education support staff were then asked a follow-on question:

> *What other resources would most help you to support individuals with ADHD?*

The responses are shown in table 4.10 below:

Table 4.10: What other resources would most help you to support individuals with ADHD?

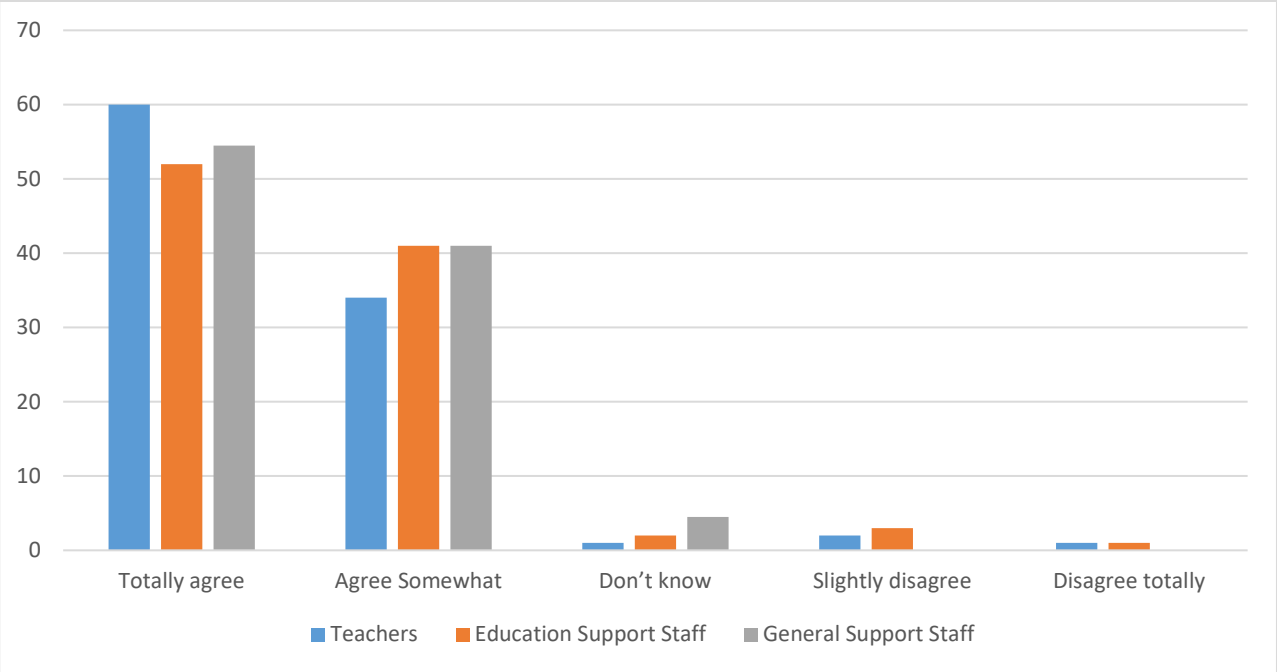
Responses	Teachers	Education support staff
Training	24	34
Staff qualified / knowledgeable about ADHD	6	4
More relevant resources/materials	2	3
More time/space	2	3
Where to find ADHD info	2	0
TOTAL	36	46

4.5.5 Perceptions – Teachers and Education Support Staff

Teachers, Education Support Staff and General Support Staff were asked to what extent they agreed as to whether or not ADHD is a genuine condition.

The responses are shown in Figure 4.11 below:

Figure 4.11: Responses to the question 'Is ADHD a genuine condition?'



4.5.6 Perceptions – Parents/Caregivers

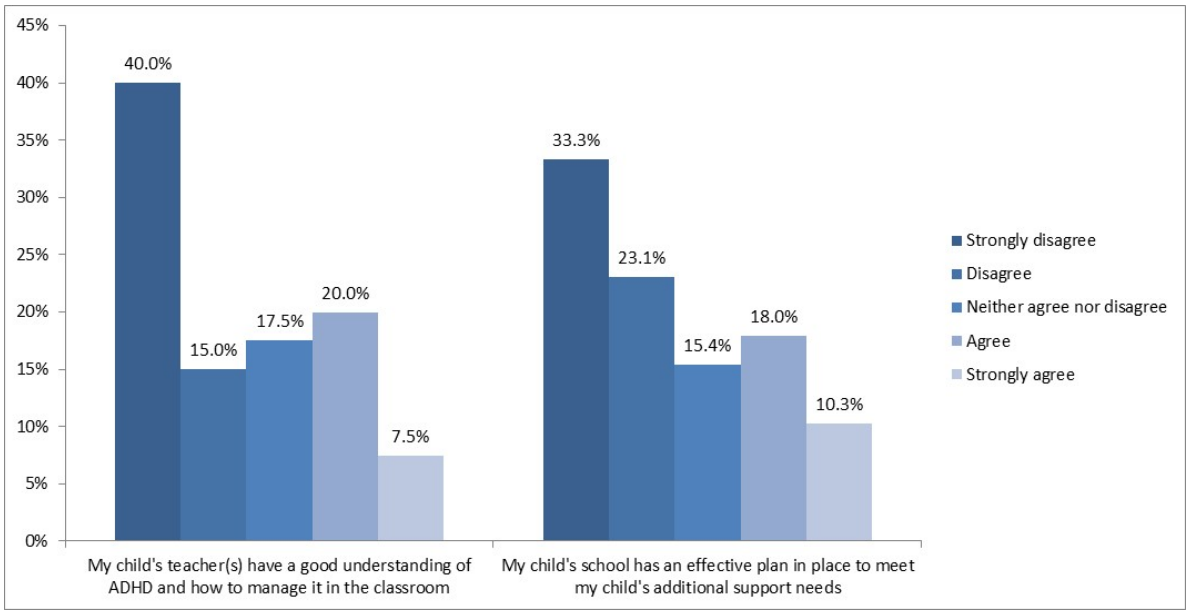
The Scottish ADHD Coalition Parent Survey (2018; Angus and Dundee City) presented to parents/caregivers the following two statements:

> *1. Over the past year my child's teacher(s) has/have a good understanding of ADHD and how to manage it in the classroom; and*
>
> *2. Over the past year my child's school has an effective plan in place to meet my child's additional support needs.*

Respondents (n=40) were asked to grade their agreement with the statements using a simple Likert scale.

The responses are shown in Figure 4.12 below:

Figure 4.12: Parents/Caregivers responses – teachers understanding, management and planning of ADHD in the classroom'[72]



Parents/caregivers were asked:

> *Are your child's teachers and/or support staff knowledgeable about ADHD?*

The responses are shown in Table 4.13 below:

[72] In response to the Coalition's Parent Survey question, 'What would you most like to see improve in education services to support you and your child better', nearly two thirds (65%; n=22/35) of those suggested staff training and/or a generally better understanding of the condition among staff.

Table 4.13: Responses to the question 'Are your child's teachers and/or support staff knowledgeable about ADHD?'

Response options	Number who chose option
Yes, very	2
Yes, somewhat	8
Mixed	21
No, not really	7
No, not at all	4

4.5.7 Perceptions – Individuals with ADHD

Two groups of individuals [n=22] with ADHD (16+) were asked the following questions:

1. *Did you feel the teachers and/or support staff had a good understanding of ADHD?*
2. *If you could recommend one thing that would have improved your time at school, what would it be?*

The responses are shown in Tables 4.14 and 4.15 below:

Table 4.14: Responses to question 1 'Did you feel the teachers and/or support staff had a good understanding of ADHD?'

Response options	Number who chose option
Yes	0
Yes they understood sometimes	10
No they did not have a good understanding of ADHD	12

Table 4.15: Responses to question 2 'If you could recommend one thing that would have improved your time at school, what would it be?'

Suggested improvements	Number who chose option
A better understanding among teachers	7
A better awareness of the condition among education staff generally	4
Being assessed for ADHD earlier	2
More suitable strategies put in place to provide support	2
One to one support	1

The following question was posed to individuals aged 16+ (n=13) and subsequently to FE Students (n=7):

> *Was there anything that you found especially difficult at school?*

The responses are shown in Table 4.16 below:

Table 4.16: Responses to the question 'Was there anything that you found especially difficult at school?'

Responses given	A group of individuals (16+)	FE Students
Concentration issues	6	5
Literacy/handwriting	3	0
Friendships	2	1
Behaviour issues	2	1

The following question was posed to individuals ages 16+ (n=10) and subsequently to FE students (n=8)(of whom five responded):

> *If you could recommend one thing that would have improved your time at school, what would it be?*

The responses are shown in Table 4.17 below:

Table 4.17: Responses to the question 'If you could recommend one thing that would have improved your time at school, what would it be?'

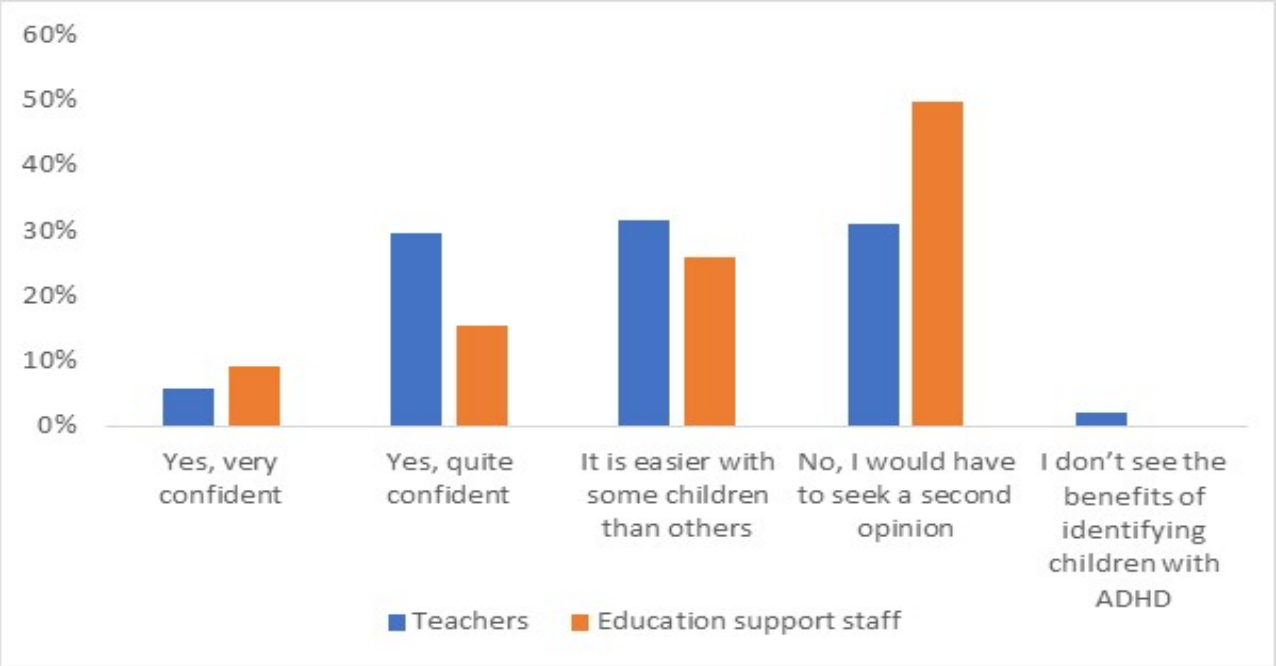
Responses given	A group of individuals (16+)	FE Students
Awareness and understanding of ADHD	7	2
Support for behaviour	2	
Smaller class/one to one support	1	1
Early diagnosis	0	2

4.6 Identification of ADHD traits

Teachers were asked if they would feel confident identifying ADHD traits in a child. Education support staff were asked the same question.

The responses are shown in Figure 4.18 below:

Figure 4.18: Responses to the question 'Would you feel confident identifying ADHD traits in a child?'



4.7 Difficulties, Challenges and Barriers to Learning

Education Support Staff were asked:

What are the main needs or difficulties within the classroom likely to be?

The responses are shown in Table 4.19 below:

Table 4.19: Responses to the question 'What are the main needs or difficulties within the classroom likely to be?'

Response types	Number of responses
Attention/focus/concentration	122
Behaviour	31
Lack of confidence/anxiety	8
Communication issues	8
Socialising difficulties	8
Lack of relevant resources / time	8

Education Support Staff were asked:

> *What have been the main challenges faced in school of individuals with ADHD that you have supported?*

The responses are shown in Table 4.20 below:

Table 4.20: Responses to the question 'What have been the main challenges faced in school of individuals with ADHD that you have supported?'

Response types	Number of responses
Difficulties making and keeping friends/low esteem	30
Difficulties with concentration	23
Behavioural issues	12
Lack of support / understanding	6

Teachers were asked:'

> *What do you think are the biggest barriers to learning children and young people with ADHD face in school?*

The responses are shown in Table 4.21 below:

Table 4.21: Responses to the question 'What do you think are the biggest barriers to learning children and young people with ADHD face in school?'

Response types	Number of responses
Lack of understanding/knowledge/support in those around individuals with ADHD	47
Keeping attention/focus/distractions	35
Challenging behaviour/impulsivity	12
Lack of communication between those interacting with the child	8
Curriculum	6
Social Issues/skills	4

4.8 Key Findings

4.8.1 Data

- Virtually no information is currently collected that would give us an indication of how those with ADHD fare in school.
- The numbers of those at school with ADHD provided from the Angus school system would appear to suggest that ADHD is inconsistently recorded on school information systems.
- Dundee does not hold records of numbers of pupils with ADHD.

4.8.2 Communication and information

- Responses received from the different stakeholder groups indicate that levels of communication vary considerably with respect to school communication with parents/caregivers, within schools themselves and with other services (such as social work and CAMHS).

4.8.3 Staff strategies

- Evidence gathered indicates imaginative, flexible and sympathetic teaching and support strategies used by education support staff.
- Teachers identified practical strategies to use in class, information on the identifiable characteristics of ADHD, and basic information on ADHD as a condition, as the information they would most like to see in an information pack.

4.8.4 Training

- Evidence gathered showes that training is increasing over the last 3 years in both Dundee City and Angus but that many staff have still never received any training in ADHD.

4.8.5 Resources

- Feedback received identifies a shortage of resources and support in dealing with ADHD.
- Education staff indicated that they are not always able to support children in the way they would like as support to teachers themselves is not available.

4.8.6 Perceptions

- The majority of those who responded reported that they believe 'totally' that ADHD is a genuine condition.

- Feedback received identified a lack of knowledge in dealing with ADHD and evidence of misconceptions / mixed perceptions about the condition.
- Feedback from individuals with ADHD, parent/caregivers of those with ADHD and CAMHS professionals on the attitudes and knowledge of education staff was generally negative, with very few wholly positive appraisals from these three groups.

4.8.7 Identification of ADHD traits

- Teachers and education support staff responses show that there is was a degree of confidence in identifying ADHD but that there is also a need to gain a second opinion.

4.8.8 Challenges and barriers to learning

- Education staff identified a number of significant challenges and barriers to learning that children with ADHD face at school:
    - Difficulties keeping attention and being distracted by noises in class;
    - Lack of understanding and knowledgeable staff; and
    - Difficulties making and keeping friends.
- Feedback from parents/caregivers identified permanent and temporary exclusions among their children with ADHD as barriers to achievement.

CHAPTER 5: EMPLOYMENT

5.1 Introduction

The Research team met with local Social Enterprises at a Dundee Social Enterprise Network meeting, held focus groups and interviews with Employment Support Agencies, individuals 16+ with ADHD and parents/caregivers but due to time constraints and geographical spread of the research no focus groups were held with employers.

5.2 Context

ADHD can have a considerable impact on the employment prospects and experiences of those with ADHD[73] and their parents/caregivers[74] with difficulties with memory, behavioural issues and disruptive sleep patterns, affecting employment and opportunities for employment.

Employees with ADHD may have difficulty managing their time, organising their schedule and following instructions, while they may also exhibit emotional liability, poor social skills, and procrastination. This can make it difficult for them to work effectively with colleagues, accept instructions from line management, and deal with the public.[75]

Whilst specific challenges faced by parents/caregivers may vary, it is possible to identify several common impacts of the condition on parents which have a knock-on effect on their employment. In a survey conducted in Europe, parents/caregivers reported having to miss or alter their work, avoiding social activities, increased worry and stress, and several other strains on family life, even with the use of ADHD pharmacotherapy.[76]

Relatively few studies have examined the implications of ADHD for occupational functioning specifically, and fewer still outside the USA. [77] To the research team's knowledge, to date no studies in the UK have examined the links between ADHD and employment, unemployment or poor occupational functioning.

[73] Currie et al., (2010); Fletcher, (2014;): Bozionelos and Bozionelos, (2013); Halmøy et al. (2009): Halleland et al, (2015)

[74] *Fridman et al. (2017); Flood et al. (2016); Ronis et al. (2015).*

[75] Adamou et al. (2013).Typical resolution of these issues from these individuals' line management might take the form of a confrontation, which may result in that individual becoming demotivated, or in the swift degradation of their working relationship with their colleagues. There may also be the potential for workaholism and subsequent burnout

[76] Fridman et al. (2015)

[77] Adamou et al. (2013)

Employers are increasingly adopting zero-tolerance policies towards aggression and harassment in the workplace thus some impulsive or even inappropriate behaviours either directly or indirectly associated with ADHD in adults may further negatively impact on their experience in employment.[78]

To ascertain what records are kept regarding employment and those with ADHD the Department of Work & Pensions was asked if the Jobcentre:

- collected information on the number of individuals it supports who have ADHD;
- had in place any specific protocols to support individuals with ADHD; and
- advised individuals with ADHD to disclose their ADHD in job applications.

Although such records are kept it was too costly for the Research team to access them as the response here states:

> *'I can confirm that we hold information falling within the description specified in your request. However, we estimate that the cost of complying with your request would exceed the appropriate limit for central Government, set by regulations at £600. This represents the estimated cost of one person spending 3½ working days in determining whether the Department holds the information, and locating, retrieving and extracting it. The information requested is recorded on each individual claimant account, following a self-declaration by the claimant. To gather the information requested every individual claimant record would need to be accessed and checked for the information requested.'*

The Scottish Government does not have in place an electronic system which would allow it to link health and mental health data with employment data. It cannot therefore say how many individuals with a diagnosis of ADHD (or additional support needs generally) are in full-time employment or further education, unemployed/out of work, or receiving out of work benefits.[79]

5.3 Methodology

Throughout this research many sample sizes are small. This was due to: the time constraints; the societal and geographic spread of the research; self-selection of research participation; and accessibility to children and young people within short time scale.

Although samples are small the information provided is relevant to the Dundee and Angus ADHD Support Group and important to the participating respondents whose voices are often not heard.

In gathering the views of a range of stakeholders in relation to employment issues, the following methods were used:

[78] *Küpper et al. (2012).*

[79] FOI (18/00658) Freedom of Information Appendix 5

- Focus Groups were held with:
    - Parents/Caregivers;
    - Individuals with ADHD 16+; and
    - Discover Opportunities Staff.
- Interviews were held with:
    - Individual members of Dundee Social Enterprise Network;
    - Dundee and Angus ADHD Support Group;
    - Skills Development Scotland;
    - Department of Work and Pensions; and
    - The WISE Group.
- Desk-based research was carried out to provide background and context.
- Online and email responses were received from questionnaires.

5.4 Employers – Social Enterprises

Due to limited time for the research study, the research team did not have time to hold a focus group with local employers.

At a Dundee Social Enterprise Network (DSEN) meeting social enterprises which work with vulnerable and deprived communities and employ local people, were asked:

> *What ADHD-related support could be provided to social enterprises working with or employing people with ADHD?*

The responses are shown in Table 5.1 below:

Table 5.1: Possible ADHD-related support for social enterprises – views of employers

Responses received	Number of responses
Partnership working to raise awareness	5
Coping mechanisms to help with behaviours	4
Focus groups for young people	1
Training to help identify symptoms/behaviour	1

5.5 Support into Employment

The Dundee and Angus Support Group has a programme in place – '**Youth Transition to Work'** – to help members of the group participate in new activities, meet new people, learn new skills and have work experience opportunities to help them in their transition from school to work and/or college.

The two year programme is funded by NHS Tayside Community Innovation Fund, the Gannochy Trust and Scottish Children's Lottery 'Chance to Succeed fund'. The young people are encouraged to try out new things and learn new skills and already a few have spent time in the ADHD Charity Shop improving their communications skills, learning about good customer service and helping with payments, display and stock rotation.

The Scottish ADHD Coalition of which the Dundee and Angus Support Group is a founding member has produced an Employers Guide to ADHD which can be downloaded from their website.[80]

Jobcentre Plus through their **District Employment Advisors (DEA)** provide support to those with disabilities:

> *'If you have a health condition or a disability that affects your ability to work, you can get assistance and advice on returning to the workplace by speaking to a Work Coach at your local Jobcentre Plus. They can help with work preparation, recruitment, interview coaching and even confidence building.'*[81]

Skills Development Scotland (SDS) provides personalised career support:

> *'To those who need it most'*.[82]

It identifies the range of supports it delivers as including:

> *'Intensive one to one coaching, group activities and/or the use of our digital services, often in a facilitated way, to encourage career exploration and learning.'*

While not providing specific provisions for ADHD, Skills Development Scotland, through its commitment to providing a personalised service:

> *'Which focuses on the individual learning journey of each person.'* [Ensures that] *'advisors have access to resources which can help them support customers with specific needs such as ADHD which have been developed in conjunction with advisers and specialist organisations and are updated on a regular basis'*.

For additional support needs generally, Skills Development Scotland's intranet:

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[80] www.scottishadhdcoalition.org/adhd-and-employment

[81] https://www.jobcentreguide.co.uk/jobcentre-plus-guide/34/disability-employment-advisors (accessed 20/02/2018).

[82] See https://www.skillsdevelopmentscotland.co.uk/what-we-do/

'Includes an ASN Section that provides information to support colleagues' knowledge and understanding of a range of additional support needs including a page specifically relating to autism and a page for ADHD.'

There are also resources that can be used e.g. picture cards to support discussion and case studies to challenge preconceptions and encourage the aspirations of those with additional support needs.

For 'Employability Fund' (EF) Trainees, Skills Development Scotland has also set up an 'ASN Access Fund', which provides additional funding to:

'Meet reasonable adjustments required by the individual undertaking training.'

From April 2018, **Fair Start Scotland**, a service run by Employability Scotland, will aim to help at least 38,000 people to find employment, including those facing barriers to entering the labour market. Dundee and Angus employment support will be provided by **Remploy** which is a chosen provider on the Scottish Government's Work Able programme. **Remploy Scotland** provides specialist tailored support for unemployed people with health conditions. The programme establishes individuals' goals and aspirations and offers a holistic package of support, focussing on health and wellbeing, personal and social development, as well as core skills and ambition.

Access to Work, delivered by the **Department for Work and Pensions**, is a scheme designed:

'To help disabled people start and maintain employment.'[83]

Employers pay upfront for this scheme and claim the costs back. Application for this scheme starts online then requires an assessment to see what support can be provided and support is based on individual needs.[84]

The **National Employer & Partnership Team (NEPT)**, set up by **the Department for Work and Pensions**:

'Focuses on working with employers to move people into, or closer to, work, developing an understanding of employers' needs while helping them to shape recruitment practices that support DWP's customers. The partnership programme addresses key challenges faced by DWP, in particular reducing employment gaps among disadvantaged groups and increasing diversity in recruitment.'

The Tesco (Retail Company) Regeneration Partnership Programme is one of many employer partnership programmes. It specifically targets long-term unemployed jobseekers, guaranteeing job placements for people who are out of work for more than 6 months.[85]

[83] Support is also provided to those with 'hidden impairments'.

[84] http://inclusionscotland.org/what-we-do/employability-and-civic-participation/employability/employability-guide-menu/access-to-work/ (accessed 20/05/2018).

[85] http://ec.europa.eu/social/BlobServlet?docId=16991&langId=en

The **Helm Employment & Training Group** is a Dundee-specific service which has many facilities which offer practical training to help young people get on the right track for their careers. It is partnered with several other organisations, as well as **Dundee and Angus College**, and helps to arrange placements and work experience with companies.[86]

A focus group was held with **Discover Opportunities Dundee** staff who provide services for individuals aged 16 – 64 years across Tayside and who also work with individuals with ADHD. Issues staff deal with regularly include medication, aggression, lack of communication skills, anxiety - especially in girls and lack of job seeking skills.

Discover Opportunities Dundee carried out a backtracking exercise which showed 9 out of 10 young people did not go on to positive destinations and had mental health issues. There is now a Mental Health Nurse in the team who carries out one to one counselling:

> *'The kids don't see him as a mental health nurse, they come in to see him about lots of different things. Because he's a mental health nurse and we're not, he gets his supervision through community mental health. He's able to pick up on the support that these young people need.'*

They also run courses covering all job seeking skills to which participants can return if unsuccessful getting a job.[87] The staff stated:

> *'There should be something like us but just focused on ADHD.'*

Although staff had participated in mental health and first aid training they had not undertaken any specific ADHD training nor training covering de-escalation techniques.

An interview took place with representatives from the **WISE Group** whose roles are to support those aged 16 and over in Dundee City to find employment. Individuals are self-referred, referred from the Job Centre, from Dundee City Council and from other organisations which know about the Wise Group. They identified four or five adults they currently work with who have ADHD, and several others whom they suspect of having ADHD or ASD. One member of staff had received training in ADHD in their previous position as a Mental Health Nurse, but the rest of the team had not.

One shared his experience working with young people with ADHD:

> *'With the guys I'm working with they all have issues with their time keeping. They all fail to attend their appointments. So, it's just constantly reminding them 'you have this coming up are you going to attend?' 'have you got everything you need?' None of the guys I'm supporting with*

[86] https://www.helmtraining.co.uk/

[87] 'What then happens is, they go away to college, or they go to a training programme, and if they don't find work they come back [to Opportunities Dundee]. That was when we developed the idea of the 'Fairy Job Mother' programme [...] Its recently been renamed and rebranded as 'employabiliTAY'. The Scottish government recognised that it was such a good programme they have put money into it for us to take regionally.'

ADHD have succeeded to find a job yet. I do have one that is going to volunteer at the ADHD shop.'

'For adults, they don't really know where they can go after they turn 16. Having somewhere they can go and speak to people with similar issues is a big area lacking in Dundee [...] Just last week I was in a health meeting and they were looking to start something in the north east for children with ASN. I mentioned the ADHD group and they didn't know it existed. Everyone knows a lot about ASD, not a lot know about ADHD.'

5.6 Employment Experiences of those with ADHD 16+

The following are responses to Facebook research:[88]

'I think there should be changes. My son who has ADHD, forgets things very often which affected his job he got when he left school. He never kept that job. He was 17. He's 19 now and has not worked again.'

'...workplaces are most of the time very rigid in tasks, how does this work for people with a 15 min attention span? As for getting a job the problem is keeping it.' (Community Centre Worker)

'We can [get] jobs [we] just find it hard to keep them.'

'Outdoor work is good.'

'Not that I've had much luck with getting a job since moving to Scotland 3 years ago, almost. But I've def not got one from the interviews I've had since announcing my ADHD diagnosis.'

Parents/caregivers (n=14) were asked:

'Does having a child with ADHD affect your employment?'

The responses are shown in Table 5.2 below:

15/02/2018. The post stated: 'As part of our research we would like to hear from you about your experiences with ADHD in the workplace! Did you or someone you know who has ADHD tell your work that you/they had ADHD? - If not, why not? - If so, how did your/their work respond to this? What issues have you or someone you know with ADHD had in work that you think might be related to ADHD? Do you know anyone with ADHD who is unemployed? What would you like to see change in the workplace to better accommodate people with ADHD? What support could we as a group provide to help those with ADHD find and keep a job?'

Table 5.2: Effects on employment due to having a Child/ren with ADHD – Views of parents/caregivers

Responses received	Number of Parents /Caregivers
Extra stress/anxiety due to being called to school and attending hospital appointments	7
Gave up work / Went Part-time	4
No effect as well supported	3

5.7 Key Findings

5.7.1 Introduction

- Time and geographical spread of the research restricted contact with employers both in Dundee and in Angus.

5.7.2 Context

- ADHD has a considerable impact on those with ADHD when seeking, gaining and keeping employment.
- As a parent/caregiver where there is a child with ADHD this can have an impact on retaining full time employment.
- Records on ADHD and employment are difficult and costly to gain access to as details are held only on individual claimant records.

5.7.3 Support into Employment

- There are several agencies offering support into employment across the age range of 16-64 years.
- Not all organisations who participated in the research provided either ADHD training and/or ADHD information.

5.7.4 Employment Experiences of those with ADHD 16+

- ADHD has a considerable impact on those with ADHD when seeking, gaining and keeping employment.
- As a parent/caregiver where there is a child with ADHD this can have an impact on retaining full time employment.

- Stress and anxiety caused due to having to leave work to meet needs of those with ADHD – Hospital appointments, called to school etc.

CHAPTER 6: FEMALES

6.1 Introduction

The research team did not have sufficient time to set up focus groups of only females. Desk research was carried out to set contextually the situation regarding ADHD and females. Some information from the NHS and CAMHS was received.

6.2 Context

Currently, of the fast-growing body of research on ADHD in the past few decades, a relatively small proportion has focused on ADHD in girls specifically.[89]

While individual males and females with ADHD may present in similar ways, more broadly there appear to be variations in development and presentation between the sexes. Subtle but significant differences exist in the neuropathology of ADHD in males and females, while hormonal factors[90] may also play an important and distinct role in determining how ADHD presents in females.[91]

As with males, the most common co-occurring disorders for females with ADHD are conduct disorder (CD)[92], oppositional defiant disorder (ODD), depression, anxiety disorders[93] and learning disabilities (LDs).

Females with ADHD are also at high risk of antisocial, addictive, anxiety, mood, eating, and substance use disorders.[94]

Girls with ADHD have been found to manifest a degree of social impairment[95] comparable with boys with ADHD, as well as considerable deficits in interpersonal functioning (compared with girls without ADHD).[96] It has been proposed that because disruptive and 'high-activity' behaviours are more

[89]Hinshaw S.P. and Blachman D.R. (2005).

[90] Nussbaum N.L. (2012) identifies two such hormonal influences on the brain. In addition to thyroid functioning, estrogen, and its impact on the development of dopamine receptors, may be a cause for a concurrent increase and decrease of symptoms in females and males respectively as they approach adulthood.

[91] Nussbaum N.L. (2012).

[92] Owens E.B. and Hinshaw S.P. (2016) In their study of females with ADHD, Owens and Hinshaw found that childhood conduct problems were associated with adolescent internalising problems

[93] Bauermeister J. (2007). Co-morbid anxiety disorders appear to be particularly prevalent among girls with 'ADHD-PI' subtype (i.e. inattentive subtype)

[94]Nussbaum N.L. (2012); Mikamiet al. (2010); Biederman J. et al. (2010)

[95] Ohan J.L. and Johnston C. (2006).Girls with ADHD have been found to exhibit more socially detrimental behaviours than non-ADHD girls, including both overtly and relationally aggressive behaviour

[96] Greene R.W. et al. (2001)

deviant and salient in female peer groups, there is a higher risk of peer rejection for females with ADHD.[97,98,99]

Very few studies have examined ADHD and the home life with a specific focus on females. It has been found that girls with ADHD experience significantly greater impairment than girls without ADHD on a range of measures[100], including those related to family functioning, such as relations with siblings and parents.[101,102]

6.3 Diagnosis and Treatment - Females

Community samples indicate that the ratio of males to females who would meet the current ADHD criteria in childhood is 3:1.[103] The ratio of males to females observed in clinical samples is 6:1, which would seem to indicate that a far higher proportion of males than females with the condition in childhood have been assessed and provided with treatment.[104] Researchers[105] have suggested four potential contributing factors to the under-representation of females in ADHD. Firstly, the fact that the vast majority of neurodevelopmental disorders show a male predominance may have contributed to a male-centric focus in research in ADHD. Secondly, the authors identify a general tendency within biomedical science to prioritise investigations of disorder in males. Thirdly, that clinical literature is based on samples of individuals who have been referred for assessment and treatment, and that the

[97] [97] Chen L. et al. (2011); Fanti K.A. and Henrich C.C. (2010); Keiley M.K. et al. (2000); Pedersen S. et al. (2007): Conduct problems can lead to short-term rejection by peers..

[98] Burke J.D et al. (2014) Conduct problems can lead to longer term rejection by peers

[99] Marion D et al. (2013. Peer rejection predicts poor adult adjustment

[100] Greene R.W. et al. (2001)

[101] Chang J. and Hinshaw S.P. (2004).A study conducted at a summer camp found that, while maternal negativity (displayed during parent-child interactions) predicted noncompliant and stealing behaviour at the camp among boys, it was not predictive of the daughter's externalising or internalising behaviour (once the daughter's level of non-compliance during the exchange had been controlled); rather, it was the mother's depressive symptoms and levels of parental stress that were predictive of the daughter's internalising and externalising behaviour at camp (even when the level of non-compliance during the interaction was controlled), suggesting the transactional processes between mothers and daughters to be more subtle in nature, and mediated through the mother's internal distress

[102] Peris T.and Hinshaw S.P. (2003) found that parents of girls with ADHD demonstrated higher levels of 'expressed emotion' than did parents of non-ADHD girls. Commenting on the findings of this study, Hinshaw S.P. and Blachman D.R. (2005) posed that the inattentive symptomology (whether or not paired with hyperactivity or impulsivity) may elicit negative, critical attitudes in the parents of girls with ADHD.

[103] Eme R. (1992); Hartung C. M. and Widiger T.A. 1998).The overwhelming majority of developmental, behavioural and emotional disorders of childhood show a male predominance

[104] American Psychiatric Association. (1994); Lahey B.B. et al. (1999). It has been estimated that the ratio of boys and girls with the disorder who have been participants in studies is roughly 3:1 for community samples, and as high as 6:1 in clinical samples (If we treat the ratio observed in community samples as indicative of the general population, and the ratio observed in clinical samples as indicative of the population who have been referred and assessed, we could infer that a higher proportion of males than females with the condition are recognised and assessed in a clinical setting in childhood.

[105] Hinshaw S.P. and Blachman D.R. (2005)

condition is recognised considerably less in females, and therefore less assessed and/or less treated, and that this is likely to lead to an under-representation in females in clinical trials. Finally, it may be that the persistent, and incorrect, belief that ADHD is commensurate with aggression and conduct problems has led to preferential selection of males, who exhibit these characteristics at higher rates.

By adolescence, the sex ratio regarding the diagnosis of ADHD in the community samples is about 2:1, approaching unity by early adulthood.[106]

Concerns have been raised that females with significant difficulties with attention are being misdiagnosed with other forms of psychopathology[107] A large retrospective study found that adult females with ADHD had higher symptom loads, including emotional dysregulation, than adult males with ADHD[108], while there is evidence that females with ADHD are more likely to experience significant internalising symptoms than males with ADHD.[109]

Angus Local Authority collects data on the number of children in the school system with a diagnosis of ADHD.[110] It provided the following breakdown by age and sex – see table 6.1 below.

The female-male ratio varies drastically depending on the age of the pupil but stands at 21% for all pupils with ADHD, aged 5-17, in the Angus school system. This is higher than the ratio of 1:6 (or 16.7% female) recorded in clinical samples of children and adolescents, but below what we would expect from community sample-based estimates of prevalence (i.e. 1:3; 33.3%).

Dundee City Local Authority do not collect relevant data.

Table 6.1: Number of children in the Angus school system with a diagnosis of ADHD – by age and sex

Age	% Female	Female	Male
5	0.0%	0	1
6	50.0%	1	1
7	0.0%	0	6
8	11.0%	1	9
9	29.0%	5	17
10	23.5%	4	17
11	12.5%	2	16

[106] *Hinshaw S.P. and Blachman D.R., (2005); DuPaul G.J. et al. (2006); Faraone S.V. et al. (2000); Wilcutt E.G. (2012).*

[107] Nussbaum N.L. (2012).

[108] Robison R.J. et al. (2008)

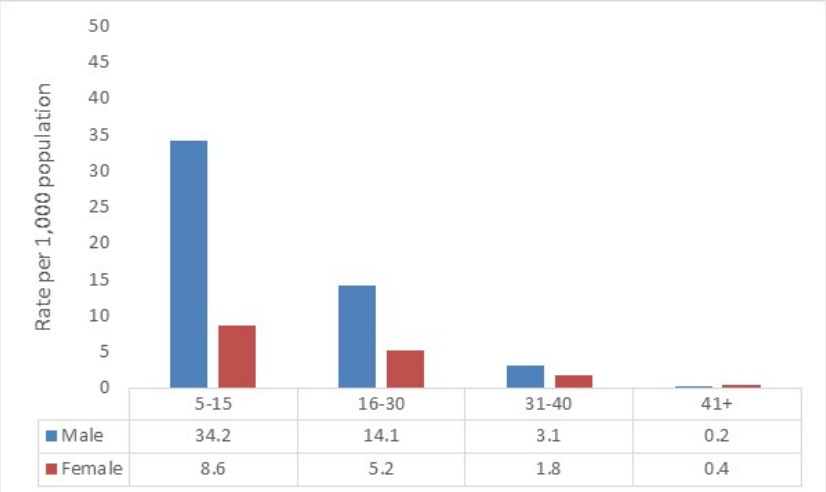
[109] *Hinshaw S.P. (2002); Staller J. and Faraone S.V. (2006).*

[110] FOI (Ref 094/18) sent on 31/01/2018 (response received 01/03/2018). Freedom of Information Appendix 2.

12	33.3%	7	21
13	4.5%	1	22
14	15.0%	3	20
15	44.0%	4	9
16	12.5%	1	8
17	200.0%	2	1
Total	21.0%	31	148

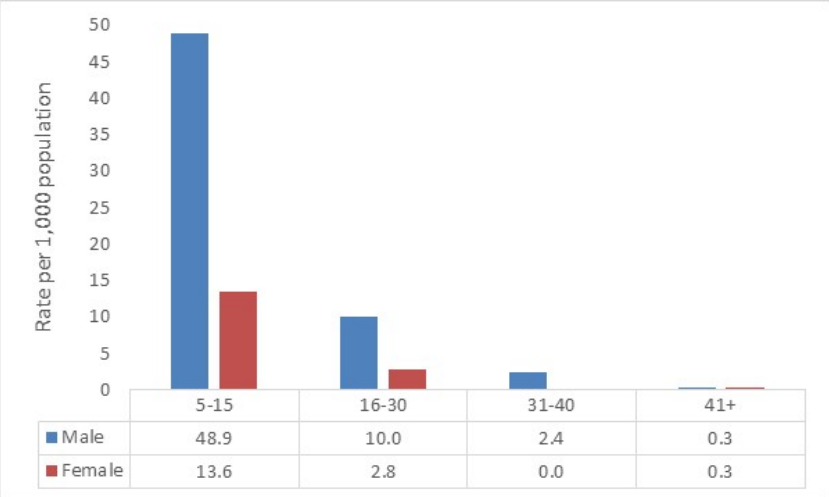
In the absence of data on the diagnosis and treatment of ADHD, prescribing data provides us with a rough proxy measure for the number of those with an ADHD diagnosis who are receiving treatment from mental health services. The Figures 6.2 and 6.3 below show the rates (per 1,000 population)[111] of prescriptions of ADHD medications by age band and sex in Angus and Dundee City.

Figure 6.2: Rates (per 1,000 population) of prescriptions of ADHD medications - by age band and sex in Angus



[111] National Records of Scotland, 2016 mid-year population estimates: https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2016.

Figure 6.3: Rates (per 1,000 population) of prescriptions of ADHD medications - by age band and sex in Dundee



6.4 Child and Adolescent Mental Health Services (CAMHS) Information

CAMHS does not have in place a system which would allow it to determine what proportion of those who are referred and treated for ADHD are female.

CAMHS staff were asked:

> *Please estimate the proportion of those who are referred to you who are female.* [112]

The responses are shown in Table 6.4 below:

Table 6.4: CAMHS estimates of female referrals

• 7 respondents - Under 25% of females referred
• 4 respondents - 25%-50% of females referred
• 1 respondent - 50% of females referred

CAMHS staff were asked:

> *Do you notice a difference between the sexes in terms of the age at which those were initially referred?*

The responses are shown in Table 6.5 below:

[112] It is important to note that individual caseloads may vary considerably with respect to the patients they see.

Table 6.5: Age and gender differences of referral as perceived by CAMHS staff

• 'No'
• 'Males likely younger'
• 'Males referred sooner'
• 'I think that girls are referred at a later age more often – mainly because they don't have as many behaviour problems as boys'
• 'Males are younger'
• 'Females tend to present later than males'

CAMHS staff were asked:

> *Do you notice a difference between males and females (generally) in terms of how those with ADHD present?*

The responses are shown in Table 6.6 below:

Table 6.6: Differences between males' and females' presentation of ADHD as perceived by CAMHS staff

• 'Some girls less hyperactive but more quietly inattentive / daydreamers.'
• 'Females more likely to have inattention difficulties (ADD).'
• 'Males more hyperactive.'
• 'Boys present with more behavioural difficulties – ODD/Conduct disorder type problems.'
• 'Girls much more inattentive and distracted [;] boys I see are more likely to be fidgety, anxious, loud, busy, sad, angry, frustrated.'
• 'Not all the time.'
• 'Females tend to present with ADD; males more disrupted.'
• 'Females: primarily inattentive symptoms; males: primarily hyperactive symptoms.'

CAMHS Staff were asked:

Do you notice a difference between males and females (generally) in terms of: comorbidities?

The responses are shown in Table 6.7 below:

Table 6.7: Differences in co-morbidities of different sexes as perceived by CAMHS staff

• 'No.'
• 'Similar comorbidities.'
• 'Hard to define.'
• 'Girls often presenting with more emotional difficulties and social difficulties/peer difficulties/PTSD difficulties – more likely to have adverse childhood events involving sexual abuse (my impression only) than the boys.'
• 'Both boys and girls ASD and ADHD.'
• 'More males present with ODD and anxiety.'
• 'No obvious differences.'

6.5 Community Mental Health Staff

Community Mental Health staff were also asked if they were aware of the gender difference in the typical presentation of ADHD in females, compared to males of the same age.

Seven from a group of nine felt that although they could identify general ADHD symptoms they could not identify those associated with females, whilst two stated they did not believe there is a significant difference between the presentation of females with ADHD and males with ADHD.

6.6 Teachers and Education Support Staff

Teachers and Education Support Staff were asked if they were aware of the gender differences in the typical presentation of ADHD in girls, compared with boys of the same age.

The responses are shown in Table 6.8 below:

Table 6.8: Gender differences in the typical presentation of ADHD in girls – perceptions of Teachers and Education Support staff

Response options	Teachers	Education support staff
Yes, I am confident I could identify all or most of them	2	2
Yes, I could identify some of them	25	17
I can identify general ADHD symptoms, but not those specific to girls	100	59
I do not believe there is a significant difference between the presentation of girls with ADHD and boys with ADHD	11	21

6.7 Key Findings

- Research shows that missed diagnosis of ADHD can occur with females.
- Male diagnosis may be diagnosed at an earlier age than females and referrals of girls can be less than boys.
- Teachers and Additional Support Needs Staff found some difficulties in identifying ADHD in girls.

CHAPTER 7: HOMELIFE

7.1 Introduction

Support services for families in Dundee City and Angus are provided by either Social Work or third sector organisations. Many of these services have resource limitations which can manifest in long waiting times and an inability to meet the needs of certain client groups.

Both social workers and parents/caregivers themselves reported that ADHD can have a severe negative impact on family functioning, in a wide variety of ways and on all members of the family. Reported experiences of home life from parents/caregivers highlighted the 'whole family' impact of an individual with ADHD.

7.2 Context

The impacts of ADHD on home life are well-documented.[113]

ADHD has been associated with:

- An increased likelihood of parent-child arguments;[114]
- Lower levels of parental self-fulfilment and poorer psychological well-being among parents;[115]
- Maternal depression and paternal drinking problems; and[116]
- Rivalry among siblings and family conflicts.[117]

It has been found that children and adolescents with ADHD and comorbid psychiatric conditions are more likely to experience family disruption, harsh or disengaged parenting and the impacts of parental depression.[118]

To complicate matters, the links between parental ADHD and ADHD in offspring are well-established. ADHD is one of the most heritable conditions in psychiatry.[119]

[113] The vast majority of studies of parental ADHD do not differentiate between ADHD symptom domains (i.e. inattention and hyperactivity-impulsivity. Farbiash T. et al. (2014) found that while both maternal and paternal inattention was correlated with child's aggression, the correlation with hyperactivity-impulsivity symptoms was only significant for mothers.

[114] Edwards G. et al. (2001)

[115] Cappe E. et al. (2017)

[116] Chronis A. M. et al. (2003)

[117] Mikami A.Y. and Pfiffner L.J. (2008)

[118] *Hurtig T. et al. (2007)*

[119] Hinshaw S.P. and Blachman D.R. (2005)

The National Institute of Clinical Excellence (NICE) include the following guidelines for supporting families and carers: [120]

> *'Ask families or carers of people with ADHD how the ADHD affects themselves and other family members, and discuss any concerns they have.'*
>
> *'Encourage family members or carers of people with ADHD to seek an assessment of their personal, social and mental health needs, and to join self-help and support groups if appropriate.'*
>
> *'Think about the needs of a parent with ADHD who also has a child with ADHD, including whether they need extra support with organisational strategies (for example, with adherence to treatment, daily school routines).'*
>
> *'Ask families or carers of people with ADHD how the ADHD affects themselves and other family members, and discuss any concerns they have.'*
>
> *'Offer advice to parents and carers of children and young people with ADHD about the importance of: positive parent– and carer–child contact, clear and appropriate rules about behaviour and consistent management, and structure in the child or young person's day.'*
>
> *'Offer advice to families and carers of adults with ADHD about: how ADHD may affect relationships, how ADHD may affect the person's functioning, and the importance of structure in daily activities.'*
>
> *'Explain to parents and carers that any recommendation of parent-training/education does not imply bad parenting, and that the aim is to optimise parenting skills to meet the above-average parenting needs of children and young people with ADHD.'*

7.3 Methodology

Throughout this research many sample sizes are small. This was due to the time constraints, the societal and geographic spread of the research, self-selection of research participation and accessibility to children and young people within short time scale.

Although samples are small the information provided is relevant to the Dundee and Angus ADHD Support Group and important to the participating respondents whose voices are often not heard.

Information was collected from organisations involved with families as well as from parents/caregivers and children/young people. Information was also received from a small group of foster parents.

[120] NICE Guidelines: https://www.nice.org.uk/guidance/ng87/chapter/Recommendations#information-and-support

- Focus Groups were held with:
    - Dundee and Angus ADHD Support Group – Parents/Caregivers;
    - Armistead Staff;
    - CAMHS Staff;
    - Dundee Early Intervention Team;
    - Angus Carers Staff;
    - Social Workers;
    - Foster parents; and
    - Children and young people.
- Online and hard copy questionnaires were also received.

7.4 Support services available to parents/caregivers and in the home

Dundee City records the number of individuals in the social care system with additional support needs but does not record how many individuals have a diagnosis of ADHD.[121] Likewise Angus records data on all individuals receiving social care services, including any disabilities the individual has, but does not identify if they have ADHD.[122]

Parents'/caregivers' support is likely to be provided via social work.

Both Dundee City and Angus have in place a system allowing social workers to access information about the additional support needs of those they support.[123]

Social work normally becomes involved when there is a referral to Child Care and Protection Services. Referrals can come from self, parent/caregiver, schools, CAMHS and other health professionals and police. Once Social Work becomes involved an inter-agency support team known as the 'Team around the Child' will be brought together, a written plan of needs will be produced and follow on support will be identified and agreed. The 'Team around the Child' includes parents/caregivers, the child or young person and any other appropriate professional agencies who may provide support.

Dundee City does not provide stand-alone support, but rather works in partnership with Allied Health Professionals and voluntary sector parent groups to provide support to parents/caregivers. Partnership agreements exist with key organisations such as Parent to Parent and Barnardo's in order to provide support to parents/caregivers. Dundee Education department has collaborated with the

[121] FOI (20180131011) Freedom of Information Appendix 6

[122] FOI (Ref 094/18) Freedom of Information Appendix 6

[123] FOIs (20180131011, Ref 094/18) Freedom of Information Appendix 7

Dundee & Angus ADHD Support Group to develop an information leaflet for those with ADHD and their families. ~~A~~ wide range of services offer support through schools and nurseries to parents of children with ASN, including ADHD: Educational Psychology Service; ESO (ASN).[124]

Angus Local Authority has in place a Service Level Agreement with 'Parent to Parent' and 'Angus Carers', while currently 'ASN Parent Fora' are being established in each locality.

CAMHS does not provide parenting classes.[125]

7.4.1 Social Work

Social Workers were asked to respond to the statement

- ADHD is a genuine clinical condition?

The responses are shown in Table 7.1 below:

Table 7.1: Social work responses to 'Is ADHD a genuine clinical condition?'

Responses	Numbers Received
Totally Agree	18
Somewhat agree	4
Don't Know	0
Slightly Disagree	5
Totally Disagree	2

Social Workers were asked:

1. Would you feel confident identifying an undiagnosed child, young person or adult with ADHD?

2.What traits in this person's behaviour or personality would you use to identify them as having ADHD?

The responses are shown in Tables 7.2 and 7.3 below:

[124] Education Support Officer (Additional Support Needs).

[125] FOI (IGTFOISA4544) Freedom of Information Appendix 8

Table 7.2: Question a) responses from 27 questionnaires are shown below

Responses	Numbers Received
Very Confident	9
Quite Confident	4
Easier with some than others	5
Would seek a second opinion	8
I don't see the need to identify traits of ADHD	1

Table 7.3: Question b) responses from 27 questionnaires are shown below – please note that multiple answers were given to this question

Responses	Numbers Received
Hyperactivity, behavioural issues, impulsivity	20
Inattentive Behaviour/lack of concentration	17
Problems with sleep	6
Relationships with peers	6
Parenting and social issues	1

Social Workers (n=29) were asked:

What specific ADHD specific training have you received?

The responses shown in Table 7.4 below:

Table 7.4: Social Worker response to ADHD training received

Responses	Numbers Received
Received Training in last 3 years	9
Received Training more than 5 years ago	4
Never received Training	14
Not aware of any Training	2

Neither Dundee City nor Angus Council were able to say how many ADHD-specific training hours/days were delivered to social workers in any of the last three years as they do not hold this data.[126]

Social Workers were asked:

> *What would you like to see in an Information Pack put together by the Dundee and Angus ADHD Support Group.*

The responses are shown in table 7.5 below:

Table 7.5: Social Works responses to Information Pack contents

Information Pack – what is needed in it	Number of responses from Social Workers
Signposting information	9
Where to go for support	8
Strategies / Practical techniques	8
How to identify ADHD Traits	6
Where to find resources	4

Social Workers (n=19) were asked:

> *Do you have/have you had or had any dialogue with CAMHS in relation to ADHD?*

The responses are shown in Table 7.6 below:

Table 7.6: Social Works responses to dialogue with CAMHS

Responses received	Numbers received
Yes	9
Dependent on Additional Support Needs	5
No contact with CAMHS	5

CAMHS Staff were asked if they had suggestions for improvement – these are shown below:

> *'Communicate on case by case basis.'*

[126] FOIs (Ref 094/18; 20180131012-1-1) Freedom of Information Appendix 9

'Shadow CAMHS.'

'Attend parenting groups.'

CAMHS Staff, parents and caregivers and individuals 16+ with ADHD were asked:

How well informed do you find Social Workers to be, in terms of ADHD?

The responses shown in Table 7.7 below:

Table 7.7: Responses on how well informed Social Workers are in relation to ADHD

Responses Received	CAMHS (10)	Parents and Caregivers (19)	Individuals with ADHD – 16+ (14)
Majority of Social Workers are very well informed	0	1	3
Real mixture of understanding	7	9	0
Majority not well informed	3	8	2
No Experience with Social Workers		26	16

7.4.2 Other Support Services

Parent to Parent is a voluntary organisation which supports Tayside-based parents of children with a broad range of additional support needs.[127] Parents may opt into different kinds of support offered, which may include support in the home. Parent to Parent reported that all parents/caregivers of children with a diagnosis of ADHD or who are in the process of receiving a diagnosis of ADHD will be referred from CAMHS.

At the Dundee and Angus ADHD Support Group parents/caregivers were asked about their experiences of Parent to Parent.

Only four responses were received as shown below:

'I did not receive much support. Was supposed to meet but [it was] cancelled;'

'[I received] one-to-one chats and talking through the New Forest Parent Programme;'

[127] Support is also available for parents of children who are seriously or terminally ill, as well as parents who have suffered a bereavement of a child. Parent to Parent also provides advocacy for children and young people with additional needs via their Young Person Advocacy Team.

'[Experiences were] good – however, I felt that if we had received support as a family unit it would have been more beneficial.;'

'I took part in group sessions in Arbroath. I was allocated a worker from Parent to Parent who I was able to contact on a regular basis [...they were] very good and supportive and easy to contact.'

Barnardo's currently run the 'Hopscotch' project, the broader aims of which are:

- To connect and engage with disadvantaged families affected by substance misuse who would not otherwise seek help;
- To respond to the needs of both adults and children to improve relationships and increase resilience, diverting children from chaotic home lives in which family breakdown is a distinct threat;
- To focus on services that come into contact with adults who misuse alcohol and drugs in order to provide a co-ordinated response to whole families and to ameliorate the impact of harmful parent behaviours on children;
- To acknowledge and respect the need for families at risk;
- To access safe, non-judgemental support; and

Individuals and/or their families may be referred directly in a number of ways:

- The named person within the GIRFEC model[128] may identify the need for an additional service

The organisation also runs the 'Strength and Families Programme' and 'Family Group Decision Making' (FGDM).[129]

Barnardo's Family Support Angus (BFSA) work with those up to the age of sixteen 'who in Angus are deemed to be the most vulnerable and in greatest need'.

These individuals are likely to fall into the following categories:

- Children living at home where there is a risk of them becoming accommodated and/or the placement is at risk of disruption; or
- Child/young person who is looked after and accommodated and the placement is at risk of disruption.

[128] I.e. GIRFEC; 'Getting It Right For Every Child'.

[129] The referral process for this service is 'only through Children Social Services where young people/children are at risk of going into care and the Barnardo's service provides a mediator role for the family, to come together to create a plan so the need of the child/children involved are being met.'

BFSA provide: time-limited intensive support, practical support, emotional and relational support; family support; and parent or carer support.

A recently-discontinued service which was available to parents of children with ADHD in Dundee City was offered by the **Dundee Early Intervention Team**.

The **Dundee Early Intervention Team (DEIT**) was a partnership of Aberlour Trust, Children 1st, Action for Children and Barnardo's Scotland, formed in 2011 and in receipt of Big Lottery funding for six years. The DEIT worked together with Dundee City Council, NHS Tayside and Dundee Voluntary Action. Unfortunately they were not successful in attracting ongoing funding and ceased their work in March 2018.

DEIT provided support to families with children from pre-birth to 12 years old and provided parenting support by modelling parenting skills, behaviour strategies, and supporting bedtime and morning routines. The team worked with families at home, in the community or at their centre. They also supported families through the diagnostic process (i.e. from the Armistead Child Development Centre to CAMHS).

Of the 653 children who have been supported by the DEIT over the past six years, approximately 280 had a diagnosis of ADHD. The most common comorbidities observed among the children who were supported and who had ADHD were anxiety, poor and disturbed sleep, emotional regulation difficulties and sensory processing difficulties.

DEIT Staff were asked:

> *What strategies worked well for improving the lives of those with ADHD and their families/caregivers?*

The responses received are shown here:

> *'I use visual timetables and routines to provide structure for children with ADHD.'*
>
> *'Support such as the ADHD Support Group and Parent to Parent help support families.'*
>
> *'Positive re-enforcement strategies.'*
>
> *'Time and space for child to process information, sensory baskets, weighted blankets.'*
>
> *'Calming or distraction techniques.'*

DEIT Staff were also asked:

> *What ways does ADHD affect the home lives of the parents and caregivers of those you supported?*

The responses are shown here:

> *'Refusal to take medication results in impulsivity and hyperactivity which limits the time they can spend outside the family home, difficulty to listen to instruction, difficulties within school,*

morning routines being of a great difficulty, struggle with sleeping at nights which affect mood the following day.'

'Some parents have a lack of understanding about their child's needs which can create difficulties in the parent being able to positively support their child. Other siblings in the household may not be understanding of the additional needs of the child with ADHD.'

'Parents may have a good understanding of their child's needs but could face challenges when family members/school staff/other professionals/members of the public have a lack of understanding. It can be challenging for families to access appropriate support while in the assessment process. Families may also not be aware of what support is available.'

In a meeting with professionals at **Armistead Child Development Centre**, all present expressed regret that the Dundee Early Intervention service was closed as it had been one of the main services to which they referred parents and caregivers. The primary service those at the DEIT referred families to was **The Yard**.

The Yard is 'an adventure play service for disabled children, young people and their families'. Family sessions run on Friday and Saturday afternoons[130], and offer children and young people a range of activities, from assault courses and crafts and baking, while their families take a break in the centre. They told us that those who get in touch who have not found the service for themselves tend to have been signposted from other services, like the Armistead Child Development Centre[131], the Early Intervention Team, schools[132], CAMHS[133], and occasionally social work.

They reported that they do not carry out ADHD-specific training amongst their staff and that they 'would benefit from specialist training in ADHD'.[134]

The **Dundee & Angus ADHD Support Group** holds a Parent Support Group in Dundee on a monthly basis as well as a monthly Parent Support Group in Forfar. The Group's weekday 'One Stop Shop' is run from their premises in Dundee where people from both Dundee and Angus can come for guidance and support. Respite care is provided on a weekday basis with the provision of three youth clubs for ages 5 – 18, with school holiday week long activities programmes and with respite holidays for both children and families.

[130] Additional sessions, Monday to Saturday, are held during the school holidays.

[131] 'We have lots of referrals from Armistead'.

[132] 'We have the most dialogue with education'.

[133] 'We have leaflets at CAMHS – unsure how much they promote our services'.

[134] 'I think the biggest challenge for the new staff, is that they do not have enough knowledge [...] something to refer to. Having experts or real-life examples should be given for training. Trying to arrange staff training days is a nightmare [...] perhaps a small accessible resource would be better, webinars is also an option as this could be shown at monthly meetings. Trying to accommodate different learning styles would be a challenge. Positive stories from those with ADHD would be great [...] very powerful.'

Angus Carers work in partnership with a variety of statutory and voluntary agencies to provide support services in Angus to those who provide unpaid care.

Carers and parents of children in Angus with a disability, frailty, mental illness, or who misuse substances, can self-refer to Angus Carers, who can provide the following services:

- an information and advice service;
- confidential one-to-one emotional support;
- practical support on how to cope;
- group support;
- families' activity programme;
- concessionary leisure passes;
- events and activities;
- signposting and referrals;
- young carers service; and
- support when caring comes to an end due to bereavement.

One staff member from the **Angus Communities Team** reported of a recent attempt they had made to set up a support group for parents of children with ADHD and ASD:

> *'A lot of parents were coming to us and saying that there was no support and that they would like to have this support. The parents felt as though all the support was on the child. We tried to put this together about a year and a half ago, but we hit a wall when parents saw the group as a weakness and were not prepared to come together. I think they felt like they would be judged If they had to tell other parents that their child was sent home; they may feel as though others would think it was bad parenting. From their position they still felt a real stigma with ADHD. I think resources should also be going to parents.'*

7.5 Parents/Caregivers

7.5.1 Impact on families

Parents/caregivers and social workers who participated in the research reported that ADHD can have a severe negative impact on family functioning, in a wide variety of ways and on all members of the family.

Social workers, parents and caregivers, foster carers, Early Intervention team and Individuals with ADHD were asked the question:

What impact do you think/does ADHD has on the home or family?

The Responses are shown in Table 7.8 below:

Table 7.8: Responses to impact that ADHD has on home and family from variety of respondents (Multiple responses were given to this question)

Responses received	Social Workers	Parents /Caregivers	Foster Carers	Early Intervention	Individuals 16+with ADHD
Anxiety/Stress/Managing	10	5	3		3
Relationships/ Family /Siblings	10	4	2	1	6
Demanding/Exhausting	11	4	1	1	
Difficulties with school/health professionals etc	6	1		1	
Behavioural issues	5		3		7
Lack of understanding					5

Parents/Caregivers were asked:

What are the main challenges you face with your child at home?

The responses shown in table 7.9 below:

Table 7.9: Parents/caregivers views on main challenges of having child/ren with ADHD

Responses received	Parents/Caregivers
Organisation, time management	10
Frustration, aggression, behaviour	4
Isolation	1
Unfairness	1

*multiple answers were received

Parents/Caregivers were asked:

How does ADHD behaviour affect:

(a) You as parents/caregiver; and

(b) The siblings in the family

The responses shown in table 7.10 below:

Table 7.10: Parents/caregivers responses regarding effects of behaviour on themselves and siblings in the family

Responses received	Parents/Caregivers	Siblings
Behaviour management	1	3
Quality of life/mental health	3	2
Relationships/isolation	2	4
Different treatment	1	2
Getting a job	1	

Parents/caregivers (n=11) were asked:

Does having a child or children with ADHD affect your health?

The responses shown in table 7.11 below:

Table 7.11: The effects of ADHD on Parents/Caregivers health as perceived by them

Responses received	Parents and Caregivers
Anxiety / Stress / Mental health	8
Feeling of guilt / failing as a parent or caregiver	6
Constantly tired	5
General wellbeing not good	4

* Multiple answers were given in response to this question

Parents/caregivers were asked:

Can you think of any other ways that ADHD affects you or other caregivers in your family?

Responses received are shown here:

'Constantly walking on egg shells. Not knowing what to expect. Others find it difficult to manage or understand why the boys behave they do.'

'I don't think my family are affected too much by my son. They understand and accept X for who he is. I am the only carer in my family.'

'I always feel I'm waiting for the next outburst and I try my best to deal with it without making things worse.'

'Not everyone knows what it's like. They think it's made up.'

'More difficult for elderly family members that have less understanding of ADHD as it is something that wasn't widely recognised when they were bringing up children.'

'Difficulty for family with learning disabilities to understand what is happening.'

'It affects other siblings as they cannot understand the behaviour so causes conflicts, anger and impatience and disassociating.'

'ADHD has affected every family member in my family. If they don't know anything about it they just think he is a bad behaved child.'

Parents/caregivers were asked:

What parental strategies have worked well to improve their child's behaviour at home?

The responses are shown below:

'Consistent rules.'

'Patience.'

'Understanding.'

'Introduced a trampoline for him to go to when angry or upset to burn off rage instead of hitting me or lashing out.'

'Uses Playdoh and kinetic sand to stop him getting to peak anger point.'

'TEP - (Training for Effective Parenting) approach.'

'Coming to this [Dundee & Angus ADHD Support] group has helped as we meet other parents going through the same things/meet experts on ADHD.'

7.5.2 Foster Parents/Caregivers

A small focus group of Foster parents/caregivers (n=4) was asked to respond to the statement:

ADHD is a genuine clinical condition?

The responses are shown in table 7.12 below:

Table 7.12: Foster Parents views on 'Is ADHD a genuine clinical condition?'

Responses received	Numbers received
Totally Agree	2
Somewhat agree	0
Don't Know	0
Slightly Disagree	1
Totally Disagree	1

Foster parent/caregivers were also asked whether they had received any specific ADHD training. One had received training over five years ago. All four foster/caregivers would seek a second opinion on identifying the traits of ADHD.

7.5.3 Support and resources

Parents/caregivers were asked:

> *What support would be most useful to improve the home life of you and your children?*

The responses are shown below:

> *'To be accepted from CAMHS before X starts school.'*
>
> *'Group activities with children the same as him.'*
>
> *'Activities for child and parent.'*
>
> *'To have a plan in place and possible diagnosis before starting school.'*
>
> *'Someone for the child to talk to when they can't talk to parents.'*
>
> *'Building relationship workshops.'*

From various questions the following **support** and **resources** were identified as being needed by the groups.

The responses are shown in Table 7.13. below:

Table 7.13: Required support and resources identified by range of respondents

Responses received	Social Workers	Parents/Caregivers	Foster Carers	'The Yard'
Support Group / One to one / Information	24	5	3	0
Training / Strategies	14	11	3	0
Activities / Clubs	9	3	2	2
Respite	2	1	2	1

7.6 Children and Young People

Children and young people who come along to the Group's Activity Clubs were asked to participate in the research and different approaches were used to engage with them on a variety of topics. It was recognised by the Research Team that time was needed to enable the children and young people to gain trust and feel comfortable providing information.

Also as club activities were still taking place there were alternative attractions to the collection of information for the research.

As time was limited, feedback amounts were small and content was restricted to areas in which participants were happy to provide information.

At the Friday night youth group (age-range: <10), each of the eight individuals in attendance was given up to ten tokens to 'spend' on options for future support and activities at the Group. Each could allocate as many tokens as they wished on their chosen activities.

The choices shown below in Table 7.14 below:

Table 7.14: Youth group activity - 8 participants (age: <10)

Choices	Number of tokens
The chance to try a new sport (e.g. skiing, archery, ice skating)	43
Cooking sessions	13
Help with school work	5
Information about ADHD to give to teachers	5
Go outdoors more	5
Meet up with other youth groups	2

A similar activity took place at the Monday night youth group (age-range: ~14-18).

The options are shown in Table 7.15 below:

Table 7.15: Youth Group activity - 4 participants (age: 14 – 18)

Options	Number of tokens
Support with getting a job (i.e. trying new skills, help looking for jobs, preparing your CV, preparing for interviews, etc.)	24
Groups that support you with school, college or university work (including evening groups where you can get out the house and come along to do homework or coursework)	5
The opportunity to tell your story, to help improve understanding of the condition (to other parents or professionals who work with people with ADHD)	3
A website with accessible and reliable information on ADHD, including ways to help manage your difficulties (i.e. with sleep, anxiety, etc.)	2
The opportunity to hear from successful people with ADHD who have learned to managed some of the difficulties they had when they were younger	2
The opportunity to meet and talk to other people with ADHD outside of the group	2
A drop-in service, where you can call or stop by to get help with any difficulties you are having	2

Individuals under 16 years of age with ADHD (n=3) were asked:

> *1. What do you think might help the ADHD support Group provide better services or resources for young people?*
>
> *2. What would most improve your life?*

One Individual responded to question 1:

> *'We need more support for ADHD, more help at school because teachers don't really get it.'*

Two individuals responded to question 2:

> *'Asking for more support with school work.'*

Further Education students [16+ years] (n=11) were asked:

Which options do you think would help yourself and others with ADHD?

The options and preferences are shown in Table 7.16 below:

Table 7.16: Individuals with ADHD (16+) responses to the question, 'Please select the options that you think would be of the most help to you and others with ADHD in order of preference (enter 1 for the most helpful; you can choose as many or as few options as you wish)'

Options provided to group	Preferences		
	1st	2nd	3rd
The opportunity to hear from people with ADHD who have learned to manage some of the difficulties they had when they were younger	7	3	1
The opportunity to meet and talk to other people with ADHD	5	4	2
A website with accessible and reliable information on ADHD	4	5	1
Groups that support you with school, college or university work	6	2	2
Support getting a job or improving workplace performance	3	5	1
The opportunity to tell your story	2	3	2

Five students provided additional comments as shown below:

'Experts in helping those with ADHD management coming in to train/teach us skills.'

'Other ways of learning/teaching.'

'More group meetings or 1 on 1.'

'Talks at schools.'

'More interactive resources.'

7.7 Key Findings

7.7.1 Context

- The information systems used by Social Work in both Dundee City and Angus do not record ADHD.

7.7.2 Social Work

- ADHD specific training has been received by some Social Workers who participated in the research study but others had never received training.
- Both Social Workers and parents/caregivers reported that ADHD can have a severe and negative impact on family life.

7.7.3 Other Support Services

- Third sector organisations offering ADHD support have limited resources.
- Dundee Early Intervention Services (no longer in existence) were recognised as effective in providing support at home and in the community and during the diagnosis process.

7.7.4 Foster Parents/Caregivers

- Foster parents/caregivers who participated in the research have received no ADHD specific training.
- Foster parents/caregivers who participated in the research would seek a second opinion on identifying ADHD traits.
- 50% of Foster parents/caregivers who participated in the research disagreed either 'slightly' or 'totally' that ADHD was a real clinical condition.

7.7.5 Impact on Families

- A range of negative impacts affect family life for those families with ADHD present in a family member/s.
- Children and young people with ADHD affect relationships with siblings and other family members.

7.7.6 Support and Resources

Participants in this section of the research identified areas of support and relevant resources to improve family and home life.

7.7.7 Children and Young People

- One to one sessions are required to collect detailed information from children and young people with ADHD.
- Help with school and college work were identified as key areas for support.
- The opportunity to hear from others with ADHD, in particular to hear about how they cope and how they live successfully with ADHD.

CHAPTER 8: WIDER ENVIRONMENT

8.1 Introduction

This section will look at the broader aspects of ADHD. The financial burden of ADHD will be illustrated and the views of organisations working with those with ADHD will be presented. The list of problem behaviours associated with ADHD, particularly later in life, is extensive.[135] Those included in this section are not exhaustive and were selected according to broader literature searches on the condition and local people/organisations who participated in the research.

8.2 Methodology

Throughout this research many sample sizes are small. This was due to the time constraints, the societal and geographic spread of the research, self-selection of research participation and accessibility to children and young people within short time scale.

Although samples are small the information provided is relevant to the Dundee and Angus ADHD Support Group and important to the participating respondents whose voices are often not heard.

The following methods were used to collect information within the wider environment of those involved with ADHD.

- Focus Groups:
- Criminal Justice System;
- Dundee Early Intervention Team;
- Discover Opportunities Dundee;
- Individuals with ADHD 16+; and
- Parents and Caregivers.
- Questions distributed at European ADHD Conference.
- Questionnaires received as hard copies and online.
- Desk-based research.

[135] Val.Harpinsheffch-tr.trent.nhs.uk The effect of ADHD on the life of an individual, their family, and community from preschool to adult life. It seems likely that those with ADHD have a predilection for certain problem behaviours later in life, while for others, adverse outcomes associated with ADHD in school, at home, and in employment may contribute to the adoption of other kinds of problem behaviours.

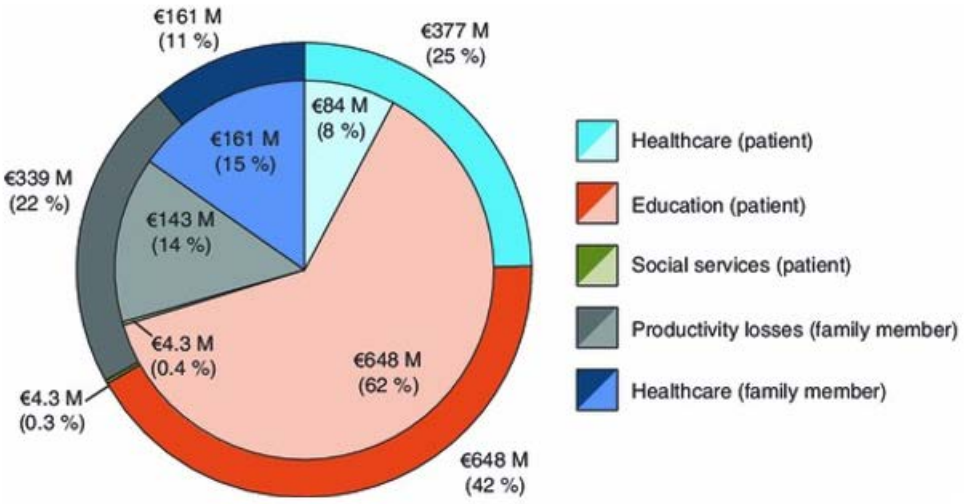
8.3 Financial Burden

Increasing attention is being paid to ADHD's burden on society. A number of recent studies has found that ADHD can have considerable economic impact[136]. A systematic review and analysis of ADHD 'cost of illness'[137] studies in Europe[138] found that education accounted for 42% - 62% of total costs associated with ADHD, with healthcare costs for ADHD patients amounting to 8% - 25%.

The ADHD-related productivity losses (14% - 22%) and ADHD-related healthcare costs (11% -15%) of friends and family were comparable to healthcare costs for ADHD patients.

Figure 8.1 below shows the share of these costs by low- and high-range estimates.

Chart 8.1: National attention-deficit/hyperactivity disorder-related costs (in millions) by cost categories.[139] (Source: Le et al: 2014)



In an assessment of the economic impact of ADHD in the United States[140], it was found that for adults the largest cost component associated with the disorder was productivity and income losses, whilst for children, the largest cost components were for healthcare (56% - 61%) and education (35% - 40%). Significantly, they found that despite most of the literature assessing costs associated with ADHD focussed on children and adolescents, 73% -74% of costs was attributable to adults with ADHD or to adult family members or parents with ADHD.

[136] Doshi et al. (2012); Hoa H. Le et al (2014).

[137] This does not preclude costs associated to non-health services.

[138] Le et al. (2014) The study included studies from five northern and western countries in the European Union: Belgium, Germany, the Netherlands, Sweden and the United Kingdom Le et al. (2014)

[139] The inner circle represents the low range estimate (€1,041 M) and the outer circle represents the high range estimate (€1,529 M)

[140] Doshi et al. (2012)

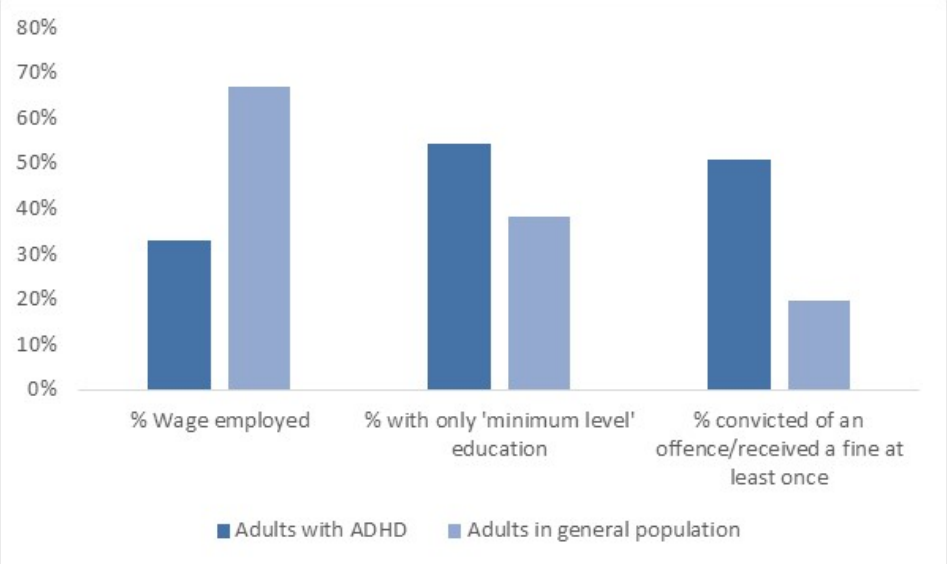
One of the most in-depth studies we found was that carried out in Denmark[141]. Adults in the general population earned an average of €41,458, while adults with ADHD earned only €26,130. Adults with ADHD were less likely to be 'wage employed' (33.1%), compared with adults in the general population (67.1%), while just over half (54.5%) had only the 'minimum level' education level, compared with adults in the general population (38.3%). One in eight individuals with ADHD completed tertiary education; nearly one in four of the general population achieved this.

Those with ADHD had higher average numbers of diagnosed comorbid psychiatric disorders (2.5 compared with 0.3), and were associated with considerably higher average spending on medicine (€1,304 compared with €209), receiving higher average numbers of primary care services (30.8 compared with 16.5) and higher average numbers of secondary care inpatient days (4.5 compared with 2.4).

Adults with ADHD accounted for a higher percentage of all individuals who had been in a traffic accident at least once (7% compared with 2.2%). A higher percentage of adults had been convicted of an offence or received a fine at least once (50.8% compared with 19.7%), of which fewer than a third were road traffic fines.

Comparison figures for Adults with ADHD and those without ADHD are shown in Figure 8.2 below:

Figure 8.2: Comparison of adults with ADHD and the general population (Source: Daley et al. 2015)



[141] Daley et al. (2015)

8.4 Mental Health

A number of studies have found an association between adult ADHD and psychiatric problems later in life. For instance, one study found that 17-22% of adults attending psychiatric outpatient clinics for conditions other than ADHD were found to be suffering from the disorder (ADHD).[142]

Staff at the Dundee Early Intervention Team identified problems with anxiety and emotional regulation as among the most common comorbidities they observed among the children with ADHD whom they supported. While in a focus meeting with Opportunities Dundee, one member of staff discussed a trend among their service users with ADHD:

> *'They're coming here and I'm hearing more about suicide.'*

Just under half of those aged sixteen and over (n=5/14) who responded to a questionnaire reported that they had anger issues and that this impacted on their lives.

Their responses are shown here:

'Struggled to maintain relationships. Developed anger issues and OCD which negatively impacted already strained relationships with family.'
'[ADHD] affects my mood and motivation. Sometimes I get angry or do not turn up for appointments at groups/courses.'
'I get angry so have broken beds. I now have a metal bed that used to be in a hospital. I stay in my room to avoid fighting with my sister.'
'I am constantly wound up and angry. Fighting with people and siblings.'
'I had issues as well as ADHD/anger management which school did not help with.'

One interviewee (aged 20) described how they had a 'mad temper' and had argued constantly with their mother. They added that at one point they were 'manically depressed' and that this confused them until their sister suggested that they may have ADHD.

Two students who returned a questionnaire identified anxiety and/or depression as another condition they suffered from as well as their ADHD.

One parent responded to the research about the degradation of their son's mental health:

> *'[He] began to feel down and would not speak to the other kids losing friends at school. He then decided he would stop taking the medication. I now feel that he has shut himself away from everyone making every excuse not to go out. So last week out of the blue he told me he wasn't feeling that great was crying every time I left the house and that he had been feeling like this*

[142] Almeida Montes LG, Hernández García AO, Ricardo-Garcell J. (2007)

for months now and wanted to eat but is finding it very difficult and was in a very sad place just now.'

The Community Mental Health staff were asked about the most common comorbidities among those with ADHD that they had experience with and the most popular response related to mental health issues (n=7/12), though a range of other difficulties were also highlighted.

Response are shown in Table 8.3 below:

Table 8.3: Most common co-morbidities experienced by CMH Staff

Response types	Number who chose
Mental health issues	7
Drug and alcohol misuse	3
Difficulty holding onto a job	2
ASD/Pervasive Developmental Disorder/ODD	2
Sensory processing difficulties	2
Learning difficulties	2

8.5 Sleep Patterns

Difficulties with getting to sleep and staying asleep are common among those with ADHD.[143] Around 75% of children and adults with ADHD have sleep problems.[144] More than half of parents/caregivers who responded to the research (n=26/45) identified problems with sleep as a factor in their child's life.

Ten out of the 14 individuals with ADHD aged 16 and over who responded to our questionnaire identified problems with sleep as a factor in their lives. Seven out of the eight students who responded to our questionnaire identified problems with sleep as a factor in their lives.

The responses are shown in Table 8.4 below:

[143] J Cassoff, ST Wiebe, R Gruber - Nature and science of sleep, (2012)

[144] European College of Neuropsychopharmacology. (2017)[144]

Table 8.4: Problems identified by Individuals aged 16+ and students

Response Types	Individuals aged 16+	Students
Problems with sleep	10	7
Problems with organisation	6	6
Interactions with the police	6	2
Regular (non-prescription) drug use	3	2

In the focus group meeting with the Dundee Early Intervention Team, the team members identified poor or disturbed sleep as among the most common comorbidities they observed among the children with ADHD whom they supported.

8.6 Crime, Police and Justice System

Research on the associations between ADHD and criminality are extensive but gaps remain.[145] One study using the Danish National Crime Register[146] found that 47% of children with ADHD had criminal convictions in adulthood, making them about five times more likely to sustain convictions than their peers in the general population.

A meta-analysis found that the estimated risks of arrests, convictions, and incarcerations in individuals with childhood ADHD was two- to three-fold higher (than the control).[147]

One study found that up to 40% of imprisoned men met the conditions for ADHD.[148] Another study, into missed diagnoses[149] of ADHD among criminal adults in the Netherlands[150], found that ADHD had been missed previously in life in 56% of (male) participants.[151] The authors state that:

[145] To date, research on females with ADHD and criminality is limited. Likewise, very limited research has been carried out on the long-term efficacy of different kinds of treatment programs and behavioural interventions in reducing criminality among those with ADHD Mohr-Jensen and Steinhausen.(2015).

[146] S Dalsgaard. (2013)

[147] Mohr-Jensen & Steinhausen. (2015).

[148] Ginsberg, Hirvikoski, Lindefors.(2010)

[149] The committee responsible for the NICE (National Institute of Clinical Excellence) guidelines for ADHD agreed that in their experience those in the Youth Justice or Adult Criminal Justice System often receive a late diagnosis of ADHD or a misdiagnosis. (https://www.nice.org.uk/guidance/ng87/chapter/Rationale-and-impact

[150] Buitelaar & Ferdinand, (2016).Participants were recruited at 'De Waag', a multicentre forensic outpatient clinic where patients with delinquency and mental health problems are treated, through referral from court, probation service or primary health care

[151] Buitelaar & Ferdinand. (2016) ADHD diagnosis was missed more often in: older men; those with hyperactive/impulsive or combined subtype of ADHD; those who reported fewer symptoms of ADHD in childhood or adolescence; those with a comorbid mood disorder in adulthood; and in those who had never received mental health care prior to their current provision

'General and forensic mental health care workers should be alert for the fact that ADHD is missed very often in individuals who have problems with delinquency and should realise that ADHD may be masked by various factors.'[152]

8.6.1 Parent/Caregivers and Individuals with ADHD 16+

Just under a quarter of the parent/caregivers who responded to the research questionnaire (n=11/45) said that their child had interacted with the police at some point.

Just under half of all those aged sixteen and over who responded to the questionnaire (n=6/14) identified prior interactions with the Police. Two students (out of eight) identified prior interactions with the Police.

8.6.2 Police Scotland

Police Scotland responded to a series of questions relating to their routine response when encountering an individual with additional support needs and ADHD specifically.[153] Their response stated that:

'There is no specific 'stand-alone' training [provided to Police] in relation to ADHD'.

The 'Appropriate Adults SOP' is the Standard Operating Procedure that made specific reference to ADHD: 'Although the Mental Health (Care and Treatment) (Scotland) Act 2003 does not specifically mention Attention Deficit Hyperactivity Disorder (ADHD) [in contrast with Autistic Spectrum Disorder, Asperger Syndrome, dementia and acquired brain injury], if the person's ADHD is such that it can be legitimately argued that it may impact upon their ability to cope with, or to communicate during the police process, the services of an Appropriate Adult[154] must be considered.'

Six questionnaires were received from members of the Police:

[152] Buitelaar & Ferdinand. (2012)

[153] FOI to Police Scotland's Standard Operating Procedures Freedom of Information Appendix 10

[154] According to Dr Harriet Pierpoint of the Centre for Criminology, the role of an 'Appropriate Adult' in Scotland is 'to facilitate communication […] in addition to this their presence may also provide support and reassurance for an individual with a mental disorder (witness, victim, suspect, accused) at police interview, specific forensic procedures or examination, precognition and at court.' Pierpoint's reference for this information was the Guidance on Appropriate Adult Services in Scotland (November 2007, paras 2.5 – 2.6), a document which was not easily accessible online. In contrast with England and Wales, the role of Appropriate Adult is performed by parents or other relatives 'only in exceptional circumstances' (www.sipr.ac.uk/downloads/vulnerable/pierpoint.pdf

- Five out of the six confirmed that they came into contact with individuals with ADHD.[155]
- All were asked what they knew about ADHD.
- Three stated they had limited knowledge, while the other three believed that it was a condition which mainly affected children and young people.[156]
- Three respondents stated that they were undecided as to whether ADHD was a genuine medical condition, whilst three stated that they believed it was genuine.

The group was asked what information they would like to see in an information pack.

Their responses are listed below and include requests for information to help support and signpost individuals with ADHD:

'Most of our contact with individuals with ADHD occurs when they are in a heightened demeanor. Information about how best to communicate/help/de-escalate individuals at times like these would be beneficial. Any information about support groups or activities for individuals would also help.'
'Any general information would be of advantage as I don't know about ADHD.'
'How to identify and deal with people with this condition.'
'Examples of difficulties faced; what would be of assistance to individuals; useful numbers/email addresses for signposting.'
'Increased awareness of the various agencies available to support or refer person[s] to when encountered.'

8.6.3 Criminal Justice System

Responses were received from four professionals working within Criminal Justice.

They were asked how frequently they were likely to encounter individuals with ADHD in the criminal justice system.

The responses are shown below:

[155] The question asked, 'In your profession, do you come into contact with individuals who have ADHD?' The sixth response stated that they weren't sure whether they came into contact with individuals with ADHD.

[156] E.g. 'Affects behaviour of young people mainly boys and manifests in their behaviour towards others'; 'Increasing condition observed in people of all ages but normally encounter younger people'; 'I believe it is condition that mostly effects children and commonly known as hyperactivity'

'Weekly, currently working with a service user who has been diagnosed with ADHD as a child and recently arrested by psychiatric services as having a conduct disorder.'

'Frequently – prob every Criminal Justice Social Worker will have at least one client on their caseload with ADHD.'

'This varies across time and case load around 2010. I had 3 caseloads at one time, however none at present with a diagnosis although some clients have characteristics of ADHD.'

'In the Public Protection Team there aren't many clients with ADHD.'

Criminal Justice staff confirmed that policies and guidelines were in place to support vulnerable individuals and those with additional support needs.[157]

The following questions were posed to the Criminal Justice Staff:

1. Are any special provisions made in criminal justice for those with additional support needs and those with ADHD specifically?

2. How much information sharing goes on when those with additional support needs (and ADHD specifically) come into the criminal justice system? Do you have any contact with CAMHS or social work?

The responses for Questions 1 and 2 are shown below:

Question 1:

'Yes, liaison with CMHT/CAMHS.'
'Yes – 1:1 or 2:1 work accordingly - support to attend groups if necessary – adjustments to sessions to accommodate learning style v's needs.'
'Try to support them as best as we can, not always open to another service.'
'Not that I'm aware of. I would imagine it's the luck of the draw and if you get a worker with an interest/knowledge in ADHD, or at least a motivation to best adapt our service to individual needs – then they may try to personalise delivery service to accommodate individual needs.'

[157] I.e. 'adult protection protocols'; 'council policies in addition to statute'; 'national standards, and local authority guidelines'; 'child and adult protection policies'.

Question 2

'None in my experience.'
'Yes, we consult with Community Mental Health Team or Leaning Disabilities Team or other services involved.'
'This varies from case to case.'
'Sometimes the first time ADHD is identified and then asked for an assessment re: ADHD. We then liaise with the person doing the assessment, usually psychologist X.'

The Criminal Justice Staff were asked:

> *In general, what recording systems/processes are in place to communicate the additional support needs of those in the criminal justice systems?*

The responses are shown below:

'Case notes – case management plans – network meetings if required – court reviews.'
'All Criminal Justice Social Worker's recording systems have to meet national standards - this would cover additional support cases.'
'Case notes – LSCMI158 risk/needs assessment.'

None of those who responded had received any information or training on ADHD.

A range of requests for information was received from the Criminal Justice Staff and are shown below:

'My knowledge of ADHD is very limited, therefore any information would be beneficial.'
'ADHD assessment criteria/critical factors – info for clients – advice guidance re how best to work with/support children who have ADHD – what the world might look like/feel like for those with ADHD.'
'Contact number for support to workers – information on meetings – any training opportunities.'
'A better understanding of their condition, to help their social skills and inclusion within their community.'
'ADHD support groups– worker to have training/knowledge on ADHD issues.'

[158] LSCMI: Level of Service/Case Management Inventory.

8.7 Substance and Alcohol Abuse

A number of studies have found an over-representation of those with ADHD among substance misusers.[159] Those with ADHD and/or CD have earlier drug debuts, abuse of a longer duration, more often progress from alcohol abuse to heavier drug abuse, have a shorter interval between debut and addiction, as well as a larger risk of treatment failure.[160],[161] A study of ADHD among prison inmates found ADHD to be positively associated with increasing levels of alcohol use, severity and alcohol dependence, while prisoners with ADHD endorsed more methadone and amphetamine use.[162]

Two parents or carers who responded to our questionnaire identified regular drug use as a factor in their child's life. Of those over the age of sixteen who responded to our questionnaire (n=14), three reported the regular use of non-prescription drugs. Another identified MDMA and Cocaine as drugs they use frequently. Of the eight students who responded to our questionnaire, two reported the regular use of non-prescription drugs.

When we met with 'Opportunities Dundee', an organisation which supports Dundee-based young people aged 16 - 19 who are not in full-time education or employment to get a job (and who estimate that 70% of their service users have ADHD), we were told that 90% - 100% of those they support who have ADHD take illegal drugs. One member of staff told us that:

> *'More recently my young people have started dealing it', another told us that 'my young person thinks if he didn't have cannabis he wouldn't be accepted in the community.'*

Questionnaires received from Community Mental Health team staff showed drug and alcohol misuse as the second-most commonly observed comorbidity.

The responses are shown in Table 8.5 below:

Table 8.5: Observed common comorbidities among service users of the Community Mental Health Team

Responses received	Number of respondents
Mental health issues	7
Drug and alcohol misuse	3
Difficulty holding on to a job	2
ASD/Pervasive Developmental Disorder/ODD	2

[159] *The degree to which this association between ADHD and substance misuse is determined by biological or environmental factors is still unclear Sullivan & Rudnik-Levin. (2001). The extent to which either condition confers a greater or lesser risk than the other is not fundamentally important to the research, as the two conditions overlap to a great extent Biederman, Munir & Knee. (1987).*

[160](Sullivan, Rudnik-Levin. (2001)

[161] Rounsaville et al (1991)

[162] Young et al. (2017)

Sensory processing difficulties	2
Learning difficulties	2
Criminality	1
Social issues	1

8.8 Europe ADHD – Conference February 2018

At the ADHD Europe Annual General Meeting in Malta[163] other support groups present were asked:

What services do you currently provide to individuals with ADHD and/or their families?

The responses are shown in table 8.6 below:

Table 8.6: Services provided by ADHD groups in Europe

Responses Received	Number of respondents
Support Groups	10
Training and workshops	6
Conferences	4
Phone support/social media	3
Home Visits	1

At the ADHD Europe Annual General Meeting in Malta other support groups present were asked:

What services do you provide which have worked particularly well?

The responses are shown in Table 8.7 below:

Table 8.7: Services in European Support Groups that have worked well

Responses Received	Number of respondents
Training for Children	7
Information Sessions	2
Training for Parents	1
Training for Teachers	1

[163] 24/02/2018.

At the ADHD Europe Annual General Meeting in Malta other support groups present were asked:

What services have people requested from you, over and above what you provide already?

The responses are shown in Table 8.8 below:

Table 8.8: Additional Services requested to European Support Groups

Responses Received	Number of respondents
Training on ADHD for teachers and children	7
Information and advice	4
Mobile support / Roadshows	2
Other single responses – Fight for Rights/Help at Work	2

8.9 Key Findings

- The financial burden of ADHD is considerable across services and across the world.
- Mental Health issues are identified as co-morbidities for those with ADHD both in adolescence and in later adult life.
- Problems with sleep occur for those with ADHD.
- There is evidence that substance and alcohol abuse is associated with those with ADHD.
- Police Scotland and the Criminal Justice Team have procedures for dealing with those with Additional Support Needs but not exclusively ADHD.
- Police Scotland and Criminal Justice Team identified Information that would help when dealing with ADHD.
- Existing European ADHD groups provide support and information similar to those in the UK but with the additionality of home visits, phone-line support and ADHD training for children.

CHAPTER 9 – RESEARCH CONCLUSIONS AND RECOMMENDATIONS

9.1 Conclusions

A small team employed by the Dundee and Angus ADHD Support Group carried out this research over a period of four months. The initial period of research was to be over six months but due to funding criteria and recruitment of appropriate researchers the time was limited to this shorter period. The research was commissioned to look into the needs of those with ADHD and those interacting with them across a wide societal spectrum and across Dundee City and Angus.

Notwithstanding the limited time and broad geographic and societal spread the research managed to collect information and views directly from around 800 respondents. The research team was further able to carry out desk research to set the information collected in context. It was noted that there are inconsistent methods of record keeping across Dundee City and Angus and within public bodies so actual prevalence of ADHD in different areas was difficult to collect and compare.

One of the main conclusions from this piece of research is that significantly more time is needed to give the findings weight, as many of the samples are small and isolated in location. The research team worked in small groups with the children and young people of the Dundee and Angus ADHD Support Group. Any future research, should consider not only group sessions but one to one sessions with children and young people and should also extend the remit to include children in educational and other third sector groups. This study does not included research into Adults with ADHD, and Girls and Women with ADHD and their respective needs. Another area which requires more research is ADHD and Employment as only social enterprises were accessed although a number of employability agencies participated in the research.

Within each section of the research the following conclusions were drawn.

9.1.1 Diagnosis and Treatment

- Long waiting times before and during diagnosis are causes for stress and anxiety for families and those with ADHD.
- Lack of non-medication approaches and related support – positive responses were received for medication but needs identified for alternative and additional multi-modal approaches.
- Inadequate resources within CAMHS which result in long waiting times and staff frustrations.
- Information is needed on Transition pathway from CAMHS to Adult Mental Health Services.

9.1.2 Deprivation

- The rates of ADHD prescriptions have been shown to be higher in areas of greater deprivation within Dundee City and Angus and it is suggested that the ADHD support group should be aware of this when providing information and support.

9.1.3 Education

- Lack of consistent recording of prevalence of ADHD across Dundee City and Angus and no recording of exclusions through ADHD so unable to compare achievement of those with ADHD and those not having ADHD.
- Imaginative, flexible and sympathetic teaching examples were identified and it was recognised there is the need to collect, collate and share these with all teachers and support staff within an ADHD Information Pack.
- Although there is an increase in training for ADHD, many staff have never received this and so may be disadvantaged in dealing with ADHD and getting the best from their class as a whole.
- There was a range of barriers and challenges to learning identified in the research and this may not only affect those with ADHD but also their peers' learning and the teachers' ability to have the whole class reach relevant standards and assessment levels.
- Although the majority of respondents recognised ADHD as a real condition some had difficultly identifying traits and because of this might not use appropriate communications and/or learning styles.
- Shortage of resources were causes of frustration and led to inability to meet the learning needs of those with ADHD.

9.1.4 Employment

- There was little time to research employers' needs in relation to employees with ADHD or the recruitment of those with ADHD therefore this is an area of research which still requires to be carried out.
- Employability agencies working with those with ADHD provide support but this is not consistent across the agencies and it would be useful if a structured approach were to be created in partnership with all relevant agencies.

9.1.5 Females and Older People

- Due to time constraints, desk research was carried out which identified the 'hidden' numbers of girls and women with ADHD, however, no direct research was carried out with females and ADHD in Dundee City and Angus. There was no research into older people and late diagnosis/life experience of those with ADHD.
- There was no significant research with adults with ADHD (only a small sample took part in this research) and there was no significant research with older people. With more time and better use of existing networks it is envisaged greater numbers could be involved in a future research project covering these two distinct sections of the population.

9.1.6 Homelife

- The findings identified extreme difficulties for families in coping with ADHD at home.
- Some Social Work staff have received ADHD training whilst many had not received any within the past three years which could restrict appropriate positive interventions.
- Although the research team met with children and young people at the Dundee and Angus ADHD Support Group it is clear that more time and one to one meetings are needed to gain any valuable information.
- There was insufficient time to secure the appropriate permissions to obtain access to children and young people in education and other third sector settings.

9.1.7 Wider Environment

- The co-morbidities and mental health issues are many and diverse for those with ADHD resulting in negative effects within families and the wider environment. There are existing services and agencies which provide support in such circumstances and sometimes, although not always, this results from an ADHD diagnosis. Areas such as poor organisation, problems with time keeping

and sleep are not as clearly dealt with and it would appear require different approaches and strategies to help those with ADHD to cope with them.

- Police have procedures in place for those requiring additional support but not specifically for ADHD and respondents showed different levels of knowledge about ADHD and a need for more information, particularly on coping / de-escalating mechanisms.
- ADHD Support provided by voluntary groups in Europe is similar to that provided by the Dundee and Angus Support Group.
- ADHD Europe member organisations provide more training for children with ADHD than the Dundee and Angus ADHD Support Group.
- Due to time constraints there was insufficient research carried out in the most rural areas to be able to draw any valid conclusions other than there are known people with ADHD supported by Angus Carers. Different approaches require to be used to involve them in any future research.

9.2 Recommendations

9.2.1 Records and Data

- Consistent methods of collecting and recording data on ADHD should be initiated in order that measures can be recorded and strategies introduced to support positive outcomes across services.

9.2.3 Areas for further research

These should include:

- Children and Young People;
- Adults with ADHD and their needs – including older people;
- Girls and women with ADHD and their needs; and
- Employers needs to support employees with ADHD and to encourage employment of those with ADHD.

9.2.4 Training needs identified

- Across all the areas of research – Deprivation; Diagnosis and Treatment; Education; Employment; Females; Homelife; and the Wider Environment the theme of training and information featured widely across the research.
- Training to help those with ADHD understand what it is and how to cope.
- Training for families to help them understand the condition and strategies to help deal with family situations and relationships.
- Training for public bodies and other agencies to gain a deeper understanding of ADHD and how it impacts within their organisations and work.
- Training to improve communication between Health Professionals, Parents and Caregivers, Social Work, Education and other agencies e.g. Police, Criminal Justice.
- Training in partnership with Education to help whole class strategies / de-escalation techniques / family communication.
- Training for children and young people diagnosed with ADHD.

9.2.5 Information

- Across all areas of the research respondents stated the need for Information and that if the Support Group were putting an information pack together, the following should be included:
- Information on what ADHD is and the possible impact/s on the sufferer and their family;
- Information for all ages – for children with ADHD; for siblings and family members; for older generation; for adults;
- Information on existing support and services in Dundee City and Angus/signposting best connections;
- Information on strategies that work in different situations e.g. employment, school, police interviews, social work family settings etc;
- Information on diagnosis and medication – timing, methods choices, alternatives, support;
- Information on Transitions – Treatment – CAMHS to Adult Mental Health; Education – Primary to Secondary to University/college/work.
- Information on training opportunities; and
- Information disseminated to areas of high deprivation and rural isolation to ensure equal opportunity of support and participation in training etc.

9.2.6 Resources

- Staff resources within CAMHS and Adult Mental Health Services could be supported by third sector partnered support and agreed pre and post-diagnosis practical advice and approaches. This would help with anxiety/stress during long waiting periods.
- Physical resources – outdoor play; distraction 'toys' etc. can be supplied as part of third sector funded projects and used in partnership with schools, families etc.

9.2.7 Support

- Opportunities provided for children and young people to meet ADHD role models to help with life skills with ADHD.
- Opportunities for families to meet together with other families and with professionals to learn about living with ADHD.
- Dundee and Angus Support Group provide help to children and young people with school and college work.

APPENDIX I - REFERENCES

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APPENDIX II - FREEDOM OF INFORMATION REQUESTS (FOI)

Diagnosis and Treatment

1. FOI (IGTFOISA4544) sent 20/12/2017, received 26/01/2018.

Question: 'What other non-pharmacological interventions are currently offered in CAMHS? What are the qualifying criteria?'

Response: 'None unless co morbid mental health difficulties but sign post to ADHD Support Group and Parent to Parent.'

2. FOI (20180131011) submitted on 31/01/2018 received on 20/02/2018).

Question: 'Does the Local Authority (Dundee City) know how many children and young people living within its boundaries have ADHD? If so, how many?'

Response 'No, this data is not collected or recorded as it is not included within the SEEMIS ASN Census collection'

The FOI also included the:

Follow-on Question: 'If so, is the Local Authority (Dundee City) able to view a breakdown of children and young people with ADHD by sex and age?'

Response 'Not applicable'

FOI (20180131011) submitted 31/01/2018 received on 20/02/2018.

Question: 'Does the Local Authority (Dundee City) know how many people living within its boundaries have prescriptions for medication used to treat ADHD?'

Response: 'No'.

FOI (ref 094/18) submitted on 31/01/2018 (received on 02/03/2018.

Questions: 'Does the Local Authority (Angus) know how many people living within its boundaries have prescriptions for medication used to treat ADHD?:

Response: 'This information is not known. For those children who have to take medication for ADHD during school hours, there are agreed individual protocols in place, currently [this] includes 67 children'

FOI (Ref 094/18) submitted on 31/01/2018 received on 01/03/2018).

Question: 'Does the Local Authority (Angus) know how many children and young people living within its boundaries have ADHD? If so, how many?'

Response: 'The number of children recorded in the school system with a diagnosis of ADHD within Angus schools is 179.'

Education

3. FOI request (sent 12/12/2017) was received from Education Scotland on 20/12/2017.

Questions:

1. The number of pupils in Scottish schools with a diagnosis of ADHD at both national and local authority level;
2. The academic performance of children with ADHD at S4, S5 and S6 against the national averages;
3. The average age at which pupils with ADHD leave school, compared with the national average;
4. The (temporary) exclusion rate for pupils with ADHD compared to the national average;
5. The number of pupils with ADHD permanently excluded from school;
6. The attendance rate of pupils with ADHD at each stage (P1-S6), compared with the national average;
7. Any research undertaken by Education Scotland into the educational performance of pupils with ADHD;
8. Any policies or guidance published by Education Scotland into educating children with ADHD.

Responses: Regarding questions 1-6 above, this is a formal notice under section 17(1) that of FOISA that Education Scotland does not hold the information you have requested.

Responses to Question 7:

'Education Scotland has not undertaken research into the educational performance of pupils with ADHD'.

Response to question 8:

'Education Scotland has not published policies or guidance on the education of children with ADHD. However, Education Scotland has continued to support professional learning activities and resources on topics such as Getting It Right For Every Child (GIRFEC) self-evaluation, personalised learning, and supporting learners through Nurturing Approaches'.

4. FOI (20180131011) submitted on 31/01/2018 received 20/02/2018).

Question: 'Does the Local Authority (Dundee) know the levels of educational attainment of pupils with ADHD in S4, S5 and S6? If so, what are they, in comparison with pupils without ADHD?'

Response: 'No, this data is not collected or recorded as it is not included within the SEEMIS ASN Census collection.'

FOI (Ref 094/18) sent on 31/01/2018 (response received 01/03/2018).

Question: 'Does the local authority know the levels of educational attainment of pupils with ADHD in S4, S5 and S6? If so, what are they, in comparison with pupils without ADHD?'.

Response: Angus Local Authority did not specify which variables they were referring to.

Employment

5. FOI (18/00658) sent 04/02/2018 received 01/03/2018)

Question: Are figures kept on numbers with ADHD in full-time employment or furthereducation, unemployed/out of work, or receiving out of work benefits.

Response: The response clarified that data was available from the Annual Population Survey and the Labour Force Survey on: severe or specific learning difficulties; mental illness, or sufferers of phobias, panics or other nervous disorders; other health problems or disabilities. However, this did not include ADHD.

Homelife

6. FOI (20180131011) sent on 31/01/2018 received on 20/02/2018.

Question:	'Does the Local Authority (Dundee City) know the number of individuals in the social care system who have additional support needs?'
Response:	'Yes'
Follow-up Question	'If so how many of them have a diagnosis of ADHD?'
Response:	'This information is not recorded'

FOI (Ref 094/18) sent on 31/01/2018 received on 01/03/2018

Question:	'Does the Local Authority (Angus) know the number of individuals in the social care system who have additional support needs?'
Response:	'The Council records data for all children and adults receiving social care services including whether they have a disability but not specifically ADHD'

7. FOI (20180131011, Ref 094/18) submitted on 31/01/2018 received 20/02/2018, 1/03/2018)

Question:	'Does the Local Authority (Dundee City and Angus) have in place a system which enables social workers to access information about the additional support needs of those they support?'
Response:	Dundee City and Angus LAs (respectively): 'Yes, through our TATC (Team around the Child) processes; and Management Information Systems'; 'Information can be accessed by social workers via the CareFirst system. If a child or young person has an Integrated Assessment and Child's Plan then their needs will be documented and shared in this way'.

8. FOI (IGTFOISA4544) sent 20/12/2017, received 26/01/2018.

Question:	'Does NHS Tayside provide group parenting programs for children with behavioural problems? If so, what kind of trained professionals (e.g. health, social work, education, youth justice and third sector)'.
Response:	'CAMHS doesn't provide parenting classes.'

9. FOIs (Ref 094/18; 20180131012-1-1) sent on 31/01/2018 (responses received 01/03/2018 and 20/03/2018).

Question: 'How many ADHD-specific training days were delivered to social workers in the local authority area in the following calendar years: 2015, 2016, 2017?'; What were the total number of hours of ADHD-specific training delivered in 2015, 2016 and 2017 for social workers?'

Response: This information is not held (Dundee City and Angus)

Wider environment

10. Police Scotland's Standard Operating Procedures (SOPs), specifically, 'Care and Welfare of Persons in Police Custody SOP', and 'Appropriate Adults SOP' (sourced at: http://www.scotland.police.uk/access-to-information/policies-and-procedures/procedures-and-equality-impact-assessments/

Response from Police Scotland regarding Procedures for dealing with those with ADHD

These, along with other documents also held on this site, including the 'Mental Health and Place of Safety SOP', are used by Officers and Staff when dealing with people with various mental health conditions, however there is no specific 'stand-alone' training in relation to ADHD.' Several of the SOPs make specific reference to the Equality Act 2010, which provides groups of people with 'protected characteristics' (including those with mental health impairments and learning disabilities) with legal protection from unfair or unequal treatment.

Additional FOIs not quoted in the main document

11. FOI (20180131011) submitted on 31/01/2018 received 20/02/2018.

Question: Does the Local Authority (Dundee City) know the rates of school exclusions for pupils with ADHD? If so, what are they, in comparison with pupils without ADHD?',

Response: 'This data is not collected or recorded as it is not included within the SEEMIS ASN Census collection.'

The rate (per 1,000 pupils) of exclusions for all pupils in Scotland in 2016/17 was 26.8, meaning that 2.7% of all pupils were excluded from school that year. Reported rates for pupils who have an Additional Support Need were reported to be more than four times higher than for those without, while rates for those living in the 20% most deprived areas of Scotland were more than five times higher. http://www.gov.scot/Publications/2017/12/3099/348580 (accessed 10/02/2018).

12. FOI (20180131011) submitted on 31/01/2018 received 20/02/2018

Question:	'How many children and adolescents with ADHD in education are provided with alternative or off-site provision?'
Response:	This information is not held'

13. FOI (20180131012-1-1) sent on 31/01/2018 received on 20/03/2018.

Question:	'How many ADHD-specific training days were delivered in (Dundee) schools in the local authority area in the following calendar years: 2015, 2016, 2017?'
	'What were the total number of hours of ADHD-specific training delivered in 2015, 2016 and 2017 for schools?'
Response:	(Dundee City) 'approaches to supporting and removing barriers for those with ADHD would be included in wider approaches to supporting learnings, and done in collaboration with school and central service staff across the 3 year period'.

SIGN Guideline 112 - (Scottish Intercollegiate Guidelines Network) as well as a standalone resource prepared by Foley ('Identifying and supporting children with ADHD'; https://adhdrichmond.files.wordpress.com/2018/01/adhd-foundation-school-guidelines.pdf) are just two of a number of resources available to teachers to assist in the implementation of effective behaviour management strategies in the classroom.