

# Finding Your Way With ADHD: Struggles, Supports, and Solutions

The Better Education, Services, and Treatments for People with  
Attention Deficit / Hyperactivity Disorder Study (BEST-ADHD)

A Research Report for the Irish National Council of Attention  
Deficit / Hyperactivity Disorder Support Groups

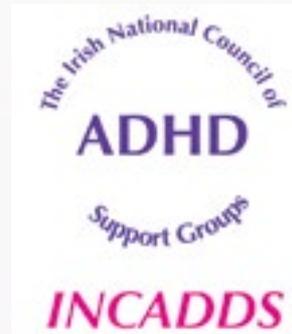
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Institute for Lifecourse & Society

School of Psychology  
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September 2016





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### Foreword

**How can Irish society learn to be more accepting and supportive of people who experience mental health conditions? That is a key question we must address to help people meet their potential. The importance of recognising and responding to these needs is especially important when we talk about adult AD/HD, which is not well known or acknowledged in our society. I welcome this research report, which brings to light many important issues faced by adults with AD/HD. Based on what we at INCADDS have seen over the years, this topic has needed urgent attention for some time.**

It seems that many people in the health care professions do not accept the idea of adult AD/HD or acknowledge what the condition means for adults. People who experience the condition need to be understood and listened to. They often find it challenging to conform to societal expectations, with negative consequences to their self esteem. Doctors should listen to these experiences of adults with AD/HD. The research report provides additional evidence of these issues. In response, we need a more direct and integrated service for AD/HD, which builds on primary care and community support for services including talking therapies.

The research also draws attention to the need for teachers to be better prepared to recognise and respond to AD/HD in the school system. The people who took part in the study spoke about the difficulty of going through school without having a name for the issue that was affecting them. We can see the long journey that many people have had to take to find that name, to seek a formal diagnosis, and take control of the condition. What a difference it makes when support is found early. Teachers have a vital role in being a positive link to support – we need a proactive approach in our schools with better awareness of AD/HD.

All of the people who took part in the research study spoke about the importance of support from family members and friends. Yet AD/HD can bring many challenges to family life. Like any mental health problem, everyone is affected when someone in the family has AD/HD. It will be by investing in family supports that we can ensure that, in the future, AD/HD will be just a feature of the person's individuality.

INCADDS welcomes this important new perspective on adult AD/HD in Ireland. The study confirms many observations made about ADHD internationally in a large and growing evidence base. Now it is time to use that research to help all of us to better understand and respond to adult AD/HD.

*Ms Rose Kavanagh, Coordinator, Irish National Council of Attention Deficit / Hyperactivity Disorder Support Groups.*

### Acknowledgements

I would like to acknowledge the generosity of the participants who took part in this study. They gave their time, spoke with such candour, and shared their experiences to help all of us have a better understanding of adult ADHD. I also wish to acknowledge the invaluable support provided by Emma Weaver and Niall Greene from Adult ADHD Northern Ireland.

This study was grounded by Rose Kavanagh's vision of what is needed to support people find their way with ADHD. Her work locally, at a national and a European level is inspiring to many in the ADHD community. I would also like to thank INCADDS for enabling this study to take place, Siobhán Kavanagh for her assistance in conducting and organising interviews, Jennifer Doherty for her excellent work in transcribing the interviews, and for the support provided by Dr John Canavan and the UNESCO Child and Family Research Centre.

*Dr Pádraig MacNeela, September 2016*

### Community Research Partnership: INCADDS and CORA

INCADDS was set up to address gaps in public knowledge and health care practice, and to support people with ADHD, their parents and families. It is an umbrella organisation for the ADHD Support Groups active throughout the country, and provides information to the Minister of Health, the Minister of Children & Youth Affairs, and the Minister of Education and Science on the disorder. Support groups provide information, advice, and emotional support to the families of children with AD/HD, with some operating additional services.

Community Engaged Research in Action (CORA) is a research cluster at the Institute for Lifecourse and Society at NUI Galway. The aim of the cluster is to provide community groups and academics the opportunity to collaborate on answering questions and reaching solutions that are of interest to both, using methods that support participation and high quality research. Our community partners include the Galway Simon Community, COPE Galway, NUI Galway Student Services and Students' Union, Galway Rape Crisis Centre, Rape Crisis Network Ireland, Spinal Injuries Ireland, and MediStori. Academic colleagues from Engineering, Psychology, Medicine, Theatre & Drama Studies, and Social Marketing have contributed to our work.

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# Introduction

This report describes the findings from a study of how adults experience Attention Deficit / Hyperactivity Disorder (ADHD). Qualitative interviews were carried out with 19 individuals to find out how the condition affected their lives. To date, there is a surprisingly small body of qualitative research on this issue internationally, and very little available from Ireland. Adults ranged from 18 to 53 years of age and were drawn from the Republic of Ireland and Northern Ireland. A majority were men and most of the sample identified predominantly with Attention Deficit Disorder (ADD), which is marked by inattention, with a minority referring to Attention Deficit Hyperactivity Disorder, characterised by inattention and hyperactivity. Although the participants in the study had a median age of 40, a majority had only received a diagnosis of ADHD in the past five years.

The researcher was asked by the Irish National Council on ADHD (INCADDS) to study adult ADHD with a particular focus on how adults with the condition experience education and health care services. This focus arose because, internationally, it is acknowledged that education, training, work place and health care supports and treatment services need to be customised to meet the needs of people with ADHD. Recent international research studies show that issues such as not receiving a diagnosis in childhood, social stigma and lack of public understanding are other factors that make it more difficult for adults to adapt well to the condition. This report describes what we found in regard to health care, education and social perceptions. The findings are described using a person-centred approach, which puts diagnosis, education and health care in a wider context of how individuals experience ADHD and have been affected by the condition over their life course. Although common issues arose across the participants, there were also more fine-grained patterns attributable to age groups, gender, and social background. Ultimately, each person had a uniquely personal relationship with ADHD, seeing it variously as a impairment of cognitive skill or an aptitude for lateral thinking, as a condition to be adapted to or an integral part of personal identity, as a label that did not offer significant personal meaning or as a critical insight on the personal life narrative.

## A Significant But Largely Unrecognised Mental Health Condition

This section of the report outlines the background to the study and situates it alongside the relatively small set of qualitative research studies on adult ADHD that have been carried out internationally. ADHD was added to the Diagnostic & Statistical Manual of the American Psychiatric Association in 1980. It is a neurocognitive disorder that affects brain functioning and behaviour, but one that can be adapted to with the right supports and personal adjustment. ADHD covers a range of characteristics. The core features are inattention, impulsivity, and hyperactivity, occurring at persistent and pervasive levels that are developmentally inappropriate (American Psychiatric Association, 2013). There is also a high level of comorbidity associated with the condition. Up to half of people with ADHD have other disorders such as oppositional disorder, learning difficulties, depression or anxiety (Biederman, 2005).

DSM 5 (APA, 2013) updates the diagnostic criteria for ADHD, and these are summarised below. A person with ADHD displays inattention and/or hyperactivity-impulsivity in a persistent pattern to a degree that interferes with functioning or development:

**Inattention.** For adults, diagnosis is associated with often experiencing five or more of the following symptoms, which need to be present for six months or more. The symptoms (inappropriate for the person's developmental level) include: failing to give close attention to details in work or other activities; trouble with persistent attention on tasks; not seeming to listen when spoken to; difficulty following through on instructions or completion of tasks / duties; trouble organising tasks and activities; problems with exerting sustained mental effort over a long duration of time; losing items such as phone, keys, or books; easily distracted; forgetful in daily activities.

**Hyperactivity / impulsivity.** Again, for adults, often experiencing five or more of these symptoms for six months or more is associated with diagnosis. These dimensions of ADHD (present to a disruptive or inappropriate extent) include: fidgeting, tapping hands or feet; difficult to remain seated; being restless; unable to take part in quiet leisure activities; high levels of sustained activity; talking excessively; answering questions before they are completed; difficulty waiting or taking turns; interrupting conversations and intruding on others.

For adults, several symptoms must be present before the age of 12, and must be affecting the person in two or more settings (e.g., at home, in work, or at college, with friends or relatives, or in other activities such as hobbies or past times). The symptoms must be interfering with functioning in the important domains of the person's life, and not be better explained by a different mental health disorder. Three forms of ADHD presentation are recognised:

a *combined presentation* (symptoms of both inattention and hyperactivity-impulsivity), *predominantly inattentive* (inattention, but not hyperactivity-impulsivity), or *hyperactive-impulsive presentation* (symptoms of hyperactivity-impulsivity but not inattention).

ADHD is thought to affect 5–9% of children and between 2.5–5% of adults (Faraone et al., 2006; Polanczyk et al., 2007; Meszaros et al., 2009; Willcutt, 2012). While often seen as a disorder of childhood, ADD/ADHD is usually a lifelong condition (Schrevel et al., 2016). Although still an under-diagnosed condition, lacking in public recognition, ADHD is known to be among the most common clinical reasons for disruptive behaviour in childhood (Biederman, 2005). ADHD can affect all domains of childhood experience, and in turn exerts significant stress on family life. Despite its prevalence, it is an unrecognised condition, often subject to doubt by health care professionals and in society. As a result, families bear a greater burden due to limited informal and formal social support. Youth with ADHD often experience difficulties that are stressful for families, including academic problems, antisocial / delinquent behaviour, alcohol and substance misuse (Sacchetti & Lefler, 2014; Wehmeier, Schacht, & Barkley, 2010). A longitudinal study in the US found that the odds of substance misuse are 14 times higher for adolescents with ADHD (Levy et al., 2014). However ADHD is often not diagnosed at this point and problematic behaviours are commonly regarded as representing ‘deviance’ or ‘willful disregard of rules’. Family communication difficulties often arise as a result (Robin, 2014).

It is now recognised that ADHD persists into adult years (Wilens et al., 2004). In adulthood, ADHD can lead to problems in interpersonal relationships, work performance, and family functioning (Biederman et al., 2006). Misuse of alcohol and drugs among adults with ADHD is a strong feature of international research. Up to 50% of patients treated for a substance use disorder may have ADHD (Johann et al., 2004). Specialised services for ADHD are radically underdeveloped relative to the health and social burden it poses. Although UK NICE guidelines state that supports should be multidisciplinary and involve multiple modalities (Kendall et al., 2008), the treatment options made available are predominantly medication-based. In primary care, some GPs do not see ADHD as a valid condition or one that they can assist with, citing time constraints, insufficient training, and concerns about misuse of medications (Shaw et al., 2003).

ADHD does not limit the individual’s capacity to live a fulfilling life. However access to the right supports is vital. This will have different meanings over the life course, from childhood through adolescence, transition to adult mental health services, in experiences of further education and occupational preparation, employment support, parenting skills, and so on. Due to limited specialised training in the area, many health care professionals and teachers have a restricted understanding of the condition, its impact, and how they can best support children and youth (Russell, Moore, & Ford, 2016). The preparation available for professionals in supporting adults with ADHD is even more underdeveloped. There is an association between ADHD and a range of personal, interpersonal and social indicators,

## Introduction

A Significant But Largely Unrecognised Mental Health Condition



such as cognition, healthy behaviours, education, occupational functioning, relationships, money management, and parenting (Barkley et al., 2007). Across a wide set of domains of daily living, ADHD can pose significant challenges to adjustment. This is especially the case if ADHD is undiagnosed, as the person cannot use knowledge about the diagnosis to reflect and adapt, to avail of services, or reconsider their behaviour in social and interpersonal contexts (Fleischmann & Miller, 2013).

### Recent Qualitative Research on the Impact of ADHD

The emergence of person centred qualitative studies has been a significant advance in ADHD research over the past decade. These look beyond ADHD as a clinical condition to understand the impact on individuals and families. Although fast developing, this base of research is still quite limited (Schrevel et al., 2016). Given the early stage of this research, recent studies have tended to be exploratory, asking what the experience of ADHD is like, what problems are faced in daily life, and exploring current needs and aspirations for the future (Schrevel et al., 2016).

Hansson Hallerod, Anckarsater, Rastam, and Hansson Scherman's (2015) interview study examined the experience of being diagnosed with ADHD as an adult. The recent impact of receiving a diagnosis extended to perceptions of the self and identity. On one level the diagnosis had a positive impact. Receiving a diagnosis had connotations with increased self-understanding and knowledge ("It was the answer to many years of wondering", p. 4), compared with the earlier life coping with undiagnosed ADHD. However ADHD also threatened the capacity to make positive evaluations of the self because it attracts negative social stigma. Participants expressed the wish to have received a diagnosis earlier in life. They valued the explanation that ADHD suggested for the difficulties they had experienced in life ("You don't feel nearly as stupid any more ... I don't have to be ashamed any more, I know it's a disease, I can't do anything about it, it isn't my fault, it's hereditary, before it was that you were careless and lazy", p. 6). The participants also valued the positive traits that they associated with the condition ("I see ADHD as something positive, almost more positive than negative. I wouldn't have been able to get everything done if I hadn't had ADHD", p. 4). Yet they did not want to use ADHD to explain everything about their personality ("It's easy for me to over-interpret things through the lens of ADHD", p. 7). Hansson Hallerod et al. (2015) identified several important coping strategies to adjust to ADHD. These were used to avoid situations where it was limiting, to compensate for the condition through the use of planning or preparation, or 'fighting' ADHD (e.g., to suppress impulses to act).

Another study used a review of existing online narratives to explore the experience of adults who had been diagnosed with ADHD (Fleischmann & Miller, 2013). Online narratives such as blogs were reviewed to assess how adults with ADHD who had recently become diagnosed

came to terms with the condition. A range of issues common to the experience of adjustment was identified. Typically the adults expressed the view that ADHD produced confusion and disorientation in everyday life. It had a lifelong impact, which affected school and work performance, could lead to the person feeling different and not accepted socially, and through the experience of depression and anxiety for some of the people studied. Latterly the adults who were studied had the sense of ‘seeing the light’ and identifying these problematic issues with ADHD. Becoming aware of ADHD led to a reflective reinterpretation of themselves and their earlier life experiences. Self-forgiveness and easing of guilt ensued, alongside the understanding that ADHD has positive aspects. Having endured personal struggles over the years, the adults with ADHD found that they had unique insights and strengths, and that life could be good. Getting a diagnosis had been an important step to achieve enhanced self-confidence and improved functioning.

Schrevel et al.’s (2016) qualitative study identified a significant challenge for adults with ADHD. These arose from social problems stemming from the core characteristics of the condition. Social and cultural factors impact on self-image, powerlessness, and degree of personal acceptance of the condition. Thus, ADHD characteristics impact on the social context experienced by participants, rather than arising inherently from the characteristics themselves. Under the theme ‘I want to but can’t’, the research participants described significant personal difficulties in daily life, in following through on intentions or keeping motivated to achieve goals. They had concerns about being judged for behaving in ways that other people did not see as normal, such as speaking too loudly or behaving inappropriately. They found a lack of understanding on the part of other people, expressed in a theme titled ‘they think you can, but you can’t’. One feature that others could not accept is that people with ADHD might struggle with everyday activities, while nonetheless engaging well in more specialised activities or tasks that interested them. The impact of these experiences was commonly that a negative self-image resulted, described in the theme ‘I come from a different world’. This impact led to the participants feeling that they are not being good enough people or able to achieve what they should be capable of doing. Nevertheless, feeling different to others was not always seen as a negative attribute. There were positive differences too, such as being able to think outside the box and being creative thinkers. The way forward discussed by participants in Schrevel et al.’s study included self-knowledge (e.g., through therapy or contact with others with ADHD), acceptance and understanding of ADHD, two-way communication with others (e.g., open, non-prejudicial interactions), and seeking appreciation for having positive and valued characteristics.

Lefler, Sacchetti, and Del Carlo (2016) recently reported on the use of a focus group methodology to study the experiences of adults with ADHD who were attending college in the U.S. They found that the consequences of receiving a diagnosis were varied. There were benefits arising from becoming aware of the condition, yet also the experience of self-stigma from feeling different from others. There were feelings of impairment, in being chaotic or having difficulty with life skills, impaired academic skills, and low motivation that was associated with underachievement. For them, treatment management meant managing better as

a result of accommodations made by colleges in academic demands, experiences of benefits from psychosocial strategies, and mixed evaluations of the effectiveness of medications. These experiences demonstrate the importance of recognising ADHD for young adults to cope with the academic demands and social dimensions of being at college.

Lasky et al. (2016) studied how young adults adapt to ADHD when they are in the world of work and further study. At this life stage of developing independence, young adults can potentially exert more control over the environment in which they are placed. Researchers wished to investigate whether having choice would make it possible for young adults to achieve better adaptation than had been the case in the more controlled environment of school. In line with this, the participants reported that, in some contexts, their ADHD characteristics were an asset. For example, when in situations where high energy was an advantage – where there were challenges, multitasking, a busy environment, and tasks that the participants found to be intrinsically motivating. They conclude that the interaction between individual and environment were critical in whether the young adults had positive experiences of work. Lasky et al. argue that this capacity to choose environments that work well for them could help account for the apparent decline in incidence of ADHD symptoms from childhood into adulthood; young adults often seek and find environments where their characteristics enable them to be functional rather than dysfunctional. The qualitative interviews that Lasky et al. conducted support this contention, as the participants spoke about finding the right fit for themselves in study and work, which in turn supported a view of themselves as different rather than defective. In such environments some participants reported being able to attend for long periods or to overcome a tendency for procrastination that would pertain with other tasks.

Matheson et al.'s (2013) recent UK study of adults with ADHD highlights a lack of awareness of the condition among GPs, difficulties in obtaining a definitive diagnosis, problems in accessing specialised services, and the challenge of transitioning from child- oriented services. Fundamentally, sufferers described ADHD as bringing chaos to everyday life (“Personal organisation is catastrophic, it’s not good.... I spend 20 times the amount of time that someone of my general level of brain power ought to take, I simply cannot organise stuff in my head”, p. 7). An earlier Australian study also used the analogy of ‘chaos’ to describe the experience of adults living with ADHD (Toner et al., 2006), along with the resilience of ‘striving for control’. Participants described a continuous cycling between chaos and control. Illustrating the importance of retrospective analysis of childhood experiences, Toner et al.'s adult participants described school problems, estrangement from peers, isolation within the family, and an awareness of being a source of parental conflict. The participants had managed to become productive adults, chiefly through the support of their families.

Childhood difficulty and family disruption are echoed in Young et al.'s (2008) UK study of people diagnosed with ADHD in adulthood. The participants remembered feeling different, being treated as ‘problem children’ (e.g., being told they were “stupid, lazy, and disruptive” by parents and teachers, p. 495). Ek and Isaksson (2013) identified the need to understand what

factors help adults with ADHD become and remain engaged in daily routines and activities. This is an issue for many adults because of a tendency to have difficulty with organisation, planning and structure, which can lead to low self-worth and disempowerment. In a qualitative study of adults attending a clinic, they found that engagement was promoted by a sense of feeling inspired or motivated by tasks (e.g., if tasks are fun, demanding, goal-driven and meaningful), feeling well supported (e.g., other people promoting and reminding the person, lists and prompts), and having a sense of togetherness with other people (shared activities, feeling needed by others).

The concept of ‘stigma’ is regularly invoked with regard to ADHD (Lebowitz, 2016). The consequences of stigma for adolescents can include low self-confidence and negative perceptions of their disorder (Koro-Ljungberg & Bussing, 2009). A UK qualitative study with children aged 9-14 reported bullying and name calling as common experiences (Singh et al., 2010). The children believed that they were viewed negatively and treated differently outside the family. Indeed, a recent quantitative Irish study of over 300 youth by O’Driscoll et al. (2012) demonstrated stigma toward ADHD by non-sufferers – the diagnosis was associated with perceptions of being dangerous, personal blame for symptoms, and social distance. Stigma extends to the parental experience, through the vicarious experience of the upset caused to their children, striving to access services, and contending with challenges despite minimal disclosure to others (McIntyre & Hennessy, 2012). Three-quarters of parents in one US survey reported experiencing stigmatisation and 40% had felt socially isolated or rejected (dosReis et al., 2010). Moreover, given its genetic basis, parents themselves are unusually likely to suffer ADHD themselves (Brod et al., 2012). Harborne et al. (2004) found that parents did not feel supported by professionals and family members in viewing ADHD as a real condition, resulting in emotional distress from feeling blamed for their children’s difficulties. In another UK qualitative study, Peters and Jackson (2008) found mothering a child with ADHD to be stressful and marginalising, with healthcare professionals unable to give appropriate guidance and support. These findings underline the conclusion that parents of children with ADHD require specialised support, including flexible, individually tailored support (Koerting et al., 2013). Such a model of service provision remains an aspiration in Ireland.

Brod et al.’s (2012) qualitative study across seven countries demonstrated patterns internationally. Adults with ADHD recalled parental ambivalence about medications and their own attempts to compensate for lack of organisation by over-structuring their children’s lives. Having knowledge of the condition was a helpful tool for parents (“My parents would have understood why I’m sometimes acting strange, why I’m sometimes this active and feeling like doing nothing the next time, and why I’m cranky to them”, p. 10). This parent with ADHD echoes the ‘chaos’ analogy: “We’re running late to everything ... and then she’s embarrassed to walk into her class late. So I feel like I’m always letting her down. ... I just feel like she is living with someone that has a disease” (p. 12). The struggle of parents with ADHD is apparent here: “I’ll have times ... where everything’s going well for a while, then when my life goes downhill it affects my son ... I’ll be depressed, some mornings I don’t get up, I forget to put the alarm clock on. Then when he comes home from school I’ll forget that he’s coming home” (p. 12).

#### Summary

This study builds on recent trends in qualitative research on the experience of adult ADHD. In doing so, it addresses the key concerns that have emerged from this body of work. This research shows that adults who receive a diagnosis of ADHD engage in extensive work to assimilate the diagnosis and condition to self-identity. This is a complex identification as ADHD has both positive and negative connotation. Negative associations arise due to direct experience, for example due to frustration with ADHD symptoms, and due to the socially misunderstood and stigmatised perception of ADHD in society. There has been relatively little development as yet of information on coping strategies used by adults with ADHD. Yet adult diagnosis affords the opportunity to reflect on the past and move beyond self-recrimination for earlier life choices and behaviour. Recent research demonstrates that ADHD has an impact throughout the lifespan and in different contexts – in school, further education and in work, as a parent and partner. A number of issues arise that merit further investigation, including negative self perceptions as a person of lesser value, partly arising from stigmatisation and bullying, the experience of daily activities and roles as highly stressful, as well as the scope to develop personal insights and an image of the self as resilient and capable of reinterpreting the past to move forward to a more fulfilling future.



# Methodology

## Research Design

**Semi-structured cross-sectional qualitative interviews were carried out with adults who identified with having ADHD. A thematic analysis of the interview transcripts was carried out to develop a set of themes that represent patterns in the experience of the participants. A maximum variation approach was taken to sampling to identify and include adults who identified with ADHD, across gender, age range and period since diagnosis.**

Within the framework of a person-centred study, which takes into account individual differences and personal context, the aims of the research were to:

1. Study the experiences that adults living with ADD/ADHD have had of healthcare encounters – i.e., with General Practitioners, psychiatry and mental health services, and other health care providers.
2. Study the experiences that these adults had of the educational system – a retrospective account of primary, secondary, tertiary education, and vocational training.
3. Identify priorities and strategies arising from the voices of individuals for improving the educational and healthcare systems to meet the needs of people with ADD / ADHD.

## Participants

**Nineteen adults took part in the study, ranging in age from 18 to 53, with a median age of 40 (Table 1). Two of the participants were under 25 years of age. Fifteen were men and four were women. The participants self-reported their diagnostic status. Three had been diagnosed with ADHD as a child, while six had been diagnosed within the past two years. Another six of the participants had been diagnosed between three and six years previously. Of the remaining participants in the study, one had been diagnosed eight years previous and another has been diagnosed 17 years before. Most of the participants referred to having other diagnosed conditions to manage along with ADHD. Eleven people referred to depression, four to dyslexia, four to addiction, and three to dyspraxia. Individual references were made to Asperger's, autism, personality disorder, agoraphobia, anxiety, and PTSD.**

## Methodology

### Participants

Two of the participants had not been diagnosed but self-identified with ADHD. These participants were included in the study because it was apparent that the period leading up to diagnosis is a period of considerable change and development in the individual's conception of themselves, ADHD and openness to forms of treatment such as medication use.

Ten of the participants were in employment, one was self-employed, three were students, one was caring for children, and four were not working at present. Five participants were living in Northern Ireland. The other participants were living in Connacht, with the exception of one living in France at the time of the interview and two others in Leinster. Four interviews were conducted on the phone and the remainder were face-to-face interviews.

**Table 1. Participant profile.**

<b>Name</b>	<b>Age category</b>	<b>Number of years since diagnosis</b>	<b>Occupational status</b>	<b>Interview length in minutes</b>
<b>Aoife</b>	40s	8	Working	93
<b>Brian</b>	25-29	2	Working	77
<b>Caroline</b>	30s	Not diagnosed	Home	67
<b>Cathal</b>	40s	17	Working	76
<b>Ciara</b>	30s	3	Student	39
<b>Conor</b>	50s	6	Working	69
<b>Cormac</b>	40s	4	Working	96
<b>Daniel</b>	40s	5	Working	85
<b>Declan</b>	50s	6	Not working	75
<b>Ethan</b>	<25	1	Student	66
<b>Jack</b>	50s	1	Not working	82
<b>John</b>	30s	1	Working	45
<b>Patrick</b>	50s	1	Self-employed	87
<b>Peter</b>	30s	4	Working	86
<b>Rory</b>	40s	Childhood	Working	72
<b>Shane</b>	30s	2	Not working	93
<b>Sinead</b>	<25	Childhood	Student	54
<b>Thomas</b>	50s	Not diagnosed	Not working	52
<b>William</b>	25-29	Childhood	Working	66

## Sampling and Recruitment

Research ethics approval was given by the NUI Galway Research Ethics Committee. Interviews were conducted over a ten month period from August 2015 to May 2016. Given the exploratory nature of the research, a maximum variation approach was taken to sampling. For inclusion, participants had to be aged 18 or older and to identify with having ADHD. The person's diagnostic status was ascertained via self report.

Recruitment took place via existing networks, an email to college students at two institutions, and a newspaper advertisement. Five were recruited via ADHD Northern Ireland's network of adults with ADHD who attend support groups in Enniskillen and Belfast. Emma Weaver and Niall Greene agreed to support the study and to disseminate an information sheet on the research to people who attend the support groups. They acted as gatekeepers and arranged interview times for a date in March 2015. The coordinator at INCADDS, Rose Kavanagh, performed a similar role in recruiting six of the participants. Three participants responded to an advertisement placed in the Galway Independent newspaper in April 2016. Three participants were recruited after self-selecting to respond to an email circulated to students registered with the disability services at the Galway-Mayo Institute of Technology and NUI Galway. The remaining two participants were recruited through the researcher's own network of contacts.

## Procedure

The researcher engaged in email, text and telephone contact with individuals who expressed an interest in the study. A date and time for an interview was agreed after information on the study and the research interview was provided and discussed. In the case of the five interviews held in Northern Ireland, ADHD NI managed the details concerning interview location and timing. The researcher explained that a pseudonym would be given to each participant and that identifying details would not be included in the write up of the findings. The purpose of the study was described, to provide a basis for other people with ADHD to read about what it is like for other people who experience it, and to identify suggestions for how health care and education can better address the needs of people with ADHD. A summary of the interview schedule is presented in Table 2.

Participants gave informed consent on the day of the interview. The researcher carried out 17 of the interviews and a female colleague conducted the remaining interviews. For four participants it was most convenient to arrange a telephone interview. In this case the researcher conducted the interview via a speakerphone in an academic office. The face-to-face

interviews were held in an academic office or meeting room, or, in the case of the interviews in Northern Ireland, in a community health service facility. The median length of the interviews was 75 minutes. Two interviews were less than an hour in length (39 and 45 minutes). The longest was one hour and 36 minutes. The interviews were audiotaped and transcribed verbatim.

The analysis was carried out using Braun and Clarke's (2006) approach to thematic analysis. In this approach, the researcher proceeds from several readings of the text to construct a coding scheme to reduce the complexity of the data into manageable larger units. These units are developed into conceptually coherent themes that are organised in a complementary manner to represent an underlying framework. The themes are subsequently written up to provide descriptive coverage of the theme content along with interpretation of the meaning of the content to draw out critical features of the themes with regard to the underpinning research enquiry.

The transcripts were imported to NVIVO, a qualitative data management software package, and then coded into a set of categories. These categories were derived from provisional categories developed after rereading and notating a smaller set of hard copy transcripts. The transcripts were coded to the categories using NVIVO. The resulting categories were then reviewed to develop an integrated narrative.

Seven main categories were developed for the write up of the findings, based on Characteristics of ADHD; Self, Identity and ADHD; Coping Strategies; Health Care: Diagnosis, Health Care Professionals and Medication; School; Later Education; Work. The former three categories refer to the direct experience of characteristics that the participants considered to be associated with ADHD, how they assimilated ADHD to their existing self-concept and personal evaluations, and the manner in which they sought to adapt to or cope with the condition. These provide a person-centred basis to understand four applied domains of experience where ADHD was relevant.

The first applied domain refers to health care, the context in which the diagnosis of ADHD was first identified and which helped to determine how the condition would be managed. The next three refer to specific life domains. Two of these are educationally focused. The first, referring to school, was a universal experience, whereas the category referring to later education was only applicable to those participants who had engaged in formal learning programmes after school. The final category relates to the experience of the workplace in terms of ADHD.

**Table 2. Semi-Structured Interview Topics**

<b>Interview Section</b>	<b>Topic Coverage</b>
<b>Welcome and introduction</b>	Describe the study and its purpose
<b>Background</b>	How the person found out about ADHD and received a diagnosis
<b>Family</b>	How the family of origin coped with ADHD, before and after it was diagnosed
<b>Peers</b>	Peer relationships, including friendships, relationships, peers at school
<b>Present day</b>	How ADHD affects your life today, including challenges and helpful strategies
<b>The future</b>	How you see things going in the future with respect to ADHD
<b>Education</b>	Experiences of school and education, including any support services for ADHD
<b>Health services</b>	Experiences with GPs, mental health services, engagement with clinicians, education and family support
<b>Peer supports / voluntary sector services</b>	Meeting other people with ADHD, at support groups, through other sources, advice received from others
<b>Resilience</b>	How you mind yourself and stay strong, including hobbies, social support, managing conflict, finding positives
<b>Conclusion</b>	Whether we have covered everything that you feel is relevant, how you felt about the interview



# Findings

## ADHD Characteristics: Information Processing, Motivation, Energy, and Positive Features

The findings begin with a description of the characteristics that the participants associated with ADHD. A number of these referred to how they processed information. These are followed by characteristics linked to goal-setting, motivation, and energy. In many ways these characteristics had a challenging impact, yet there were also positive associations with many aspects of ADHD.

### Apprehending and Perceiving Information

This characteristic involves having a narrow channel or ‘bandwidth’ of attention at times. It was difficult for participants to perceive and take in information, especially in situations of stress or pressure, oral sources of information, or when there was a need to register lots of information quickly. Patrick described this well: “this is in all sorts of scenarios. So ... my wife will say, will you do this, this, this, and this, and I’ll say, hold on a second, I’m getting white wall here. I hear something is coming at me, but I don’t know what you’re saying”.

The difficulty was particularly evident when an oral channel of information was used, for instance through conversation, in lectures or via work instructions:

People could be talking to me, and this is what I try and explain to people now. I don’t hear what they’re saying. My brain wanders off. I daydream. It’s real hard ... it’s very difficult in social circumstances. I can’t follow conversations because my brain doesn’t allow me. And then people say “oh, what do you think?” And I think shit, what have they said to me? (Declan)

One of the main struggles would be the speed or something of the lectures. ... Because you’re trying to take notes. It’s hard for me to remember what I’m writing, because I’m trying to listen to the next sentence and remember that. It’s like you’re lost for the rest of the class (Ciara)

People talking to me and I don’t know what they’re saying. I can hear the words, but do you know, it’s, what did you just say? You could repeat something to me over and over and over, and I still wouldn’t get it (Jack)

**Aoife** responded to this issue by pretending that she understood what she was being asked to do at work, because she did not want to be seen as having a problem:

If somebody tells me something, I'll pretend. I want to act smart, and I'll say, 'oh yeah, yeah, yeah', but I'm not even listening. And then I don't know what I have to go and do. I've an awful habit of doing it. Because I don't want to give in. I don't want you to know that I have this problem.

The mental stress that resulted from this difficulty with perception affected the person's ability to respond or think in unsympathetic environments or when feeling pressurised:

I can feel confronted very easily, just with the chaos. Just can feel like there's a lot going on very, very quickly. And yeah so that really is the main thing, and that's something that I have wanted to work on (**Caroline**)

### Tuned Out or Dreamy

Several participants felt that, at times, they were inattentive to what was happening in the environment around them, associating this with the ADD component of the disorder. They felt that other people noticed this, and saw them as 'tuned out'. **Patrick** related to this as a lifelong experience:

Because the classical idea I have of somebody with ADHD is a six or seven year-old child that's ballistic. And I was never ballistic in my childhood experiences. In fact, if anything, I was the opposite to ballistic. I was becalmed, dreamy

**John's** mother had said something similar to him about his childhood ("[she] said I always just thought you were a bit zoned out ... she'd be talking, and I'd be either watching the TV or looking out the window").

That characteristic persisted into adulthood, and had an impact on parenting, work performance, and appearing present to others. **Jack** spoke about negative, bullying reactions from others ("I was getting an awful slagging down there by a couple of them, a form of bullying. 'Oh **Jack** you need to wake up'. Or 'Jesus where are you? You're half asleep'. One fella said to me one night, 'it's like talking to a wall'"). **Ethan** was conscious that he could be seen as inattentive at work ("I would start daydreams when I was in work as well, and I

have to snap myself out of that, because ... I'd be crucified"). **Ciara** described how she was seen as inattentive ("Even talking to people is the same thing. It's like 'are you sure you're listening?"). **Rory** joked:

it would just be seen like somebody who is lost in space, or leaving things behind, that kind of, almost the executive functioning bit. ... well if I've been given the ... kids to take care of, I'll take [medication]. Jesus because they'd be running off under cars, and I'd be off thinking about some abstract notion in the world.

### Sustained Concentration

The participants associated a difficulty with sustained concentration as being central to their experience of ADHD. They described poor concentration and distractability as having a significant impact on the ability to engage in focused conversation and led to other practical issues such as study problems. **Patrick** described the inability to concentrate as "the continuous strain right through". **Thomas** found that becoming an adult did not change his childhood distractability ("I could just be easily distracted when I'm doing something and just stop doing it"). **Conor** saw himself as intelligent but having a specific problem with the cognitive capacity for sustained attention ("It's attending. It's that ability to attend. To attend for long periods of time").

Several factors were identified as affecting concentration. These included medication ("I find that sort of thing very hard to do whenever I don't have my medication. My concentration levels would be terrible", **William**), having good / bad days ("You get days where you're more mixed up than others, you know. ... When I say about a manageable life as I call it, some days are better than others", **Thomas**), and the duration of concentration required in a task ("I had to keep reinforcing it, don't wander off. You've got to concentrate on the job. But what it does is, it mentally drains me so much, because I'm really forcing it into myself, and I forget what I'm doing", **Declan**).

There were differences between people as well. For instance, **Thomas** was better able to concentrate in a busy environment:

I'd be better sitting in a café with people all around me talking. I could nearly concentrate on reading the newspaper better than I could if I was sitting at home, or sitting here in a quiet room.

## Findings

### ADHD Characteristics: Sequential Thinking

Whereas **Ciara** preferred to tune out other stimuli:

I suppose distractions and stuff in certain rooms. When I was doing [a] course, I had earbuds in. The noise isolation things. Stuff like that. Just because I could hear the clock ticking, and it's like, what time is it now? Or someone clicking a pen ... and then sometimes I would be kind of like 'aaaah! It's putting me off'.

#### Applied Issues: Concentration in Conversation and Studying

**Concentration difficulties posed challenges in completing everyday tasks. In this example, Jack describes having problems focusing his attention when having conversations in a group, which impacts on his social engagement:**

It's all noise. All I hear is 'brrrr'. ... If I'm in a group of people and everyone's kind of talking, I find it very hard to keep track. You know, 'what did you say?' 'Sorry?' 'What?' I can't do that. This isn't too bad because it's only the two of us. But if a third or fourth person came in and they were all talking, aw Jesus I would be kind of... I'd probably walk off like.

In the next example, **Ethan** has trouble sustaining focused concentration when studying:

if I run into anyone that I know, or find something that interests me, or I think of something I have to do, I'm gone. I'm gone with that, and all of a sudden it's three hours later and I haven't gone back to the library. Same with study, for example if say I'm on my laptop or something like that, I go to study, I'll start looking up my topics. When I start, I'm fine, and then within you know, 15, 20 minutes, that's when I start to drift off ... I'm going off in all different directions with my thought process. It's like, I've gone back on to Facebook and I've gone on to YouTube.

### Sequential Thinking

There was extensive difficulty reported in engaging in thinking or actions that are linear or sequential. This had an impact in prioritising, planning and completing mental or physical tasks. **Rory** saw it as a memory difficulty in learning which required extensive adaptation:

I need props to remind myself. It's almost like someone with an amnesic disorder, a memory difficulty. My memory difficulty is in sequential learning, and learning poems, or learning things that should occur in order.

... I have to learn or adapt to things, knowing that I haven't got that normal sequential style

This issue affected the completion of tasks. **Shane** described the experience figuratively as being lost in a set of possible actions ("it's like walking up and down the hall, and knowing that you've got ten things to do, but not knowing where to start. And probably doing the least important"). **Daniel** found it hard to go through a task sequentially to completion ("The difficulty would be to say right, sit down. Do A, B, C. Do the stuff sequentially. And move on. But I just. I couldn't").

These problems were very difficult for manage. Having to engage in structured planning makes **Caroline's** "head go to mush", she prefers to "dart around between things", she will "automatically rebel" against the structure, without even wanting to, but then "scolds" herself and forces herself to keep trying to structure her thinking. **Aoife's** experience was similar, giving her a very dissatisfying sense of not achieving closure on a task:

the starting things, never finishing them. Again, chaos. Tidying ... The sequence of events. How do I even go about it? The logic. ... I know when I'd go back to something, I'd miss bits, you know. And therefore that gives you a feeling of... I never get that click feeling that, I know that was right. ... It's like a sense of a door shut. You know it's closed properly by, it makes that noise.

**Ethan** compared his mental experience to a clamour of different thoughts, which helps explain how his attentional focus shifts continually, how tasks remain incomplete or get carried out in the wrong sequence:

there's, say if there's a crate of bottles in your head, and they're all rattling at the same time. Say they're all shouting at you, just drink me! And you pick up one of the bottles and you start drinking. And then you hear another one shouting even louder, over here! And then you hear four or five of them at the same time. ... There's so many different things going on in my head at the same time. The way my thought process works then, I'll start jumping around between all of them, and then it will take me off, ... I've lost it then. Rather than what I'm actually supposed to be focusing on.

#### Is It a Problem?

Several participants saw their characteristic thought pattern in a positive light, as a distinct way of thinking rather than one that is defective. **Rory** found it helpful to think in a non-linear way when completing his work: "you're getting random things and putting them together into a complex formulation. So it's perfect for ADHD. ... Maybe working from a

disintegrated place makes it easier to see the wood from the trees”. **Conor** saw his thought process as an alternative (but not disordered) style of thinking (“I actually don’t think it is a disorder at all. I think that my brain’s wired a little bit differently to somebody who is more used to linear thinking ... I think ADD thinkers think in a lateral way”). **Caroline** had found it useful to read testimonies written by people with ADHD to better picture her own form of thinking (“one person saying she felt like regularly people would think in a pattern of A, B, C, D, and she found that she thought in a kind of a spider web, where she would bounce back and forth between subjects. And that really made sense to me”).

#### Applied Issues: Work and Studying

**Although it could be seen as an alternative form of thinking, having difficulty with sequential processing posed challenges in work and academic environments that are based on a sequential model. Cormac described his difficulty coping in response to a work demand:**

I have an idea in my head. You put pen to paper. A phone call comes. It’s lunchtime. You come back. What was I doing? Oh crumbs! I need to do this. I’ll do it in a bit. I’ll go and do something else. And we close in an hour. I wouldn’t put things off necessarily, but I’d be distracted, and when I would put things together and I’d formulated something in a bit of a rush, I would get it done, but people would look and go, ‘that’s very abstract. What’s your schema behind this?’ ... I could never do anything from scratch.

**Peter** found that writing academically required a sequential mindset: “It would have been great to be able to focus. Whereas I always found I’d have loads of different threads of thought and different ideas. And like in the beginning it was fine. ... it really got a lot worse after. ... It became a lot harder to focus academically at that point”. **Conor** described what it is like to try to follow a linear thread: “I don’t notice myself jumping around. ... I’d be reading, and I’d be thinking, you know... I’d be reading something about personal development, and the next thing it would be, what are we having for tea? Or what’s Liverpool gonna do this weekend etc. etc.”.

### Impulsivity

Being impulsive involves making choices for action without thinking through the consequences or weighing up the options. Acting in an impulsive way was associated with ADHD for a minority of the participants: “I just think jeez, that was crazy, and I sometimes do crazy things. I’m very extraverted, so like I would be very attracted to doing, I don’t want to say outlandish things, but adventurous things” (**Peter**). This could be a positive feature, as when **Rory** described being a fun, spontaneous person at home: “I think they compare it to Tigger.

... in my family, in the morning I'm into the shower singing, and the kids are in singing or dancing, so it's very much like Tigger from the morning, once we start". It could also pose problems, as in **Declan's** description of impulsivity leaving work: "when I first started work, I just used to get pissed off in work. I'd just go home and go ride my motorbike. I was bored and that was it. I'd go".

Verbal impulsivity was also evident. **Rory** described it as talking in a manner that could be inappropriate, but that can be positive too: "In other situations, I'm not sure if it's the blurting out bit, the impulsivity, or if it's that you get a good reaction from it. It could be funny". Throughout his adult life **Cathal** had spoken his mind. He framed it in an adaptive way ("I would have been taught to externalise. ... I've never been one to hold back. You know, to allow something fester"). He also saw it as generating problems in some situations ("I still have problems with that the whole time. If I think something's wrong, I'm quite happy to tell somebody, even though it's probably not the best time or place. ... you fly off the handle I suppose, and you regret it"). On balance he felt it was a positive characteristic for him ("nine times out of ten I'm happy with the decision I made").

### Learning and Memory

One of the critical problems in learning that the participants reported was in not being able to easily comprehend and remember new information. This had applied implications for studying and learning new skills. These issues arose in particular when reading, where retention, distraction, and focused concentration were required. **Ciara** had an awareness of what she was reading. However she was not able to retain that information in her memory and experienced distraction as well:

I know what I'm reading, but it's not going through ... I keep going back and rereading, and kind of forcing myself to notice what that word is and comprehending ... I remember there was some referendum thing out, and I could vote, and I was reading the pros and cons of it, whatever it was. I remember I couldn't read it ... It was weird. Like I had been 45 minutes reading it, and I was still on the first paragraph. I just couldn't stop thinking of something else.

**Caroline** had a similar experience and described her frustration ("I could read it and read it and read it. I would find that it takes me a long time to take in what I'm reading, so you end up getting frustrated and quitting"). Several other participants spoke about the difficulty of reading. **Sinead** spoke about the importance of medication in enabling her to read and understand: "I can see that if I didn't take it, I could be trying to read this [piece of paper] And I would be reading that line for ten minutes before it would stick in my head".

## Findings

### ADHD Characteristics: Learning and Memory



## Findings

### ADHD Characteristics: Learning and Memory

The issue with retention of information generalised to other situations. **Declan** had been seeking help and was told by the professional he was working with that he had a serious problem with retaining information (“She said you know we’d been doing the same task for like two or three weeks and she said you’re not grasping the nature. ... I said I can’t remember what you’ve asked me ten minutes ago”). **Shane** spoke about having had a similar experience since childhood (“I would have been the kid in the corner that just... As I tell people, I don’t have that buffer. Information just goes through one ear and out the other, without the buffer that stops it and processes it”).

Applied Issues: Managing Household Tasks, Attending to Work Tasks, Learning to Drive

**Numerous examples were given of the impact of problems with retention and learning. Jack spoke about the effect it had on his ability to do household tasks:**

Oh, ‘did you forget the shopping? You’ve got ADHD!’ It’s not that simple, believe me. We’re talking forgetfulness all through the day. We all forget things. We all go to the top of the stairs and forget, ‘oh crap, I forgot to bring up the Hoover’. I’m on about all the time. And then an hour later, back up again. Put in the washing. I didn’t put the machine on. Come back a day later, ... ‘Aw the fucking machine isn’t on!’ All the time! ... Daily yeah. Forgetfulness, forgetfulness, forgetfulness. That’s the biggy, that one.

**Ethan** had trouble with short term memory at work (I’d go to the storeroom ... I’d forget what I was going out to get. Ten seconds, the difference of ten seconds and I’ve already forgotten what I went out to get. Come back in and ask my manager, ‘sorry what did I go to get?’ I forgot. It slipped my mind”). **Thomas** and **Aoife** described how learning difficulties impacted on the ability to acquire the skill of driving a car, which each of them wanted to do in order to achieve personal independence. **Thomas** knew he had to spend time concentrating on learning the theory part of the exam but found it difficult to focus (“I used to sit down at my ... computer you know, ... I’d be twenty minutes and I’d be out the door again. ... I went in and done the theory and I didn’t hardly know any answers. I told the man and he says ... You should sit down for an hour or two every night. I was thinking, I couldn’t sit for an hour or two at a computer”). For **Aoife**, the issue was when she was on the road and had to access the knowledge required (“it opened a whole new, the floodgates again. ... it requires your memory, it requires retrieving the information. You got to be able to read the road”).

#### Motivation

The need to be interested or stimulated by a task was commonly cited as a feature of ADHD (“if you’re not doing something you’re interested in, there’s no point in doing it at all, because you’ll just not concentrate”, **William**). If motivation was not engaged, it could act as a significant block on the ability to do a task or learn something new (“I was nearly back into the same place as when I was a kid in primary school. The learning. It’s like the brain shuts... The motivation, the interest just isn’t there. ... Then I’d just stop and just literally shut off”, **Rory**). **Caroline** found that her learning was interrupted if she was not interested: “Even now if I was to try and sit and listen to something that’s not naturally piquing my interest, I’ll be sitting there thinking about listening the entire time, as opposed to actually listening”.

For **Jack**, the motivation issue was also a generalised one, the drive to be goal-directed (“It’s a state like. ... There’s no drive, ... There’s no, do you know what, I think I’ll apply for a job today. I don’t do that. You’d have to come into the house and hold a gun to my head. Or I’d have to be in a very good mood”). **Aoife** also spoke about this problem and her awareness of it even when it is happening: “Sometimes I go in in the morning and I think, where do I start now? Then I’m feeling tired and lethargic, and it’s like, I gotta wake up, I gotta do this”.

#### Hyperfocus When Fully Engaged by a Topic

A small number of participants spoke about having excellent motivation and concentration when a task was fully engaging because of personal relevance and interest. They referred to this as “hyperfocus”. **Brian** experienced this, comparing his attention state to “being in a supercar with full throttle or no throttle. Hyper focus does exist, and you can take advantage of that. ... Being single-minded. Zoning in on one thing and one thing only. ... I think a lot of people with ADHD, it’s not so much a lack of concentration, as an inability to control it. ... There are times when you get engrossed in a task. ... hyperfocus there is a useful skill”.

**Rory** also spoke about this motivated capacity to focus, describing it as a strength: “so when you meet a subject you enjoy, you then can do about twice the work of the average. It’s like a superhuman skill then”. **Cathal** described it in the context of being motivated by having an interesting book grab his attention: “And then you give me a book that I’m interested in, or even if I’m not that interested in, but it’s, for me it’s well-written, I can sink into it. I can read it in a day. The television can be on full blast. My wife can be calling me. My kids can be falling down in front of me, and I won’t hear them”.

#### Motivated by Conceptual and Idealistic Issues

**Conor** described another nuance to the issue of motivation, talking about being motivated by issues that had an idealistic focus: “I think outside the box. I think maybe linear thinkers might think inside the box. So I have a very strong view of society, politics, the world, injustice”. He explained this tendency as reflecting both his own life experience

and his mental aptitudes: “I think that was heightened by some of my experiences in life as well. And because my mind jumps around. It links things. It wants to go sideways”. **Shane** also described being motivated and having his attention grabbed by injustice, although he experienced frustration in connection with this: “one of my main struggles I would say is grabbing hold of something and not being able to let go. And forgetting about everything else around. It’s usually righteousness, or being wronged. I find that very, very difficult. ... I get very wound up and frustrated”.

#### Motivated by Ideas and Conceptual Issues

Issues that had a conceptual basis were more motivating for some of the participants. Idea-based thinking that allowed for original perspectives and deep reflection were appealing to **Ethan**: “I like thinking like that anyway. I’m a very philosophical thinker”. **Cormac** spoke in similar terms: “I like things that are malleable, subjects where there’s various angles to come from. Like philosophy”. **Rory** had found that conceptual thinking was one of his strengths, and had learned to find other people to help carry out the plan: “So I’m good at the blue sky, the abstract, the conceptual. I’m good at making a plan. I think I had to learn then to get the people who can do it”.

#### Energy, Activity and Hyperactivity

Most of the participants associated ADHD with energy, at least at certain times. This was also linked with needing freedom of movement and stimulation. **Rory** found this to be a positive experience, as he enjoyed having energy when motivated by a topic or task of interest (“when it was something I liked, high focus energy, but it would be focused ... when I was doing something interesting, I was getting twice the amount of work done”). This was very helpful in his work (“that was highly valued. It wasn’t causing me stress or tiredness. ... and coming out with loads of energy. It would be energising”). **Cormac** described having a general sense of restlessness (“there’s times where I’ll be stood in a queue in say Aldi or Lidl, and I’m tapping and constantly looking around. If I’m in a restaurant or a pub or something, it annoys the hell out of [his partner]”). This tendency was accentuated for **Declan**, who framed his experience in terms of need for independence (“I like to be able to just get up and go out. If I can’t get up and go out, it’s a problem for me. Because independence is a great thing for me, that I need to be able to get out”).

Descriptions of energy extended to a feeling of mental alertness. This was valued by **Daniel** (“a thousand miles an hour. ... Sometimes I loved it. I loved the thought processes I’d have. I loved it”), but he also found it wearing to have a never ceasing thought process (“then I realised it’s not fucking sustainable because it’s too hard on you”). **Conor** spoke positively about his experience of mental alertness (“I’m delighted to be this way, ... I have a fast active mind. It moves around here and there. It’s great. I’m a good manager. ... I can oversee how things link in together. You know I enjoy the way my mind works. I don’t see it as an impediment at all”). **William** found that his mental alertness tended toward impatience (“you always rush things. You want one thing \*Clicks fingers\* Done like that”), and he

had to rein in his expectations (“It’s realising that you can’t do that, that some things take longer than others”). **William** also spoke about times of having low energy (“at other times you just, you can’t function at all. You just can’t get up in the morning. Those are the bad days”). A low energy state described **Ciara**’s typical experience (“The opposite of hyper. Just very slow movements and sluggish I call it. ... When I’m tired I can fall asleep literally in the middle of a class”).

**Sinead** described having a high energy level, which led her to channel the energy constructively through structured activities like sport:

I’m never tired. I could sleep two hours a night and keep going. I’d eventually burn out, ... But I like that sense of go, go, go. ... And I want to be involved. I want to do this. I want to do that. But one thing that it does hinder me is, say if I played a match, I want to go play another match. Now I want to go out. When I come home I want to go [do something else]. Like I have to be doing something.

It also meant that she had difficulty in sitting still to enjoy things with her friends:

Well I suppose I’d be giddy. I would never, in my life sit down and watch a movie. I wouldn’t be able to. I’d be on my phone. I’d have to get up.

Her energy led her to think ahead continuously to forward planning, which she described as an inability to “just live in the moment”:

Say if I’d be in school I’d be like okay, when I leave school I need to walk to the bus stop. Then I get on the bus. Then I get to study. Then I’ve to go get food. Then I go into study. Eat the food, then go straight into study. ... I’d never just go with the flow. I have to know what I’m doing. I can’t just lie around all day. I have to do something.

### Hyperactivity

Some of the participants identified with ‘hyperactivity’ in describing themselves as have a high energy disposition. This entailed being ‘bouncy’, moving constantly, or needing to remain engaged in several tasks at the same time:

You do find yourself hyperactive. Even now, I would find myself at times quite bouncy and happy and leery at times (**William**)

[my friend] said you know by... Say if we’re ever in someone’s house drinking before a night out? The most noticeable thing about me is I’ll

stand in doorways, or I'll get up and I'll move around the room. I'll never sit down in an area of the house (Ethan)

I'm not stimulated enough to stay at one thing. I seem to be better at trying to do three things, moving from one to another, as opposed to just doing one thing (Thomas)

### Difficult Emotions: Anger and Anxiety

Anger and anxiety were described by a minority of participants as emotions linked to ADHD, either as part of the experience or in reaction to it. Here we see Declan having his anger come out without his inability to control it:

I'd like to be able to cure that instant anger that comes out. ... I think it stems from the ADHD, is I'm straight in their face. If they're rude to me, you better be good and strong to hold what's gonna come. Because I will let rip. There's no control. It's just like switching the light switch on. It will just go bang and that's it. It's out. I can't stop it flowing until it's finished ... I'll walk away and within two seconds, that's forgotten for me. It's finished. End of. ... Instantly.

Cathal recalled having got into numerous fights when he was a young man: "I would have been scary for some of them as well I suppose. My fight or flight impulse was always fight. I mean I had a big mouth and I was cheeky, and I had absolutely no problem. I was involved in a lot of fights growing up". Sinead managed to keep a lid on her anger during the school day but not afterwards: "all day in school, every day. ... I'd hide my ADHD. I'd hide my anger. And then when I get home, I explode". Peter described an experience where he responded aggressively to a bar customer and got involved in a fight: "I told him he wasn't getting served anymore. And his friend then came up to me two minutes later and asked for two beers. Obviously one of them was for the other guy, so I told him to F off. And from behind him, yer man punched me straight in the face ... I could have handled it better".

Anxiety was typically linked to the consequences of ADHD experiences and characteristics. These consequences included frustration, low self-esteem, and worry about the future:

You could be very anxious with ADHD. Especially as I said there, before I started going to the groups, I was frustrated with myself. I was angry with other people. What I really was, was frustrated with myself. Why am I like this? (Jack)

So I think that I was obviously overanxious because of my self-esteem (Conor)

You're always kind of anxious of what's ahead and the next day, and if there's something coming up. How will I go about that? (**Aoife**)

In this extract from **Cormac's** interview, we can see how a spiral of negative thinking builds up to get outside his control, leading to negative emotions for him:

I tend to find I get very fidgety at times, and more so when something's not holding my attention. ... And then the mind usually formulates a pattern in the head, where I start thinking about certain things. It would be something that's predominantly important to me that's not resolved, or that maybe should have been resolved in a slightly different way. Something that you regret, which... I don't like regrets. ... I start thinking and ruminating on things. It gets into a spiral where the depression kicks in to some degree. Because I've gone through depression. Feelings of guilt is another thing. You feel guilty about something that you've done to somebody. ... Or just things. It could even be something that's socially sensitive to me in my social circle, or even politically that I'm aware of that's got me fired up. It will be just running around, and I'll be playing with it in different angles. I'll get myself into a state.

### Organisation

A feeling of being disorganised was a common part of the ADHD experience (“lateness or flakiness”, **Caroline**), which could verge into a sense of living in chaos. Here **Daniel** describes how not attending to his paperwork led to significant and unnecessary problems for him: “This is the sort of thing that typically happens. ... Got a letter from a speeding ticket, didn't pay it, didn't open it. ... So I ended up in court. Got a load of [penalty] points”. Likewise, **John** described not attending to his bills in an organised way: “Late on bill payments. Debt collectors. Just because I didn't sit down to pay the bloody bill. I had the money. There was no reason for me not to. I just never got around to paying the bloody bills”. ‘Not getting around’ to day-to-day tasks and responsibilities was a significant theme for many of the participants. **Aoife** talked about how this felt, comparing it to living in chaos. Being disorganised raised a number of issues for her, including negative comparisons with other people, having to continuously exert mental effort, and not achieving closure on everyday tasks:

I seem to work in chaos. That's just how I go about things. ... It's that my mind then has to be really overworking to get organised. It's a big effort. ... For me, it's something I have to almost draw from somewhere. I don't know where, but it's not automatic. It should be. Well it seems it should be. And it's not in me.

These issues made it difficult for **Aoife** to identify with the lifestyle that she felt other people enjoyed:

You're always going round in like a mumble. A sense of chaos. And even like... There's never a sense of free time. You know, people [would] be talking about doing things and I be thinking, oh my God, how do they have the time to do that? I'd almost be getting exhausted at the thought of what they do in normal everyday life ... have time for maybe studying or going to the cinema or things like that. I find it very hard to switch off and settle and do those kind of things. ... There's always a sense of, everything is incomplete. There's nothing finalised.

#### Implications: Procrastination, Work Organisation, Money Management

Difficulties with organisation had many applied implications. One of the most significant of these was procrastination in putting off or avoiding tasks (“I’ll put everything off until the last minute. I don’t know. It’s part of it. ... It’s kind of like a fear of starting stuff and then not being able to finish it I suppose”, **Ciara**). **Cormac** had found this to be a major issue for many years, and it had also surfaced more recently in a college course:

Never getting it in on time. The big thing was always procrastination. That’s always been a huge stream running right through life. Procrastination. From day one. ... even if it was an exciting subject. I’ve got time to do that later. Maybe I’ll look at it a little bit around the subject as I said before, but I wouldn’t actually put pen to paper or start typing until two days before. ... You just think to yourself, God you were cutting it awful fine.

**Aoife** described her experience of procrastination as one of “overthinking and doing nothing”. She knew she ought to do certain tasks, would reflect continuously on this lack of completion, become determined to do something, but then found that it did not happen: “this big, thinking about it and, I’ll get up early and, oh today I’m gonna do it. It’s gonna happen today. And... It’s like a lead balloon”.

#### Applied Issues: Organisation in Work

**Employment brings with it expectations for timeliness, consistent performance, and engaging with complex tasks. However these were aspects of organisation that the participants struggled with in a work environment:**

[Paperwork] I didn't like that. That's where it came back in. Oh! The ADD would come in. Totally. I'd be sitting there switched off for two hours (Rory)

Not being as I saw it, up to scratch. Not being able to stick to a task in ways that were not explained by [other factors] (Brian)

I was feeling truly atrocious. Because it was the same pattern again [as in a previous job]. This started off in a \*Clicks fingers\* blaze of glory, 'Jesus this lad is mighty, he can do anything'. And after the initial while, the nitty-gritty and all that just really got on top of me. And none of this was conscious at the time. I was just wondering like Jesus Christ, what's happening! (Daniel)

Late for work. Late for meetings. ... A lot of stuff spiralled. I couldn't understand how anybody else had time just to sit and have lunch at work. I was always like, I need to do this, or I've got this on. I never really felt in control of my life (John)

#### Applied Issue: Money Management

**Several of the participants spoke about having problems in organising and managing their money. William spoke about this as a defining issue ("money management certainly would be my biggest problem in life at the moment"). John had also experienced significant problems until his partner helped him with practical strategies for budgeting and tracking his spending. At an earlier point in his life, Declan had run into major problems with his money management: "I just kept putting it on the credit card because I thought well I have no money".**

#### Positive Features of ADHD

Many of the characteristics referred to here had mostly negative implications. However there were also positive appraisals made of some ADHD characteristics.

#### Creative Thinking, 'Outside the Box'

**William** acknowledged that “with ADHD, there is the down side”, but also noted that “there’s up sides too”. He highlighted creativity as a positive association, and felt that impulsivity can be good too (“it leads you to thinking on your feet quite a lot ... People with ADHD tend to be problem solvers. Definitely, there are plus sides that employers should know as well”). **Daniel** also described creativity as a feature that he enjoyed, along with intuition. Speaking more generally he said “The thing about it is, it seems to give me a lot of joy”. **Rory** thought that his wit and creativity might have arisen from having ADHD: “Because you can’t remember things off by heart. You have to learn witty ways to respond, or different ways to manipulate the information that’s given to you. So you’re learning in a different way. ... It’s because I haven’t learned in a formal way. It means that I’m not bound by the structures of only seeing ... through a certain lens”.

#### Wide-Ranging Interests

Several of the participants spoke about having a wide breadth of interests, which brought an original perspective to their view of the world: “It’s a broad knowledge of different things, ... Jesus I could have a conversation about anything and anyone. That was because of the fact that I was a pure magpie” (**Daniel**). **Ethan** described a curiosity about “how things work, and why this happens and why that happens”. Although this could interfere with thinking clearly at times, he enjoyed a lot of different interests, including “politics, science, natural environment ... general culture, art”. **John**’s current interests ranged across numerous topics: “Gaming. Games consoles. ... Working on cars. ... I’ve got all my tools. ... a lot of it’s music based. CDs. DVDs. Hundreds and hundreds of DVDs. Movies is a big interest. PCs, computing in general”.

#### Good with People

Finally, ADHD characteristics were associated with positive social skills for several of the participants. **Jack** said that “You can relate to people very, very well and some people love it. They love my kind of idiosyncrasies”. **Peter** described being able to manage a high pressure social role (“I was a ski rep even when I was doing [college] ... We’d go for a week or two weeks to France. ... You’d get on a bus with like 40 students ... It was like twenty hours. ... You just supervise. It’s kind of like a holiday rep you know on those sun holidays? You bring them out and that side of things”). **Cathal** spoke about his social presentation to others in positive terms (“I’m enthusiastic, and I’m polite, and I’m interested in people, which is all very good in short-term relationships”). **Cormac** had recently found that he had an aptitude for social care work: “People have looked at me and said, ‘you were made for this kind of work’. You really are made for working with people. People who are marginalised. ... It was like a rusty key in a rusty lock being turned”.

## Findings

### ADHD Characteristics: Positive Features of ADHD



## Identifying with Being a Person With ADHD

Building on descriptions of the characteristics of the condition, this section explores how the condition affected the participants' self concept over the years, before a diagnosis and since. It also assesses the explanations and labels that participants have developed over time in terms of the implications for self esteem.

### Integrating ADHD With the Self-Concept

**Brian's** view was that the facets of ADHD ("things like concentration and organisation") were not character traits that should inform his self concept. For him "those are skills", which situates ADHD as a dysfunctional cognitive module rather than something to identify with at the level of the self or personality. Nevertheless, the concept of adult ADHD was a useful tool for him. He spoke about adult ADHD as "a recent invention", a tool only recently available::

It used to be that you would grow out of it as a teenager. I think to an extent a lot of people do. A lot of people don't. There wasn't the awareness that there is now. ... ADHD wasn't something known to affect adults, or for that matter high achieving teenagers.

**Peter** did not see ADHD as a separate part of his personality ("It's hard to again disassociate between who I am and this brain disorder"), and therefore did not reflect a lot on what was 'ADHD' and what was 'his personality'. Whereas **Sinead** was conscious of 'having ADHD' on a frequent basis ("I think about it all the time though. Like I know I have it. It doesn't come out of my mind and come back in"). **Cormac** had initially resisted imposing a label on himself, but had come to see it as offering insights on how he should cope and adapt ("as bad as labels are, they sometimes can be of a huge help, because you know which way to go to").

As he was at an early point in assimilating ADHD to his personal story, **Jack** was integrating the condition with his understanding of his earlier life ("That's the process I'm in now. That's exactly the phase of my life I'm in now"). He was finding it helpful as a tool to understand his past ("It's not retrospect with regret ... That's why I was always looking around the classroom. Or that's why I never did my homework"). **Conor** had already gone through that process and had found it unlocked a deeper understanding of himself ("It made sense of so many things that really didn't make sense without that piece. ... It was just part of me"). Not having access to an alternative explanation in her childhood, **Aoife** had learned to present herself as a passive person ("I was the good girl. Don't upset anybody. ... So I'll be the obedient quiet girl"). She was now using her understanding of ADHD to help drive positive change and determination to take control of those issues she wanted to address.

Here we see **Jack** and **Ethan** actively intruding ADHD as a new explanation for something they had earlier presumed was part of their own make up:

I'm a bit of a messer. Now mind you, just having said that... Because I'm only recently diagnosed, I'm kind of wondering was that part of the reason, that it wasn't just entirely my personality. That there was genuinely, because of the chemical stuff going on that I was having problems. It was making me that way (**Jack**)

Originally I thought [his wide ranging interests] was me, but now I'm starting to think more so that it is that [ADHD]. I mean it would explain not focusing on any particular thing (**Ethan**)

While **Conor** spoke about the importance of discovering ADHD to making sense of his life, for him it added to an existing narrative he had, based on a family history of limited emotional expression and affection (“that my problems really arose from those developmental experiences”). He continued to find that explanation helpful and made the point that ADHD was not the only key to understanding his past: “So ADD isn't the full experience of my life. It's just part of who I am”. Likewise, **Cathal** saw his school experiences as sitting alongside ADHD in understanding how he developed as a person: “some of that is to do with ADHD, and also the experiences I've had through the school system ... From a young age, I would have been considered a bad boy like. Even though I was trying my best not to be”.

The importance of ADHD as an explanation of character and experiences was an open question for participants to work out. This was apparent when participants wondered about whether an experience was ‘ADHD’ or just something that could happen to anyone (“so I mean you don't have to be ADHD to have those traits”, **Daniel**; “I'm not good at reading things on screen. I prefer to have things here. ... Maybe a lot of people are like that. I don't think it's part of it. You know you can start to over diagnose yourself”, **Rory**). **Sinead** also identified with this issue, but did feel her reactions could be extreme compared with her peers:

some of the girls would say they come into school the next day being like ‘oh I'm so angry!’ [because of a minor issue at home] ... So I don't think it is just me. But they might have a fight with their mum over that, but I would take it to the next level.

#### Positive Identifications with ADHD: Playful, Empathic, Intelligent,

Several of the participants identified with having a playful side to their character, which they thought others might see as akin to a ‘childishness’. **Thomas** described this in negative terms when talking about the reactions of others: “People would often suggest to me, you know you haven’t grown up. You go on like a child”. However he did not see it negatively himself: “It’s just me. Some people say it’s young at heart, or maybe it’s the trait of ADHD. ... I just go out and go around town, and I’m away for hours. It’s just like a child still. I like keep going out and about”.

On one level, **Jack** did see himself as not adopting an ‘adult mentality’: “I kind of watch silly programmes sometimes. I don’t think I act my age ... I can be very sort of **Peter Pan**-esque”. This extended to not wanting to accept responsibility at times: “I don’t take responsibility very well. ... I don’t like responsibility”. However he saw this in positive terms too, that he could balance this with being a responsible adult: “I can be very free spirited ... immature is a bad word, because I pay my bills. I’m not irresponsible. ... I actually like that kind of, because I think it kind of keeps me young”. **Rory** had a similar identification and saw it in positive terms: “It’s a kind of playful Tiggerish look. Of we’re not bound by the rules, but not being oppositional in a way. Playful is the word I suppose, rather than being anarchistic”.

There were positive associations made between ADHD, intelligence, and empathy. This helped **William** to explain why he would need stimulation (“a lot of people with ADHD are of above average intelligence, and do get bored very easily”). **Ciara** had difficulty in focusing in some areas, but this did not stop her seeing herself as an intelligent person: “I know that if I do concentrate, I’m kind of intelligent in some areas and can focus on something”. This self concept was in line with other participants’ accounts. **Brian** spoke about doing well at school because “I am smart”, **John** saw himself as an excellent student: “I achieved, I achieved well”, and **Rory** had been given positive feedback by teachers as a child (“he’s very bright”).

**Caroline** identified with having an excellent insight on other people: “I would find it very easy to have insight or to look into situations of human nature and human behaviour”. This resonated with **Conor**’s self-description (“very in tune with people ... very much a reader of people”), and **Shane**’s understanding of himself (“I’m all about helping people”). For **Rory**, his own experience had given him a positive insight on other people (“it gives me a nice kind of non-judgemental way of looking at other people ... It’s a kind of compassionate bit”). He saw that, in combination with his positive traits, ADHD was a good characteristic: “what happens if you’re gentle like me? If you’re caring like me? If you add that into it, and if somebody’s creative, and they’ve got enough IQ to learn adaptive strategies and get support, then it can be nearly an advantage sometimes to have [ADHD]”.

### Self-Evaluations of ADHD

Despite positive identifications with ADHD, the condition was also seen as a burden. This duality was expressed by **Daniel**: “I’m here today and I’m thinking I’d hate to be boring, but there’s other times I just think ‘aw Jesus I just wish I was normal’, and I could just do and be sensible”. **Declan** had listened to the positive messaging that doctors had transmitted to him, about the importance of accepting himself, but still wanted to be ‘normal’: “You wanna feel normal. [but] They’re saying you are who you are. It’s okay not to be run of the mill sort of thing. You’re your own personality. ... I feel that people have mistreated me because of just the way I am. I’m different. ... And it’s very difficult living life like that with people, when you don’t feel like they do, and you don’t listen like they do”.

**Jack** related to this idea of being seen and treated differently by people over the years: “I pick it up in people. I know people see me differently. ‘There’s something different about him’. And it explains a bit of the bullying. ... A lot of people with ADHD and autism get bullied”. **Aoife** also felt outside the mainstream: “You’re trying to hide this from other people because you are an adult now. I’m an adult. I can’t get away with even that I’m a teenager or I’m in my twenties, ‘ah sure she’ll get over this.’ Or, ‘She’ll learn.’ It’s like no, this is me established, and I’m still not really doing the things I’m meant to do”.

**Thomas** spoke about feeling judged by others: “Normal people. I call them normal people. ... They look at you ... wondering why are you doing that, you know? You’re doing three different things. Your concentration doesn’t seem too good”. **Rory** had not experienced very negative experiences linked to ADHD as a child or growing up. He identified this as a critical protective factor for his development:

I think the huge thing is if you are ridiculed. I wasn’t ridiculed. I was witty enough. If someone came at me, I could really put them back in their place very quickly. In a nice way. Just going, don’t cross that line. ... If I had been downgraded or made fun of. I think that could be quite different. ... there’s definitely a stigma label, which I didn’t realise ... I wasn’t aware of that much, because I’ve had lots of nice people around me through life. And friends in college would have always said, well **Rory’s** a bit ADD, but in a very caring way, and a fun way. And they’d enjoy when I get a bit skittish.

Issues such as these meant that many participants were carrying a weight with their past experiences of ADHD and its consequences for them over time. **Conor** spoke about how he had managed to overcome a negative self-image very successfully through personal development, but that this success had required a lot of work: “I also had very low self-esteem. Very hidden sort of ashamed based carry on going on. So I didn’t really feel like I fitted in”. **Aoife** had the capacity to describe from her adult viewpoint the strain she had experienced as a child without the appropriate supports. There were numerous examples like this, for instance **Daniel** seeing himself in the past as a “fucking shambles” and being at one point trapped in a negative cycle (“no matter how much I

## Findings

### Identifying with Being a Person With ADHD: Self-Evaluations of ADHD

do that, it doesn't work for me"). **Jack** talked about feeling without value as a person at one stage ("Jesus Christ, give us five more lashes while you're at it. That's me like. It's obviously a sense of... I don't know ... It's obviously a worthlessness thing"). One of the reasons that **Caroline** was exploring ADHD was to develop a more positive, adaptive perspective on issues that she had judged herself on over the years ("It makes you... You don't want to feel like a twit when you're having a conversation with people. You don't want to feel like you've nothing interesting to grab from").

**Conor** did not have the support he needed to cope with ADHD growing up. He described how this fed forward into his later life, and felt that this was a typical pattern with adult ADHD:

you're being perceived as something being wrong with you. Not knowing what that is. Not being able to do anything about it. Feeling like you're flawed and a failure, and then developing maybe shame around that. And frustration. Not being able to reach your potential. Not being able to succeed. Then having to pay the consequences of that, financially, and in relationships and other ways. I think that's the shared experience. It's that.

His contention resonated with the stories told by other participants, such as **Aoife** ("as you get older, obviously there's more demands in life. Life changes. And you expect more from yourself I suppose, and externally, there's more of an expectation. ... You're trying. But it's kind of like running a marathon and you've done no training, and you're panting internally"), and **Patrick**, who spoke about having become aware of having absorbed a negative self-perception: "you're useless'. ... that self-talk, that negative self-talk".

For many participants there was a sense of regret over not having reached their potential in regard to various achievements. Although successful in life, **Patrick** expressed this as a nagging feeling: "There has been always that nag. Am I doing the best that I can do? And sometimes I would be satisfied with my lot in life, and other times I would be extremely dissatisfied with my lot in life". Looking back, **Thomas** felt that ADHD had limited the choices he made in life: "It frustrates you that you only took them jobs because of your self-worth. My self-worth was 'aw, I don't deserve anything else'. 'I'll stick with the factory'. 'Go drinking at the weekend'". For **Jack** this meant a regret, "that you could have done more and been more of a success. ... Just get the best from me". **Caroline** concurred with this from her experience ("A feeling of underachievement, not out of laziness, but out of frustration I suppose. ... It's a shame I suppose when you feel like you'd be capable of more"). Although he had got to a positive position in seeing himself, **Conor** also acknowledged the cost of ADHD in his life:

I feel that my attention deficit disorder has, I've had to pay a good old price for that. ... I think that my sense of failure was very much linked with that. So I do see that as being very pivotal in my life. I paid a heavy price because my attention deficit disorder was never recognised or understood by me or anybody else.

#### Forgiving Yourself

Despite the experience of regret in life, the participants also spoke about reaching a point of acceptance with ADHD, now that they had learned about it and assimilated it to their view of themselves. **Thomas** had thought that he was “stupid” because he had difficulty in learning, “and because of the way that I do things”, but now he did not see himself in such negative terms: “I just don’t get frustrated about it. I don’t ask myself why am I doing this the way I’m doing it”. **Ethan** said “I’m okay with who I am like. I know it’s harder for me, but like it’s just something I have to cope with like. Everybody has something that’s like that with themselves”. **Conor** also saw ADHD as a feature of his life that he had to work with: “I don’t see it as good or bad. I’m not quite sure I would put that kind of a value on it. It’s just the way I am”. **Cormac** knew that he could berate himself for his procrastination (“I could kick myself all day every day, but I know it’s not going to change”), yet spoke about adopting a more positive framing: “be happy with it”. **Peter** recognised positives that he associated with ADHD (“I’m open to new experiences. I like talking to new people, doing new things”). He also said that other extraverted people could equally have these without the issues attending the condition, and that he would prefer not to have it: “if you asked me like if I could be more balanced and still have that about me. ... Yeah, if I could flick a coin I’d probably go for that ... I guess maybe fundamentally I don’t have too much positives to say about it”.

#### Managing ADHD

**This section describes the overall approach taken by the participants in adapting to having ADHD as part of their lives. The key issue in managing ADHD was to work toward achieving personal control. This key principle operated on several levels: to be determined and take responsibility for making positive changes, to assert control through having a routine that worked for the individual, and to exert control within situations through the awareness of ADHD that has been earned over time.**

#### Personal Responsibility

Being in control of ADHD and finding a way to manage it meant taking an overall approach of being active in working with it, to take responsibility for the condition. **Aoife** spoke about reaching a point in her life where she could now do this:

I really felt like I’m an adult, and I have to deal with this. For the first time, I couldn’t run away from it. ... I thought, I have to deal with this. I cannot keep putting this in a box and pretending it’s not there. ... So now at my age, because most people seem to have gone and settled and done the thing, I feel less pressure. I don’t feel as many people are watching me, because

they're too busy doing their own lives now. ... I'm ready for it now. I wasn't ready for it in my twenties.

**Daniel** described how he had made many significant changes in his life to manage ADHD. This was not an easy solution, as he would find his good habits slipping at times and in need of renewed determination:

I've implemented a lot of changes. I gave up drink four years ago, cigarettes. Took up exercise. Meditation. All of that helps. But what does happen is that I fall out of the habit, and then I'm wondering then what the fuck is wrong with me? And then I realise I have to go back into all of this again. ... I accept that because I do try. I do try. I've tried very hard. I've changed an awful lot of things in my life.

**Peter** felt that personal learning was important, and that it would be the individual who would have to take responsibility for making changes: "you can't expect the world to change for you, if you follow what I mean. It's good if there's some support around it, but at the end of the day, you have to try and take responsibility". In reflecting on his life, **Patrick** found that he had been finding ways to manage ADHD for many years, although he had only recently had a label for what he had been doing for some time: "that's the way I'll always be, it seems. Unless I get some magic bullet of some kind. But it seems that's the way I'm built. And I've obviously learned to cope with it. I didn't realise right through my life that I was developing coping mechanisms in order to overcome these things".

Beyond the overall determination to assert personal control in order to achieve life goals, it was also necessary to develop good habits and routines. Developing and maintaining a structured, predictable environment made ADHD easier to cope with. This was reflected through daily routine, sleep / diet, and other ways to achieve personally acceptable levels of structure. **Daniel** spoke about how he had lost structure during an episode at college, and learned from his mother how to engage in good self-care: "She said 'listen, get the basics right. Get your sleep back. Get food'. ... Yeah I had become extremely chaotic. She said I used to forget to eat, which was the truth. I could literally. I used to literally forget to eat". In a similar vein, **John** spoke about the important of developing life skills, which might require some classes or formal input.

**Ethan** recognised the important of routine in his life, as this would be the way for him to cope and adapt in his college life: "Routine. I need routine. I've a very bad habit of breaking it on a regular basis. But once I have some sort of routine. ... I get up, I go to college, I stay in college until a certain time, I go home. I go out then, and I can do what I want when I go home". **Patrick** spoke how maintaining good habits was an ongoing project, during which there would be periods of feeling like some progress had been lost: "I was getting up. I was doing the basics. I was getting the kids to school, feeding myself. I wasn't going to rack and

ruin like that, but my sleep was pretty well disrupted. ... I've been trying to, but failing to watch what I'm eating. I'm kind of on a food carelessness situation at the moment. I want to get back into some exercise, but I haven't been able to motivate myself to do".

**Peter** spoke about how he had come to use his awareness of ADHD to monitor and manage himself in particular situations. He knew that he could be inclined to distraction and he monitored himself as a form of self-control to counteract this:

there's the self-monitoring, because you've actually read it twice and you're like, 'hold on, what did I just read?' You become aware that, okay I really need to focus. I wouldn't describe it as an erratic state. But probably during that period I've either been distracted with something else, or my mind might have raced ahead to think of something else. Like maybe some task I have to do later in the day will intrude, and you have to actively ignore, inhibit that thought. ... A conscious level of focus. You really have to inhibit any intruding thoughts or distractions.

### A Challenging Disability

Attempts at achieving control were spoken about positively as a real step toward managing ADHD. Yet this was in the context of understanding that ADHD is a challenging disability, one that catches you out, catches up on you, and has ups and downs. It was seen as a disability with a very significant impact ("Even when you have your diagnosis, and even when you do have your meds, I've found that it has still been pretty tough handling the condition", **Brian**). It is something that is a struggle to manage, even when trying to address the issues, and one that requires personal determination, as **Aoife** described:

I'm on this roundabout and I can't get off it. That's what I'm on. I just can't get off it. It's the same roundabout. ... It's so easy to keep avoiding things and keep hiding this. ... The world doesn't know. Nobody's gonna help you if you don't know what it is and you're not talking about it. ... Just like in school. You're not able for it. You're just left there.

Daniel found that, alongside his personal effort, there were also key supporters who were central in finding the positive orientation required to manage an ongoing condition:

I'm still struggling. Even today I'm really struggling, but not struggling as much. I just saw myself going into a hole ... and ... If I hadn't maybe met [INCADDS coordinator]. If I hadn't... I would possibly, probably be on the dole, drinking, resentful ... And these things are very real. They're huge realities ... I think it's being aware of it, and when I'm aware of it, I can work around it to the best I can, but ultimately realise that it will always sneak up and catch me somewhere.

It was important to accept that ADHD required continuous efforts at adaptation, across different areas of life (“Adapting is a skill. I think people underestimate the humongous amount of effort that goes into coping strategies”, **Brian**). This was a personal life task that changed over time: “ADD isn't really gonna go away. I think you have to learn adaptive techniques yourself. You know obviously it changes when you become more mature or more adult anyway. The symptoms, even ADHD, you learn to adapt to them as an adult, because you're more familiar with them” (**Conor**). **John** had been able to cope through a combination of factors: “[my spouse] has been a big transformative thing in my life. And then medication and diagnosis is helping that”. Looking ahead to the work environment, **Jack** saw that he would approach things differently in the future: “The next job I take up, there will be allowances made. There has to be like. There has to be accommodations. There has to be ‘look **Jack**, don't worry, give yourself an extra half an hour with that job if that's what you need to do’”. **Rory** found he could make adaptations to balance his tendency to speak without editing himself with his liking of being witty: “When I blurt things out, which I think are funny sometimes, I just have to learn that in certain situations, you don't ... I've learned the hard way”. For **Cathal**, a key adaptation required was in how the educational system managed ADHD, as much as for individuals to adapt themselves: “For me it's not a medical problem really. It's more of an educational problem”. **Daniel** felt that ADHD was not in itself a disorder or a problem, except for the demands placed on him by the external world and his need to adapt to this: “If I wasn't in a world that demanded a lot of paperwork and that, it wouldn't be a disorder, because it wouldn't have any impact on my life in that way”.

## Findings

### Managing ADHD: A Challenging Disability



## Coping Strategies

At the more specific level of managing ADHD, the participants had much to say about how they have coped in the past, their current coping strategies, and the importance of social support. This section covers the coping strategies that were described.

### Avoidance, Alcohol and Drug Use

#### Avoidance

Avoidance was a strategy whereby stress-provoking situations and responsibilities were dealt with through inaction. For instance, **Daniel** described avoiding paperwork: “I just kicked everything to touch, long-fingered it, but with massive stress going inside”. **Aoife** gave a powerful description of what it was like to avoid the issues that she found challenging to deal with at work:

it's the duvet effect. Let's go home to bed. I've had a tough day. Today was tough. It really came to the surface. Let's go and hibernate. Tomorrow it'll be all okay. But you know inside it won't be. ... You start to avoid. But avoid is fine, but we've got to get out of the bed the next day, and we gotta get into the same chaos. ... So you're always hiding. Always have to be a step ahead that way. You see I spend such wasteless energy on hiding than actually dealing with the situations. ... It's not good though. It's not good for you inside. It's festering more self-loathing. That's what it's doing.

#### Alcohol and Drug Use

In response to his stress, in the past **Daniel** had relied for a time on alcohol and also used headshop drugs: “So I was putting myself into you know, self-medicating”. This escalated (“And every week there was more and more and more”), and had a significant effect on him (“That was affecting my mood. ... I was more difficult to be around. I was very distant”). **Conor** identified self-medication as a feature he associated with ADHD (“it causes massive problems in people's lives”). **Conor** had experienced years of addiction himself to both alcohol and to drugs. Problems began for him when he ran into difficulty with school and left early:

I was smoking more cannabis, and I was drinking more. ... I was probably enjoying that yeah. ... Absolutely. I'm not sure I was enjoying being me. Maybe that's why I was enjoying it. So I was struggling. And I was struggling with a sense of self ... It kind of turned sour then I think, when I hit my mid-twenties. I'd been dabbling in heavier drugs ... And you know it was a fairly futile pointless existence at the end really. It was just like kind of getting up in the morning to get stoned. ... I had become addicted to substances as a way of coping.

**John** expressed an awareness of the potential for addiction. He saw his own interest in achieving a buzz as potentially dangerous but was forearmed with self-knowledge and awareness:

Every night I'm trying to look for a little bit of buzz or something. And it can be dangerous. I can see how it could go into addictiveness, you know of alcohol. Knowing your propensity for that, and being aware of it I think will help you make better choices. It may be very hard to make the choices, but at least you know why you're battling it so hard.

For him, **Cathal** saw these issues as reflective of early adulthood norms rather than as a feature associated with ADHD. He linked his heavy drinking and cannabis use in the past to his jobs and environment. Here he refers to working in one job that gave easy access to alcohol:

there was a lot of drinking involved. ... the nature of the job. Well I mean there would have been a high number of alcoholics in the job too. ... I've never used alcohol to forget, or to remember, or to not think about stuff, you know. ... I've never turned to the bottle if you know what I mean?

Then in terms of cannabis use:

And I would have smoked a fair amount of doobie as well. ... Young people go through this stage of experimenting and everything else I suppose. I mean I went to Holland and worked for a while. I would have smoked pretty much solid for months on end if you like. But I wonder is that a growing up thing? ... I knew it was a crutch, and I might have used it once or twice as a crutch, but it was more along the lines of teenage experimentation or young adult, you know.

Similarly, **Ethan** framed his alcohol use in the context of a student lifestyle rather than something attached to him personally or to ADHD, although disruption to important routines was evident:

Because you can do what you want. First year for me, I went absolutely wild! That's the only way I can describe it. ... I was out four, five nights a week like. Non-stop, on the go like. ... Like it was a great year. It was so fun I had to do it twice. \*Laughs\* ... I just developed the coping mechanism where I can go with very little sleep, and come back and get the few hours' sleep before I go out again. And then I'm out again, sleep. My sleeping pattern went all over the place basically.

## Getting Organised

### Organisers and Diaries

There were a number of references to developing skills based on information, organisation, reminders, and prompting. Several participants relied extensively on diaries and organisers to help address the problems they had with organisation. These could be written or using technology:

There's a great skill to having to be methodical with your diary. ... To get things done, I really need to write myself a to do list the previous night  
(Brian)

So my phone's full of reminders and alarms. If I put the dogs out into the yard, I set a ten-minute timer, religiously, because I'll forget the dogs are in the bloody yard. ... So little tools like that, ... So I've kind of adapted a lot of that in my personal life. ... I now use the phone for checklists, notes, camera (John)

For me, having a planner or having things. So I plan a year in advance now, as a reaction to it, as a coping mechanism (Rory)

Well I'm so organised myself like. Everything's done on time. I'll be in places where I need to be, I'll go there. ... Like my folders in school are so organised (Sinead)

Patrick spoke about adopting a general approach of becoming methodical in tackling tasks he had found difficult. He developed these skills largely on an intuitive basis over the years and found he was able to adapt well to the demands he faced:

I would have, in many ways, kind of assumed that everyone had to do this. And in many ways, it's very useful. I mean sometimes it's not a burden. If you are very methodical about how you do things from A to Z, and you develop these skills, put it that way. The ability to do something. The ability to speak to people, to listen to people, to whatever. You know you go through life. You develop these mechanisms. And that's how your life is organised. ... I know where everything is on that desk. I pretty much do. Don't put your hand in there. ... Because I'll be utterly... I'll have to go through the whole lot and put it back to the way that I know where it is

#### Task Management

Several strategies were described with respect to breaking up tasks in order to manage them.

**Declan** had developed a start-stop approach to task completion:

I'll kind of go off and find something else to do. Then I will go back to what I was doing. If I have a problem that I can't concentrate on that one particular thing, I go off and find something else to do. Then if I come back and just set my mind to it, I can normally continue it. I'll walk away from it. I'm not taking the easy way out, but I'll walk away from it and then come back to it when my mind's in the right frame of mind.

**Ethan** was utilising a commonly used study technique that was similar in purpose to that used by **Declan**:

The best thing I got told was the twenty-minute break thing. That was what I was told. Twenty minutes, take a break. I used to do forty minutes and break, but I find twenty minutes is an awful lot better. Twenty minutes and literally just go. Don't do anything. Just go and get a glass of water or go and get a cup of coffee and come back straight down. Just change scenery for a few minutes, and you can go back, and you've got instant focus again.

**Thomas** managed his frustration with task completion by carrying out multiple tasks at the same time. **Declan** also spoke about having multiple tasks going on, so that he could move his attention from one to another without getting bored:

I will start three or four jobs, and I will go back to them individually. I've learned to go back to them individually in the house, if I'm doing something. Say I was hoovering. I'd get bored of that. I'd go back and I'd polish, or I go back and do something else. I'll have three or four jobs on the go, and that's my best way of coping.

Unlike **Thomas** and **Declan**, **Peter** described enforcing a discipline of completing one task before moving to the next:

You just got to say to yourself look, I'm getting distracted here, back to task A. Forget about B, C, D, until A is done. Just that kind of constantly reminding yourself

**Patrick** spoke about how he managed procedural tasks or instruction that he would otherwise find overwhelming, by consciously breaking these down to assimilate the steps sequentially:

If it's something reasonably easy to do, then you just slow it down. You either write it down or you get the person that's giving you the instructions to say okay, this is this, and I'll say mentally, that's the first step, that's the second step, that... Okay, got it! Solved. We will never have to have the conversation again. This is how you turn on the washing machine. You know. Don't assume that I know. Or just because you have waved a magic wand in front of me, that I can assimilate what needs to be done

### Daily Structure and Routine

Going beyond individual task completion, the importance of maintaining a habit or rhythm to the day was discussed. For instance in regard to studying, **Peter** spoke about the need to be disciplined, despite the challenge involved: "I think it's a good idea to treat it like a 9-5 job", and he has now continued that in paid employment by becoming an early riser, having a run, then eating breakfast and getting to work early. **Patrick** also spoke about how he found regular physical exercise and reliable sleep patterns to be the best match for him. At a more general level again, **Brian** highlighted the importance of having goals ("aims in life") to help steer by.

Ideally, the workplace would support adaptation by being a good match with the person's skills. For instance, for **John**, "I enjoyed much more, solving problems, having people come with issues and figuring it out. I kind of just tailored my career path to that", while for **William** "I love sales. Sales is my thing. I love talking to people. I love meeting people and all that sort of stuff. And I love the way sometimes that I can get out of the office and go and meet customers. ... whenever you have to go out and actually speak to somebody, you get a ... rush from it I find".

Maintaining personal dignity contributed to the ability to manage well. For instance, **Declan** said that "I don't like people to see that I've got issues. The doctor said that is a common thing. Like my dress sense has to be... I don't like being dirty. I have to be smart and clean". For **Brian**, being assertive enabled him to feel good: "to stand up and defend myself against people or family ... I like to be in control of something. It doesn't matter how other people have done things. I will always find my own way of doing it".

#### Researching

Finding relevant information was an important means for some of the participants to achieve control (“I went into the researcher [mode] first of all, to understand how the medical system works and how the treatment works, rather than jumping straight into the GP. Doing it that way, I wouldn’t have any control”, **Brian**). This information was normally obtained online (“I do a lot of research online. I read and read and read, and I take notes myself”, **Jack**) or through books (“it led me to the library again ... So I got the two books out, women with attention deficit disorder, and I got the other book out, ... a lot of people, through computer generated programmes, are trying to make other parts of the brain work for the parts that aren’t working”, **Aoife**).

#### Exercise and Personal Development Activities

There was extensive discussion of exercise and related activities such as yoga. Many of the participants had multiple forms of activity in this area (“I love cycling. I do yoga. I do martial arts. I do drumming. I do a load of bloody things”, **Jack**). Doing exercise was rewarding in achieving a good balance. **Brian** referred to how “everything’s better” when he gets into a pattern of exercise (“I spend less money, drink, food, I’m more productive in work, I sleep like a log every night”, **Brian**). This greater sense of equilibrium and sustainability was described by **Caroline** as well (“I’ve introduced exercise into my life in the last few years, and that’s helped me a lot in calmness in my head, but also just regulating everything”). **Patrick** saw achieving activity and a balanced diet as essential coping strategies (“So if you’re eating well and you’re exercising well, that’s the medicine. Or it’s a very large part of the medicine. The more I’ve gone through life anyway, the more I say, there’s almost nothing psychologically that won’t be improved by a bit of exercise”, **Patrick**). **Thomas** strongly agreed with this (“I always knew that doing something physical made me feel better”).

Here **Cormac** refers to how exercise is difficult to maintain, and that it might not take a highly structured form, but with self-regulation it can be sustained and have a really positive impact:

because I’ve always got a million and one threads running through my head, ... I wouldn’t say there was any real program of exercise. I’m just making a conscious effort to keep fit. I find that I might stop doing press-ups for a few seconds to get my breath. And then I’ll be in the kitchen making a cup of tea and thinking, what am I doing this for now? Knock the kettle off. Back to the punch bag or whatever. When I get to the end, and I know I’ve done everything that I set out to do, it’s like wow! I wish I could have done that in daily life years and years ago.

By comparison, **William** was more structured in how he accommodated exercise in his life (“I go swimming most mornings before work. I don’t start work until about 10 o’clock”). The impact for him was evident: “I find it clears my head and makes me less anxious”. He also referred to horse riding, which had a particular benefit (“it’s a bit like driving a car, you have to have all your attention focused on that. Otherwise it can be quite dangerous. So I found that quite good. I found that quite therapeutic to have something that I just had to completely focus on. And it has really helped with my ADHD”).

**Thomas** referred to having become involved in mindfulness, meditation and yoga, which he found very helpful: “I suppose mindfulness is just being aware of the now. Being mindful of where you are. Being mindful of your breathing. Being aware of your breathing, which helps you to slow down ... It kind of goes hand in hand if you have mental health problems. The mindfulness slows your mind down, you know. Whether it be depression, anxiety or whatever”. **Rory** had a similar experience: “I find mindfulness is really good, because it really ... If you do that, it gets you into a focused zone. ... literally using cognitive neuropsychology coping mechanisms”.

## Attitudes and Acceptance

### Acceptance and Self-Awareness

Acceptance here refers to coming to terms with having ADHD, becoming more at peace with it, as well as accepting that different accommodations would be necessary. This was helpful for **Thomas** in dealing with having a difficult day, “you can actually say, that’s just one of my days. You accept it. ... I’m more forgiving of myself ... I don’t beat myself up as they say. They used to say, get off the cross”. **Caroline** also spoke about reaching an acceptance that moved beyond self-reproach (“I used to sort of beat myself up about it, and then I kind of said okay, you find that hard, and accepted it”). It was described by **Daniel** as an acceptance that “I’m always going to struggle in life. ... But if you can make peace with that, it’ll become easier”.

In this example, **Aoife** describes becoming more accepting after having a tough time learning to drive. For her, at this point in her relationship with ADHD, acceptance involved facing up to this challenge: “it led me to coming out the other side ... I actually had to accept something, which I normally don’t. ... it was raw. And I couldn’t hide it anymore”. **John** used his acceptance to accommodate to having to use a timer, acknowledging that he could not rely on his own memory: “knowledge and self-awareness to me is key. ... I think awareness now is the biggest thing. I’m aware of my weaknesses instead of ... I admit to myself, ‘I will forget that’. It’s okay. I’ll set a timer. Rather than just before being like, ‘it’ll be fine’”.

#### Positive Attitude

Perceiving oneself as resilient and resourceful were important capacities for developing a positive attitudes and beliefs about the scope of one's personal potential. **Brian** was interested in future possibilities: "the importance of motivation and having a good mind-set in the first place. ... Things like the can do mentality. Just get on with it! ... to keep my options open in future, rather than [the] job ladder from an employer who's going to dictate to you where the rungs are on that ladder". **Ethan** saw himself as resilient: "I don't give up easily. That's my main thing". **Conor** described himself as having learned from his past experience, having healed and come to view himself as a good person: "The more I recognised how normal it is for me to experience the things that I've experienced, and to have responded to them in the way that I have responded to them. ... I've become very aware that actually, I'm a really decent person. I'm a kind caring person. I'm a loving person. I'm quite an intelligent person".

Instead of not dealing with ADHD, it was important to put in place a positive plan. This was evident in **Ethan's** interview, where his worry was reduced as a result of being proactive and open: "This year it was like alright, you know you have this. Grand. But then I started to actually deal with it, put the procedure in place, you know what you need to do and start working with". **Aoife** described how she had come to a turning point in her relationship with ADHD, of being open to change: "I can't hope that it's going to go away. It's not going away. It keeps popping up. And the more I do to avoid it, the more it seems to come around the corner and bite me, bigger and harder than ever before. So now I know at this stage, okay, I gotta deal with these things. I can't keep pretending. ... If I knew more about it and understood it more, and could really put a claim on what's what. Is it the learning disability? Is it the attention deficit disorder? Is it a combo of both? Or whatever. Then you feel more satisfied to deal with it I suppose. But I know now".

#### Coping with the Help of Others

##### Supportive Family: Prompting You to Get Help, Taking the Right Approach, Feeling Supported

One function of family support was to help the person get the right help. **William** said "My father sort of decided 'right, I've been watching him struggling for too long'. And he sort of took the reins over. ... he has been very supportive. Very supportive. I think he just wants to see me settle down and able to have a good life, you know. ... and medication and a job and a steady apartment and stuff, you know. Still a bit of a rocky road, but I think he can see a light at the end of the tunnel". For **Ciara**, that role was enacted by another family member: "She knows when she's talking to me and I'm just not listening. I'm somewhere else if you know what I mean? So she always said there's something wrong kind of thing. She picked up on it".

## Findings

### Coping Strategies: Coping with the Help of Others



**Declan** recalled that his father had a more effective approach to managing **Declan's** issues than his mother. This was an important support: "He was so mellow. I could really be screaming and shouting at him, and he would just stand and look at me. After I'd finished he'd say, 'are you finished?' And I'd say yeah. And he'd say, 'can you go and do what you're supposed to do?'" **Sinead** also described her father taking a calm approach to the situation: "dad would just sit there. And then he'd come up when I'd calmed down and he'd say 'okay, you can't do that'".

The participants were lifted when they felt supported by family members. **Caroline** said "I would say a big positive would be that I do feel like I have a really great family behind me, you know in terms of my parents and siblings, and also my husband and children". Similarly, **Patrick**, with grown up children, saw himself as being blessed ("I've been very lucky in my life. I've got a wonderful wife. I've three wonderful kids. ... Day to day bills are always paid, etc. etc. ... My family is around me"). **Ethan** also felt the support of his family, in his situation as a young adult. Here he says the diagnosis of ADHD helped his relationship with his parents: "my dad had always been quite hard on me when it came to college and stuff like that, not passing exams and things like that. I remember he said to me, we were just in the car on the way back and he goes, 'I'm sorry, I didn't realise how hard it was for you.' ... They kind of understand it an awful lot better now ... it was kind of like you know, we need to sort this out like. And they were very supportive that way as well. Mam especially as well. I'm lucky. I've good parents".

### Support from Friends

**Ethan** spoke about his friends as being a critical support to him ("I suppose ten officially know. ... They were the people who helped me through it ... if I didn't have the support structure I have with my friends, I'd be all over the place"). He had struggled in college, but had found his friends' support very important in getting him back on track: "he would have to keep me in shape if I don't go into college. That's exactly what I say to him like. You have to make my life as awkward as possible if I don't go in. Because that will give me an incentive to go in. ... Basically what he'll do is now in the mornings, he'll come into my room. ... and he'd start kicking me until I got out of bed. And he was like, you're going to college".

Another young adult, **William**, had also obtained good support from his friends: "I have now surrounded myself with some really good people, who do know about my diagnosis. I can sit down over a few drinks and talk to them about the problem that I'm having. It's quite important". **Cathal** was older and had found the support of his friends to be important over decades: "I had established a network of good friends that could put up with me, and were willing to accept the good with the bad if you like". Similarly **Cormac** said he had found people who he clicked with: "I've got those people, those friends that have stuck by me for twenty or thirty odd years, and in some cases [since moving to Ireland]. It's almost like, look you are just who you are, and we'll take you for what you are. And then we get on like a house on fire".

#### Spouse / Partner Support

Those participants with partners spoke about the important support that provided to achieve greater adjustment to ADHD. For **Declan**, this involved a lot of practical support (“You know reminding me, doing paperwork, doing tablets, doing appointments”). **Shane** said that his wife was an important person in helping him keep active and have a structured lifestyle: “She’s a very get up and go sort of person. What are you doing still in bed? Or, you know. And I think only for having her... I think that’s a good thing. She’s very positive and very, you know. Come on, we’re going out! That sort of way. There’s no time to mope about”. **Rory** appreciated how his wife gave him orientation to what was appropriate in different social contexts (and feedback later if necessary): “I could get into a comical thing and make something funny. So I’d have to literally say what, whenever I go out, what can I not talk about here. ... She acts as the external cue. But I think a lot of Irish men have that anyway. So I’m not sure if... Well it is different, because sometimes she’ll say why the hell did you say that?” **Peter** suggested what he would look for in a partner: “someone I would say who is accommodating and accepting that you’re not always going to do things normal, or you might react differently in situations. Maybe take things sometimes too much to heart, or read into stuff too much”.

Each person had a particular form of relationship with their partner. For **Declan**, achieving trust and feeling understood was very important (“[Partner’s] been my closest person that I’ve ever been able to let into my life, into my world. And I think that’s always been an issue. [She’s] been the first person that I’ve ever sort of opened up to. I met [her] and sort of, I don’t know, I suppose clicked with [her]. There was just something that I trusted about [her]”). For **John**, there was a sense of complementing each other by being different from one another (“My wife and I complement each other in some ways for organisation and logical thinking. It’s kind of yin and yang with my impulsivity and creativity”).

The openness of his spouse to change was an important support to **Daniel** in transitioning to a healthier lifestyle: “we’re very, very lucky in that we began to realise all this stuff. And we’re both very much into healthier foods. ... she began to see I think what meditation and exercise did for me. So she began to start meditating and exercising maybe two years ago. ... we’ve really become a lot closer since I started becoming more aware of myself. You see I wasn’t aware of the fact of how difficult I could be to live with”.

For **Caroline**, the issue was not in respect of unhealthy lifestyles, but did involve finding an adjustment with her husband to some of the characteristics she associated with ADHD. She recalled having talked about it with him: “yes I do this, but also there’s these other ways in which I’m much more relaxed than you, in ways that are kind of necessary in parenting, and in life. But yeah. There’s definitely things that I feel that he has had to adjust to, and that that’s taken some time. An understanding that’s developed through a lot of very honest communication”.

Jack spoke powerfully about how his diagnosis enabled him to rethink his experiences as a single parent:

And then there was a line in one of the books, I can't remember now. And I had copied it down and underlined it for myself. And it was about forgiving myself as a parent for being undiagnosed for this. ... I think I cried when I read that part. I said Jesus! Because I beat myself up big time over past mistakes ... And they'll tell you 'dad you did fine. We're here. We're grand!'

### Peer Support

Most of the participants did not regularly take part in a peer support group. For those who did, the importance of the group was evident. Several benefits were identified, based on self-acceptance, normalisation of ADHD, and achievement of valued skills. **Thomas** found that being at the group helped him to refocus on his priorities and how he wanted to proceed in managing his ADHD (“I’m only learning myself, you know. I forget the way I am and the way I used to be, until I go to the meetings again. ... I remember that’s the way I am”). He went on to say that he believed the group was instrumental to all who attended in reaching acceptance of ADHD (“everybody in the room has got them symptoms, or had them maybe yesterday. It’s more of an acceptance of your illness, or whatever you want to call it. You accept it better because you’re with other people, and you’re able to talk to the other people who have it ... When you have an acceptance of it, you’re not as frustrated”). **Conor** had attended group seminars rather than a regular group meeting, and that had helped him with acceptance (“I went to seminars that INCADDS put together. There was guys in there who you know, you could have them sitting here. We’re all the same. We’ve got exactly the same experiences. So then I started to recognise, look this is it”).

For **Cormac**, the group experience was via a Facebook group for adult ADHD, and he had found it helpful for his needs. He started by getting familiar with the main threads and identified with the themes that emerged and the approach taken (“people were coming up with practical solutions, or at least being very, very accepting of things, rather than saying you must take drugs. The arguments were just that, proper structured arguments as opposed to heated debates. People were prepared to listen to each other. ... that Facebook peer support thing is pretty important at times”). As time went on, he learned as much as he needed to from the Facebook group (“From the articles and links that they put on, I’ve got to a point where the buckets almost full. ... I’ve learned as much as I need to learn that’s practicable ... But as it is, I don’t actually look at that Facebook page that often now, just occasionally. I just dip my toes in”).

**Thomas** had no reference point prior to the group starting up in his community and it had made a big difference in his life (“You accept the way you are because you’re in a group. You feel you belong. Whereas before the ADHD group started, you’re lost. Why am I like this? Nobody else is like this”). **John** had found that talking to other group members had enabled him to learn a lot about ADHD, in a way that health services would not be able to do:

you learn a lot from other people’s experiences. One of us will typically come in with something about, ‘aw I did this the other day. Do you guys ever do something similar?’ So you’ll learn a lot I think, just from sharing. So it’s very helpful in that way. It’s a bit of a normative experience. You don’t feel such an oddball at times, you know. Everybody’s saying, ‘aw I did this’, and you have a laugh about it. It’s okay to be like that. ... You don’t gain that level of understanding of your own condition I don’t think, from the health services. So I think groups like this yeah, should be a necessity for, or should be available for everybody. I think the benefit is very large.

New perspectives and skills became available from being in a group situation with other people who experienced ADHD. **William** got a perspective on how his own parents might have experienced his ADHD (“There’s a lot of parents go to it, so it’s good. I can understand how my parents felt better through hearing what they’re saying about their kids”). **Shane** referred to specific self-management skills and techniques available to group members (“They look at new ideas. I mentioned the WRAP course. ... Because I’d done the wrap course. And they went away and got trained on wrap, so they can do it”). **Brian** learned about the experience of people who he might not have otherwise met or learned from (“we had a guy who was in a position of senior management. Apparently he was doing it very successfully. ... Apparently he was doing very well. But these are the stories and the benefits that I gain from peer support”). For **Ethan**, group support meant finding a new way to succeed at college. He had found a group study technique from another student who had ADHD, which matched his learning style:

He said the best thing you can do is get a group of people that you’re in college with that either think like you, or ... have some idea of what they’re doing with questions, and then bounce it off each other. He said that’s the most constructive environment you can have, if you actually focus on the work. He said, ‘I know the way that you think. It’s like, if someone says it to you and explains it to you, it’s easy. That’s it. You know it then’. ... But if you’re trying to learn it off a lecturer or a lecture slide, that’s not going to make any sense to you. I understand that like. I tried that then, and I found that so much more of a constructive environment to learn in.

## Findings

### Coping Strategies: Coping with the Help of Others



## Diagnosis

This is the first of three sections that deal with experiences of the health care system, especially primary care and mental health care services. In this section, the route to diagnosis is described. To a large extent, the participants had been active in identifying a diagnosis themselves, and then sought to find a way to get medical validation for this. The following two sections describe their dealings with health care practitioners and with medication for ADHD.

### Being Open to Adult ADHD Diagnosis

It was important that the person was open to the diagnosis of ADHD. **Jack** described having reached a point of frustration in his life, which led to him being ready to look at a new perspective: “I need to do something! This is going to blow! ... I felt I was at a sort of a junction in my life. Sod this like!”. **Conor** described his journey through life to a counsellor who suggested that he had all the symptoms of attention deficit disorder. While surprised and skeptical at first, he reflected on it over a period of weeks and came to a realisation that it was “actually a big central piece of my jigsaw. ... that actually I do have all the symptoms if you like of attention deficit disorder, without the hyperactivity I would say. It had never been diagnosed. And yet it had actually had huge repercussions in my journey through life”.

There was a strong trend toward self-diagnosis or identification with ADHD, based on having matched personal experiences with information found through research and on the Internet (“I observed myself over a period of months, and put things together, ... I self-diagnosed ADHD”, **Brian**; “The consultant didn’t inform me of it. Maybe I’m not a good reference case because I brought him the checklist and said I have ADHD”, **John**). Typically the self-diagnosis evolved in a stepped manner. **Daniel** completed “all these personality tests, and one of them just said maybe you should check yourself for ADHD”. This did not fit with his understanding (“Jesus no. I know what ADHDs look like”), but after finding several such tests over months he felt it was a significant pattern. **Jack** also described a journey toward self-diagnosis, from initial exposure to the concept (“[it] plants a bit of a seed”), to becoming immersed in researching books until he got to a point of realisation (“I read them and read them, and took notes and notes and notes. I was there Jesus Christ! Waw that’s it!”). Similarly **Caroline** used the internet after the initial prompt of a family member being diagnosed and a subsequent review of her own past (“I’ve done a fair bit of looking into it in so far as you can online, just being also aware that you can’t Google your way into every answer. I have looked into it, and I’ve done a few of the online tests on it. And I’ve also read testimonies of people who have been diagnosed”).

**Ethan** had a chance encounter with an article on ADHD, which led him to look up the symptoms. He ignored it but after a while asked his doctor. Finally, after several months “it kind of dawned on me” while “I was procrastinating ... doing assignments and procrastinating

from my summer exams”. The initial chance encounter was very important, and reflective of the availability of information on the Internet. **Patrick** said: “I inadvertently came across the article on ADHD, or ADD, whichever. So I scanned through it, as I often do. . . . it came to the symptoms part and I read through the symptoms. As I said, there was about ten symptoms, ten classical symptoms, and I was kind of stroking the seven or eight off, I think. Stuff like procrastination, inability to complete tasks, avoidance of tasks that may require large amounts of concentration”. Although having been diagnosed as a child, **William** had had to develop a new, adult understanding, in order to take ownership of the condition as an adult (“I was taking tablets, but I was trying to deny myself that there was nothing wrong. So it’s only recently now that I’ve started to really start researching ADHD and stuff, and find out exactly what it’s all about”).

### Getting a Diagnosis

A minority of participants had been diagnosed with ADHD as children. **William** recalled having been diagnosed when he was seven, but only after an extensive period of uncertainty: “I was quite disruptive in primary school. . . . we got in contact with a paediatrician, . . . And he came with the diagnosis of ADHD. Before that, for about two years beforehand, I would have been bounced from doctor to doctor”. **Rory** had a memory of being assessed at a similar age, remembering the report “would have said ‘significant concentration and memory difficulties’. . . . ‘an inability to learn. Poor episodic memory’”. **Sinead** remembered having a resistance to being diagnosed at the age of 11 (“they were saying that I should go to a psychologist and see if there is any further diagnosis. My mum was like ‘okay’, so I went. And I was diagnosed with ADHD, but I didn’t want to accept it at all”).

There were varied routes to getting a diagnosis of ADHD as an adult. **Jack** described a stepped, formal process of assessments, first by a psychiatrist to rule out depression, followed by a psychological assessment of family background, a cognitive assessment to explore memory abilities, and a specific ADHD assessment (“How often do you forget to bring the keys for the car? Do you know? This kind of craic. I filled in a load of those”). He was prescribed medication, describing it as a final criterion (“right, we’ll start you on the meds, and that’s the test, is the meds. Because if the meds don’t work, . . . then you don’t have it”). In **Ethan’s** case, he first spoke to his GP, then his mum accompanied him for an assessment meeting. He was then referred on to a psychologist and psychiatrist, followed by prescription of medication.

**Cathal’s** experience was more ambiguous and less satisfying. He was assessed while in college some years before. He possessed a lot of knowledge of ADHD through his own research. He felt he knew more about it than the doctor who assessed him:

She’d never dealt with anybody with ADHD before . . . But it was the closed psych unit as well. I would have had to have been buzzed in. And the door locked behind me and all the rest. . . . you’re saying good luck to

the guys you're in class with and you're walking into the enclosed secure psych unit. ... That you could deal with I suppose. But I mean for me it was like she's now on page three of the book. That's really what I thought. It was like, I'm wasting my time here. ... the following session, she's now read twenty more pages. Do you know what I mean? I really felt like I was work experience for her.

**Ciara** consulted her GP for problems with concentration after researching it herself. She was given a referral to a mental health clinic, and on to a psychologist. It was not classed as ADHD or ADD, she said, because the symptoms need to be apparent before the age of seven. However, the principal doctor in that service doubted this criterion, leaving **Ciara** in an ambiguous situation (“So they kind of left it that I do have it”).

**Brian** referred to having had “a horrendous experience with the mental health system” in relation to another condition. He did not want to deal with the public service and got a diagnosis from a consultant in England who had set up a practice on Skype. However that doctor was unable to prescribe medication. **Conor** started to explore ADHD after his counselor suggested that he might have it. He did this by going to INCADDS seminars. Later, he finally sought a diagnosis privately (“I wasn't very impressed with [the doctor's] diagnosis, or [the] diagnostic techniques, which were minimal”). **Aoife** also sought out her own path, travelling to several private assessment clinics in the UK (culminating in a diagnosis of “dyspraxia, attention deficit, and dyslexia”). These were helpful in clarifying her condition for her, but did not lead to any treatment. She compared this unfavourably with treatment for physical conditions like cancer:

It's like someone being told, well you've cancer. You toddle off there now and... What do you do with it? Well there's a step. You go and get treated. Radiotherapy, chemo, a combination of both, operation, or whatever. That's all I want. ... it's pass the parcel with people like me ... I'm not looking for a cure, but I know there has to be a lot more being done. And it needs to be done when you are in national school.

**Shane's** route to diagnosis began while he was receiving psychological support for an event that had happened several years previously. One mental health practitioner noted he was not getting benefit from mindfulness (“The psychologist brought me in one day, and he [said] ... There's underlying stuff here. ... And I said well you know, I find it very hard to learn”). This led to **Shane** getting support to see an educational psychologist (“She went through it all and said that yes, she gave me a dyslexia diagnosis. But at the end of the report it said inattentive ADD. She believed, but she couldn't diagnose it, because it wasn't her remit”). Finally, an ADHD charity put him in a touch with a doctor who he consulted privately in order to receive his diagnosis (“There was a two hour assessment. My wife came in with me for some of it. I think she helped with the diagnosis”).

## Findings

### Diagnosis: Concerns about Identifying with ADHD

Three of the participants did not have a formal diagnosis of ADHD. **Thomas** was one of these: “I haven’t got a diagnosis yet. ... I used to say I have an open mind as to whether I have ADHD or not. But [an informed person] was more or less smiling thinking ‘oh you have it alright!’ ... he recognised things in me, and my family recognised things too”. **Caroline** had begun to investigate her symptoms recently from the perspective of ADHD. She was going through the stages that other participants spoke of in the past tense (“I’ve spoken to my GP and I’m kind of waiting to speak to somebody else. ... I do want to go through the process of seeing about a diagnosis and everything, because it feels like lots of my life has been quite vague, and I would like clarity, and then just to see where I can go from there”). **Cormac** described having consulted with a college counselor who strongly suggested that he had ADHD (“Was I a restless person? How do I manage to study? And a few more questions. \*Clicks fingers\* And she said, that’s ADHD to a T. And she said I can tell you now, if you went for a diagnosis it would be a foregone conclusion”). He had also spoken with his GP about the issue, and had moved forward from there on the basis of self-identifying with ADHD.

### Concerns about Identifying with ADHD

The main concerns about a diagnosis of ADHD arose from negative associations with the condition, the perception of ADHD as a disorder or disease, and feeling different from others. The negative associations were based around identifying ADHD as a disorder of childhood, and the link to hyperactivity:

associated with, you know, kids, and fecklessness and that, and I had real baggage around it. ... and becoming nearly an advocate for adults. But at the time it was like aw Jesus Christ. I don’t want this for me! (**Daniel**)

It was kind of a controversial thing. Because it was seen as recent, it was therefore maybe made up ... ADD would have been seen as something that kids in America got, and were drugged up to the eyeballs for. That’s what it would have been in my head (**Caroline**)

I didn’t know what it was, to be honest. ADHD is the hyper kid in the corner. I watched [a] documentary ... They were ripping the door handles off (**Shane**)

Because the classical idea I have of somebody with ADHD is a six or seven year-old child that’s ballistic. I was the opposite ... But actually there is a non-hyperactive ADHD (**Patrick**).

## Findings

### Diagnosis: Concerns about Identifying with ADHD

Thinking of oneself as an adult with ADHD appeared to have been disorienting initially, but a change soon began, as it offered a helpful perspective on significant coping issues that had cropped up throughout life:

The first reaction was, I just have to resign myself. I said I'm fucking thick and that's all there is too it, and I have to accept that now. ... like they've just smacked you in the face again with another blow. ... [Then on reflection] that's who my personality is, and that's who my brain is (**Declan**)

As I've thought about it, I have found it helpful in ways. And in other ways it is a sense a grief and a sense of panic at times (**Caroline**)

I was afraid of it. And I thought, am I a bit nuts? ... But now I would be able to talk about it, but I'd be constructive about it (**Aoife**)

People used to actually suggest to me, oh there's more wrong with you than the fact that you drank too much. At the time I felt bad that they said that, but they were right (**Thomas**)

Another bloody problem! Now what is it?! ... When is it ever going to be right or normal for me, you know (**Jack**)

**Ethan** and **Sinead** were among the youngest participants. Both of them spoke about not wanting to feel different from their peers. **Ethan** described his initial assimilation of ADHD in these terms ("in my head I was just going, I'm not the same as everybody else that I've gone to school or college with over the last while. That was a big thing for me"). He also spoke about having progressed from this to realising it was a problem that he could now exert some control over ("And it took me a long time to come around to the fact that, if this is an actual problem, I have to get it sorted out"). **Sinead** wanted to speak to people about it ("I'd love to open up to someone"). But she was concerned that she would be judged, as she perceived a negative stigma toward any mental health issues in the school environment ("I think they would slag. ... I've noticed jokes in school, or jokes in study [period] of ADD. ... And then people laugh").

**Aoife** had been told several years ago that she had ADHD, but had only recently come to work through what it meant for her. At this early stage, she spoke about her concern of being associated with what is seen as a mental health disorder: "It's very hard to come to terms with that as well. It's a big thing. That's my diagnosis. That's my disease".

#### Disclosing the Diagnosis

The participants expressed varied views on disclosure of ADHD to other people. There were examples of openness, reservation and, less commonly, highly restricted disclosure. **Brian** was very clear in saying that he was open in discussing ADHD: “What’s the point in keeping these things secret? All my family know about it. My friends know about it. ... I talk about it openly with my colleagues”. This was echoed by several others. **Daniel** said “I’ve told my boss. I’ve told my family. Even colleagues know that I have this condition”. **John** was very open about ADHD as well. He saw this as a positive tool to improve social attitudes and understanding: “I’m trying to use it as an advocacy learning thing. I told my boss, told friends in work and everything. No, I’m not shy about telling people. ... And when you start talking them through it, they don’t realise it can persist into adulthood. They don’t realise there’s a variance of it without hyperactivity. ... most people have been very open and very interested to learn and hear about it.”

Similar to **John**, **Aoife** felt that it was important to change social attitudes. She felt that things had changed over time, marking a change from the ‘old Ireland’ to the “new Ireland”, in which open discussion of mental health and individual differences was more acceptable. She associated the ‘old’ Ireland with blame and shame: “it was wrong to have something wrong. That was the way it was”. She saw the “New Ireland” as a place where change can take place and she could take greater ownership over ADHD:

we’re opening this up. And people like me will get more help for the struggling people. ... Rather than being the insecure twenty-year-old or thirty-year-old that wanted to hide this and keep it in the box. It’s gotta come out and we’ve gotta put it on the table. It’s the only way we’re going to get help for it. ... the way I look at it is, it’s caused me to lose my dignity in lots of ways, so the only way I can do with it now is if I talk about it constructively like I am now, I really don’t care what anybody else thinks. As long as I know I can go and do what I need to do, and I’m chiselling that kind of path for myself.

**William** was illustrative of those participants who were reserved about disclosing the diagnosis to other people. He had disclosed it to people close to him, who he trusted (“I have now surrounded myself with some really good people, who do know about my diagnosis”), but typically waited a while before sharing it, at a point when the a new person in his life could see beyond the label (“I wouldn’t be in a big hurry to tell girlfriends or anything about my ADHD, you know. Because a lot of people don’t understand it you know. ... But by that time they don’t see it as a bad thing. They just see it as part of who I am”). **Ethan** felt the same way, having told his inner circle of friends (“all my best mates. I know it wouldn’t make any difference to them”), but waiting for a while with new people because of a negative association with being ‘different’ (“I’ll hold off a long time before I actually tell them about it. Because ... It’s different to normal people kind of way”). **Peter** saw disclosure as something

that would happen as and when it was appropriate (“even if I knew someone for months, I wouldn’t necessarily tell them. If it came up naturally in the conversation that’s fine, but I don’t launch in with it ... I don’t think I ever got a negative reaction. A lot of the time people just don’t understand what it is”). **Sinead** was less inclined to disclose having ADHD (“I don’t want them to know”).

### Not Getting an Earlier Diagnosis

Having now come to a realisation that they had adult ADHD, the participants thought about what it would have meant to have received an earlier diagnosis. Many concluded that it would have made a large difference in their lives (“if I had have been diagnosed at fourteen or whatever, probably my... I’d be sitting here a totally different person”, **Shane**). **Brian** felt that an earlier diagnosis was not feasible for him because of his family context (“social conservatism and an aversion to risk influenced how they would deny the existence of what is a huge part of my identity”). **Ethan** identified primary school as the obvious and important point to have diagnosed this condition. **Aoife** felt that she had not received support she needed in the education system as a child. Having a diagnosis at a young age would have made a big difference, as it was her recollection is that she was written off as “lazy”:

they brought me to child psychologists, and one of them said, ‘you’re lazy’. They could find nothing wrong. They do the questionnaire, and basically they ask silly, quite patronising questions, even to me as a child. ... especially in the educational system in Ireland back then, they put you under the same umbrella that, well if you’re not learning, you’re stupid, or you’re God forgive me, handicapped. So you probably aren’t even aware that you’re like this. And you probably don’t care.

For **Conor**, there was a contradiction in that it had always been an important part of who he was, yet he could not conceive of having ADHD for most of his life:

It was just part of me. It was in the bones of me. It’s what I’d always known. People go through life oblivious to what’s going on for them. It’s just who they are. It’s their day-to-day experience from moment to moment. So you don’t even think about it. And I just didn’t really look at it very deeply at all. ... I carried on struggling. I don’t know, for some reason I was blocked out from really looking at it.

#### Post-Diagnosis Rethinking of the Past

Once the identification with ADHD occurred, there was a tendency to re-think the past from this fresh perspective. **Conor** acknowledged the need to have balance when undertaking this personal review (“The danger is to just try and narrow everything down, to pin everything on ADD. You know you just can’t do that”). For **Peter** the label did not provide him with a meaningful alternative narrative on his previous life:

It didn’t change my feeling about myself. I suppose maybe for a few days I was like buying into the label a little bit. This is why I do that. This is why I do this. But after a few weeks, or not even, after a week or whatever, I was just back to normal, you know, just accepting who I am. ... When I say I don’t buy into the label, I think it’s a thing that exists, but I don’t think there’s a huge amount to gain by using it kind of as an excuse, or just accepting that this is who I am and I can’t try and cope with it or work to my strengths type thing and self-monitor.

**Ethan** had received a diagnosis quite recently and identified strongly with a review of his past: “that’s happened a lot over the last say three or four months. Things that have stood out in my past and I never really wondered about before, I started to notice things. ... I’m starting to question things from my past now an awful lot as well”. **Cormac** was also able to see his childhood in a new light (“I look at my behaviour, and I did stand out quite a lot from the crowd. And now, it was extremely clear why”).

**Patrick** had the opportunity to get professional support when he worked through what ADHD meant to him, and this had enabled him to free himself of some longstanding negative self-perceptions:

you have this internal message going on in the back of your mind saying, you know, you’re not really any good. You’re pretty useless. You’re pretty shit. ... maybe you’re not that shit after all. Maybe you just need to understand a little bit more about yourself and you can be a lot less shit than you think you are.

**Cathal**’s assimilation of the diagnosis also involved a review of his life to date, which he found challenging. What he had taken for granted as part of his personality was now labeled as the artefact of a mental health condition:

I did have a major rediscovery of myself to do afterwards. ... it was very difficult. I mean I had come to terms myself with the fact that I was the way I was if you like, without having a label or a difference. I thought that was just me. ... Bugger anybody else that didn’t appreciate it, if you know what I mean?

#### Benefiting from Identifying with ADHD

Ultimately, there were important benefits to be accrued from assimilating the diagnosis of ADHD. Self-acceptance was typically referred to, that these often problematic characteristics or associated life events were not the fault of the person. **Declan's** new ability to see his issue as a medical condition ("something in my genes") meant that he was more accepting of himself ("I don't beat myself up so much about it. I'd really get upset with myself, and... I used to think why me? But now I sort of ... now I understand that it's not actually my fault"). **Jack** cited the movie 'Good Will Hunting': "There's a line in it. He's a psychiatrist or a psychologist, and he said, 'it's not your fault. It's not your fault'. And he keeps saying it. And that's what I related to ... That sense of being let off the hook. Not escaping. Just a sense of, you can come down now. It's not all your fault. You tried your bloody best. ... And that's a revelation".

Having been diagnosed quite recently, these benefits were still very fresh for **Jack**: "Through the talking and the medication, and the reading, ... there's a reason this is going on now. ... I'm not behind it in other words. I'm not deliberately trying to be difficult. ... I'm kind of forgiving myself a bit more now". He had been bullied and mocked in the past, but now he felt surer of himself and on firmer ground as a person: "I'm starting to own it now. I'm starting to say right **Jack**, this is something you have. This is your condition, so no one is going to be bullying you, or walking over you".

Similarly, **Ethan** spoke about the negative self-narrative he had developed in the past ("I'm distracted and lazy, ... You just need to sit down and get yourself focused ... It was my fault. That's why I was the way I was"). **Ciara** was glad she received the diagnosis, "because I felt stupid or something beforehand", whereas now she could identify with a reason for her experiences. This prompted a life change for her, and the decision to re-enter education:

I think I'd still be at home living with my mum and dad, still looking for different jobs, not knowing. ... rather than something academic. Because I didn't think I'd be capable. ... I suppose I just wanted to prove to myself that I wasn't stupid I suppose.

**Cormac** had to overcome his own concern about labeling to develop a more complex sense that, while ADHD is a label, it can signpost what he can do to improve his future: "I've always been extremely non-conformist all the way through life. So for me it was a case of, I'm certainly not going to conform to a label. ... But you have to realise that those labels sometimes, as bad as labels are, they sometimes can be of a huge help, because you know which way to go to". For **Cathal** it was more important for his parents to hear the diagnosis than it was for him: "they spent an awful long time getting told by all the professionals that it was their fault. You know. That they weren't good parents, and this, that and the other. Going back, they almost split up ... you can imagine what the rows in our house were about".

## Engaging with Health Care Services

### Difficult Relationships with Health Care Professionals

There were many examples given of problematic encounters with health care professionals, including GPs and psychiatrists. A number of issues emerged in this regard. One of these was medical resistance to the legitimacy of an adult ADHD diagnosis. **Jack** had varied experiences with professionals. His first attempt to find out about ADHD was with his GP. He felt that his doctor was dismissive and was not interested in listening to him: “he turned around and he said something like, ‘well now **Jack** I’ve been practicing for whatever length of time, and I’ve never heard that’ ... Now I would regard that ... as a dismissal”. **Daniel** had a similar experience with a psychiatrist:

The senior psychiatrist there, the consultant psychiatrist said, you know, ‘you’re 36. You went to college. You did this. You don’t have ADHD’. She said that shows up when you’re a child. ... she was very dogmatic about it. ... [Later] She felt no, you’re still anxious and I was saying I don’t think that’s anxious. That’s just probably ADHD, and she said forget about that ADHD. ... she used to do all this kind of feigned active listening. ... She had it in her head what she was going to do. ... She’s not listening to me. ... she just wants to dope me up to the eyeballs, and I don’t want that.

**Patrick** took a forthright approach. Once he had self-diagnosed himself he approached the GP mindful of the need to be clear in stating what he needed out of the encounter:

an adult, a 50 year old male comes to a doctor saying I think I have ADHD. And they’re kind of saying ‘it’s kids that get ADHD’. Not so much. I have this, this, this, this and this. I need to see someone who is able to treat this. ... anywhere between 2 and 5% of the world’s kids are ADHD, which apparently they are, you know that’s a lifetime. There’s no known cure. There’s only treatments. So that means that there’s a lot of adults out there, undiagnosed.

**Brian** spoke about gauging doctors in terms of how well they can communicate, as this was a critical issue for him in determining whether the patient receives the right care. As a result he avoided one doctor who he thought was otherwise well-informed: “That’s why I did not touch him with a barge pole. ... That’s why I did not approach him for a diagnosis. Because I did not see him as approachable. ... And I said well if he can’t communicate with me like that, I don’t see him being able to care for me properly as a patient”. **William** felt that many doctors have difficulty relate to the concept of adult ADHD because of their privileged position: “They can’t relate. A lot of these doctors never had a problem in their lives you know. ... Especially medical doctors tend to have a certain attitude”. On the basis of his experience he came to the view that most doctors in the field do not possess the requisite

knowledge and expertise: “there are good doctors out there who know what they’re talking about, but they’re really well hidden. You have to see a lot of crap doctors before you get to the one good one who will actually be able to help you”.

**Sinead’s** difficulty with the pediatric service that she attended in earlier years was that it was not attuned to her needs or stage in life:

I hated going there. Because I didn’t like talking to them because I felt like they were judging me. Every time I went in they’d say, what are you doing that for? ... I didn’t like hearing stuff like that. I wanted to hear, oh you’re fine. You’re no different than anyone else, but I knew I wasn’t. ... I didn’t want to be different.

She did not attend some appointments with the service, even though her parents were going to find out about this: “I’d made up excuses. ... There was no way they couldn’t have found out, because they’d get a letter in the post, or the phone call, where’s **Sinead**?”

One basic issue in the area was the perception that doctors lacked knowledge of adult ADHD. **William** talked about this point:

They need to start training psychologists in adult ADHD. I’m quite lucky. I was diagnosed as a child, so I was able to get the medication. But it’s a lot more difficult for someone that hasn’t got a diagnosis as an adult to get it. ... A lot of doctors aren’t aware of adult ADHD. A lot of psychologists don’t necessarily believe in adult ADHD ... Get them diagnosed. Get them the support services. ... Start getting the mental health nurses and psychiatric nurses trained up to deal with ADHD.

### Good Relationships with Health Care Professionals

Positive experiences and relationships were based on achieving good levels of trust. **Brian** had finally found a psychiatrist who he could trust: “I’ve got a consultant who I can potentially build a working relationship with. [She] has had an exceptional amount of patience. Exceptional. She’s built a relationship to the point where I don’t need to know more than she does. 99% of what she says I will take at face value”. Although **Daniel** had encountered a psychiatrist who he felt was dogmatic and not listening to him, he also described someone who he had connected with successfully: “I did have an excellent psychiatrist also ... She was much more humanistic. Like I saw hope with her”.

**Declan** spoke about consistency and trust being essential for him to form a productive partnership with a health care professional: “It takes me a long time to trust someone. I have to see someone regular. I can’t skip from one person to another. ... I need familiarity every time. Routine. ... he would talk to me face to face. He’d make me look at him. If I

wandered away he'd say, 'look at me so you're listening to what I'm saying to you.' ... He was soft. Not soft as in personality, but soft in his mannerisms. He never got cross with me". **Peter** had experienced a positive encounter with a psychiatrist, however the issue was that there was no follow up, which he attributed to the vagaries of the public health system: "We sat down for an hour and went through the DSM and whatever. The outcome of that was kind of like that I'd hear back, but I never did. I don't know. I guess the Irish health system, certainly in the public is a bit of a black hole".

**William** wanted to achieve self-determination in his care, and really appreciated how his psychiatrist was able to adopt a collaborative approach that involved him as an equal:

Actually she listens to you. It's not just her saying 'aw we'll try this medication' or whatever. She listens to what you say, and then we'll come to the decision together. You know she'll give me papers and stuff, and she'll show me websites, like 'go and research that drug and tell me what you think about it and pick one'. We'll sit down and we'll decide on one. ... I like to control my own life you know. It's very good now.

It was also important to perceive a sense of commitment from the health care professional. The negative experience with a GP that **Jack** described contrasted with another GP he encountered who gave him a lot of time: "She rang me then and chatted for the hour. That's incredible. An hour from a GP. Jesus like, it's incredible". This corresponded with the positive achievements he had from a constructive experience of counselling. The counselor had committed to him over a long time: "it turned things around substantially for me. ... it gave me a great foundation, you know, and I've been building on it. Like even the things I'm doing now, I think a lot of it's down to her. She didn't give up you see. Stick with it for as long as you need it".

### Specialisation and Varied Treatments

Apart from access to diagnosis, medication, and a positive relationship with health care professionals, there was much else that was expected of the health care system. **Aoife** spoke about what she would have needed to help her: "It's kind of a chaos. A chaotic world you're living in, and it's worse when you're young. That's when you need the help of like an occupational therapist. You need so many things, and you need those services where you're living [rather than having to travel]". **John** spoke about the lack of specialisation in ADHD evident in his experience of health care provision:

They don't have a lot of specialisation or expertise in the area. And they've no other provisions. Talking therapies or anything else to try and help you get the life skills. ... Proper money budgeting and prioritising, and your actions. So I think that's one big gap that's missing, is life skills. Yes they'll

give medication, but they don't provide any counselling. Anything where they would assess your life or your issues and go, actually we could provide you training or knowledge in this area. So they're very much symptom treatment based I think, and that's the limit of it at the minute. ... I think awareness at the GP level is lacking. And then there's no specialists. It's just general mental health units.

In a similar vein, **Declan** spoke about the hit and miss nature of the service, in whether there would be adequate follow on from receiving a diagnosis:

It's only been this last two years, since they got me on to seeing for the ADHD. This is the best run that I've had. Prior to that, well you might as well waste your time. They just sort of said to you 'well, there's not a lot we can do'. And that was the attitude we always got. They'd give you the report. They would label you. Then 'thanks very much'. You're out the door. ... [his partner] said, 'well all you've done is you've given him a label, and now you're telling him to piss off. That's it. We can't do no more for you'. And what does that do? ... You're left high and dry again

**Jack** had identified a short term counselling option open to patients on the GMS system in the HSE: "there's six to eight therapy sessions ... And I've booked those in. And the reason I've done that is to talk about this stuff. The effect it's had on my life, and to deal with that side of it, and going forward then. ... And then say right! Where are we going now? What do I really want to do for the rest of my life". **Peter** spoke about biofeedback as an important but largely inaccessible treatment option: "what is happening is it's changing how the neurons are synchronising in your brain. ... So whatever way the neurons are communicating, this is kind of training them to fire a certain way. And you're getting positive feedback ... it's like what fires together wires together in neurons. So then eventually apparently you don't need it anymore. You can just meditate and you can focus".

### Transition to Adult Mental Health Services

Two of the participants spoke about making the transition to the adult mental health service from the pediatric service. **William** reflected on how unsuccessful the transition had been for him, a factor that contributed to several years of personal difficulty and challenge subsequent to his eighteenth birthday (which marked the point of maturing out of the pediatric service):

They thought by the age of your eighteenth birthday you know, you're cured! Magically! ... The doctors been telling us for years I'll have outgrown it by the time I'm eighteen. I don't need it anymore ... And then of course once you're off it, once you turn eighteen, you're not under the care of the paediatrician, ... Where do I go now to get back on my

medication? ... We did try. I spoke to a few people and they were like, 'sure the ADHD will be fine'. 'It'll be grand'. 'Don't worry about it'. 'What do you expect us to do?' 'We can't prescribe Ritalin to an adult', you know. ... I was lucky because I had a childhood diagnosis. There was a diagnosis there

**William** had stopped taking medication as a result of these issues, which had a negative impact on his experience of young adulthood:

Then after [leaving school] I came off the medication. I spent a couple of years bashing from job to job, not really in education, drifting in and out of education, just not really being able to finish anything. And I got to a low point, and I just... I thought to myself right, I've gotta get something sorted here. ... without the medication and without the support, I wouldn't be in this position at all. God knows where I would be at the moment.

**Sinead** spoke about moving from the pediatric to the adult mental health service. It appeared to be a move that lacked a sense of transition or adequate preparation. The experience was very concerning for her as she grappled with being associated with an adult mental health treatment environment:

I had to go in by myself, and it was so hard to sit in the waiting room with... I don't know. They weren't weird people, but I just ... There was maybe fifteen people in the waiting-room, and I was the only young girl there. And they were all men. ... And I was waiting there for an hour in this waiting-room to go in. And I eventually got in, and the man, he was nice, but I don't know. ... I wish I could have gone back to CAHMS that day. ... when I went in they told me that I couldn't have brought my mum in because I was eighteen. And aw, I don't want to go back there. ... I just thought they were... It's awful rude, but they just looked so different! ... And I was so scared. Oh the scariest part I thought was when I walked in. I seen all these men, and then I went up to the reception and there was bars on the door, on the window of reception. I was just like 'oh my God'. I didn't want to say my name or anything.

## Medication for ADHD

### Diagnosis and Prescription

The immediate impact of diagnosis was to get access to medication designed to control the symptoms (“She confirmed the diagnosis and wrote me a prescription for Ritalin”, **Brian**). **William** and **Sinead** had been prescribed medication as children. In **William**’s case he accepted this (“Nothing really worked until he ... said look, that’s ADHD. Put him on Ritalin”), but **Sinead** did not accept the medication route initially (“they put me on medication called Ritalin, and I rejected it completely. I just didn’t want to take it”). **Cormac** had sought medication to help him concentrate while at college, which is why he wanted a diagnosis, but his GP was not able to prescribe it for him without an official assessment (“I wasn’t in a position to pay for the assessment, I couldn’t get the diagnosis, which meant that I couldn’t get it. And the GP wouldn’t prescribe it”).

**Brian** described his understanding of the options for medications:

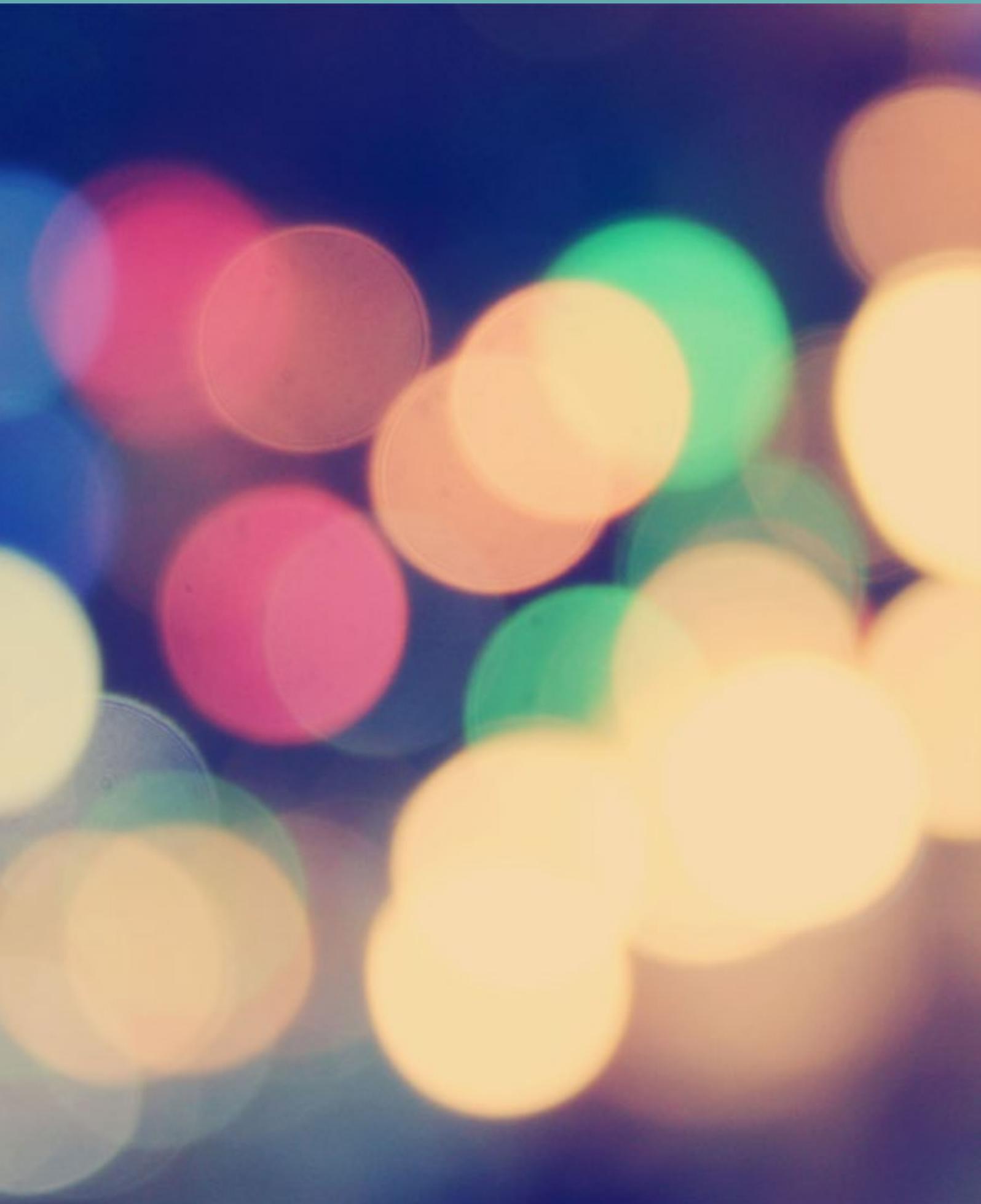
You can have Ritalin, Vyvanse, ... Those are both stimulants. They are like super strong versions of caffeine. You pop them in. They hit your head immediately and they generate your dopamine. They are available in long release forms, like Concerta, which are easier to use. But they’re still basically the same drug. The odd ball is a third drug called Atomoxetine, otherwise known as Strattera. Now this isn’t a stimulant. It works a bit more like an anti-depressant. And the thing about it is, it takes about six weeks to kick in. So if you just don’t take it one day, it’s still in your system. You don’t notice. You can’t switch off ... In the North you can also have Dexamphetamine, which is basically speed, and in America you can also have Adderall, ... That’s a bit of a crossover between Atomoxetine and the stimulants.

Two participants who had not received a diagnosis described some hesitancy around medication. **Thomas** described a fear of medication but was becoming more open to it: “I’ve a fear of taking [it]. And it’s only medication really ... I get this fear that if I take medication, it’s going to change me. But it actually will help me. [others] talk about how much it helps them”. **Aoife** shared **Thomas**’s concern but was currently less open to medication: “if I had to start on that stuff, would I ever really trust how I think then. I’d have a problem with that. ... But I do know I need something to help with the motivation, that tiredness”.

Several other participants felt that medication was not necessary for them. **Conor** saw a role for medication solely in regard to academic study (“That’s all I would use them for. Just to attend maybe. And I’m not even sure if it would work”). That is the same function **Cormac** had thought about (“I wanted some kind of stimulant that was going to allow me to concentrate on the things that I needed to concentrate on, and nothing more”). **Cathal** felt that

## Findings

### Medication for ADHD: Diagnosis and Prescription



he had managed to develop strategies that bypassed the need for medication (“I don’t take medication now. I honestly don’t feel the need for it. I think I’ve grown up learning to deal with it otherwise. Maybe it might help a small bit. I don’t know”). **Patrick** was ambivalent. He appeared to want to find a way to manage ADHD without medication, but felt at times that he would benefit from it:

you’re kind of saying, your dopamine or your serotonin, or those transmitters are either low or they’ve been taken back up too quickly, or you know. You can medicate to that degree, or you can physically exercise ... But you’d often say to yourself, jeez I should get some Adderall or whatever and just... Now I haven’t gone there, but this morning I would have said to myself, I probably could do with a course of that and get myself back up and running. But I’m not sure that’s the way to go.

### Medication Effects

Those participants who used medication for ADHD on a regular basis spoke about its positive impact. **William** said that his concentration levels would be terrible without using medication. **John** found that his focus in work was much better (“It was just the ease of doing mundane tasks”). He found that the impact was directly related to those ADHD characteristics that he had described: “I noticed one time I was in the shower on a Thursday night or something going, ‘right so this week I know I’ve got this on, so I better wash the clothes and get those all.’ ... And I went ‘holy shit! I’m planning! What’s going on?’ It was cognitively a very new experience for me. I know it’s coming up and I’m preparing for it. At that moment I was very aware of the difference [between taking medication and not taking it]”.

As he had only recently started with medication, **Jack’s** description of his first time using it was very specific:

I was in the kitchen ... Next minute, everything started to calm down. ... and the next minute, Jesus! It was like as if you just kind of landed. **\*Laughs\*** And everything comes into focus then. Everything’s kind of clearer, and you’re more aware of what’s going on around you. I’m there. I know it’s going on. But it’s just this... It’s like as if somebody turns up something

He found that this mental focus translated into an ability to perform in a more cognitively attuned way in different circumstances, such as a hobby class where he had been making relatively slow progress. He was able to answer questions and recall information:

## Findings

### Medication for ADHD: Medication Effects

‘Jesus that’s right **Jack**’. Ding ding! You see? And I’m actually kind of taken aback myself sometimes you know. I’m saying ‘Jesus how the feck did I know that?’ Do you know? Because sometimes you can equate it to that you’re stupid. And he’s looking at me now kind of, ‘how the hell!’

**Jack** liked how this improved effectiveness felt: “normally if someone’s telling me something, I’m not really listening. I’d be kind of looking around and getting bits of it. But this time he was telling me and I just... I was taking it all in”. He spoke about feeling more confident: “The confidence has gone up. And I’m not afraid to look stupid. I’m not afraid to make the mistakes. ... And they’re kind of, oh he’s asking questions all of a sudden”. Regarding the concerns raised by **Aoife** and **Thomas**, that medication might change them as individuals, **Jack** had found that he had not changed in a negative way from taking medication to counteract the ADHD symptoms:

And the good thing about this is that I don’t feel my personality has changed, in so far as in a negative sense. It has changed my personality in so far as I’m more confident now, and I’m better thinking, and I think even my mood has improved because it’s having a knock-on effect. But I wouldn’t like it to change me. You know, that I was going on like a zombie or something.

**Ethan** had also begun taking medication in the recent past. He described his experience of the medication as a direct counterbalance to the lack of focus associated with ADHD:

It’s not agitated almost, it’s kind of like a focus. ... and I’m focusing, I’m trying to get my work done. And I find it better. I find myself more able to bring myself back and I can concentrate on what I’m doing. ... They’re slow releasing tablets, so after about an hour then, I can kind of feel them starting to kick in.

**Ethan** was now able to address the issue he had described about getting distracted while studying:

My thought processes are more organised and direct, put it that way. ... Like say if I take a break now, I’ll have it in my head. I’ll go for coffee. I’m going to meet one of the lads. Have a chat with him for ten minutes. I’ll go back upstairs and I’ll do my [study] ... It helps me organise and structure myself better, rather than actually helping me concentrate better if you know what I mean?

His friend had noticed that his conversation was more coherent since starting on medication:

But he said since I started taking the medication, I'll either continue on with my sentences again, I'll trail off, but I'll come back to it, or it just won't happen as often.

Ethan had also experienced positive effects at work. He found that his focus was increased, and his confidence improved as a result. In addition he received positive feedback from his manager:

even my manager said it to me. He doesn't know anything about [the medication]. After the first week, I went back to work at the weekend, and he goes, 'what's going on with you? You're so much more focused than you normally are.' ... So literally I've my stuff together for work now like. I'm so much more into it. I've got so much more direction. I'll put it to you that way, and more focused.

Sinead had been resistant to using medication as a child. It was a couple of years before she started to use the medication. She started after experiencing difficulty with exams: "it was maybe at the end of first year. I was like, I better see what these are like. ... I didn't like taking them, but they did make me concentrate". There was an improvement in her performance. She seemed to have some ambivalence as to whether it was her or the medication that was responsible for the good performance, as she had become a high achieving student:

If I did good in a test. That wouldn't be because of me studying, that was because of the Ritalin. And then my mum would say, if you didn't take Ritalin, you wouldn't do well in the test. But that would get to me and I would say no.

Over time, she had got to the point where she had developed a very close association between academic performance and medication for ADHD: "Because I feel like there's no point in being here today [in school], because nothing's going to go in because I haven't taken a Ritalin".

#### Selective about Taking Medication

ADHD medication seemed to be an important tool for those who had adopted it. Those participants who were using it for work performance had a complex relationship with the medication, in that they also looked forward to breaks in medication use. **Brian** described it in this way:

Being able to switch off and have a ludicrously lackadaisical day without any dopamine in my head. Yes absolutely! ... Now I mean yes, it's going to make it very difficult to drive. It is difficult to drive without Ritalin, and it will not be a very productive day. But if I want to have a muck about the city centre, have a few beers and watch a few films, and do a clear-up tomorrow, that's great relaxation, because you feel like you haven't a care in the world.

**Brian's** attitude to medication is reflective of his view of it as a tool rather than an answer to the issues arising from ADHD: "First of all the meds only go so far. They make you capable of watching paint dry. In other words, sticking at the one task that is mere concentration, that doesn't need any organisation, no multi-tasking. Example, reading a book, driving. ... Ritalin hits you in about ten minutes. It's great. You then become capable of reading that book". However, there was more to adaptation to ADHD than this: "real life is unfortunately more complicated than that. For example, what will I do when I do home?"

**John** also described planning to take a break from medication when on holiday, and associated this with a state of relaxation: "But if it's a few weeks off and we're heading away, I'd probably like to go off it, and switch off and just relax and enjoy it". He spoke about an issue with one medication he had taken. It seemed to stop him experiencing the 'buzz' that he enjoyed in life:

I wasn't enjoying stuff as much. [for example] concerts. I wasn't getting the excitement and the buzz. So I didn't like not having that side of life where I genuinely enjoy being very excited about stuff, and letting go and enjoying it. ... I appreciated [the concert]. I just wasn't buzzing. So I thought they maybe weren't right for me. So I just recently moved [medication].

**Ciara** found a positive impact from medication ("I wasn't as sleepy and stuff. ... I did well in [recent courses], but I think it was because of the [medication]"), but she did associate it with that area of her life only ("I didn't like taking it when I wasn't in a school setting"). **Rory** did not take medication on a daily basis. He found the characteristics of ADHD could

be managed through adaptive strategies, and were also helpful to him in his work. However, he saw a role for medication as a complementary assistance: “So when there’s a long meeting or that, I’ll take it. The sensation of it is, it’s a bit like having, when I do mindfulness. . . . it’s the exact same sense as that”.

There were issues concerning medication in that it required some time to find the right therapeutic dose. **Jack**’s initial experience of “having landed” wore off over time (“they kind of level off a bit, and it wasn’t that initial sort of feeling”) and at the time of the interview he was trying to find the right dosage for him. Similarly, **John** described that “it took probably a couple of months to really level out and get stable, where I could notice a consistent effect”. **Ethan** reported the same process: “It is helping, but I think it’s just I might need either a higher dosage or maybe a different type of medication at this point”.

### Medication Side Effects

There were some significant side effects of ADHD medication reported. **Cathal** had tried using medication for ADHD, but it did not work for him because he felt that he had not been given a level of medication to take that was too high. **Shane** reported having used two different types of medication. Neither had worked for him (“I’m like a rabbit in headlights on both of them. . . . Just a buzz. An unnatural buzz. That I was just too high”). **William** had found medication did work for him, but it had a negative side effect (“the medication makes me anxious. So I tend to only take it when I have to”). **Declan** had experienced side effects with a few medications that led him to cease using them after medical advice. With one medication, he had become uninhibited and spoke in racist terms to strangers (“I was quite abusive and racist towards him, but I’m not a racist person. I only ever look at people as an equal”). He had had to stop using that medication. He had used another one which did have positive effects on his ADHD, but did have negative physical side effects (“The only trouble with it was, I had urine retention, couldn’t pee. So they said it’s a common effect. And then I went to see the doctor who prescribed the medication, and they just said, ‘you’ve gotta stop taking it’”). **Ethan** reported that, although he did experience a positive effect from his medication, there were also side effects (“I feel exhausted after that then, because when it wears off, that’s how I feel. You feel you get very tired”).

The issues surrounding other conditions also had to be taken into account in taking medication for ADHD. For instance **Daniel** was taking medication for another condition and had not taken medication for ADHD. He had found that he was very sensitive to changes in medication levels. This was complicating the decision to take medication for ADHD at some point in the future.

## Findings

### Medication for ADHD: Medication Side Effects



#### ADHD and Experiences of School, College and Work

The remaining sections of the findings describe how the participants found the experience of school, college and work. Particularly in the case of education, they had to operate in systems that are challenging for people with ADHD characteristics. Information processing skills such as sequencing, retention and organisation are critical for success in these domains. Support and self-awareness were just as important in being able to respond to these issues. The workplace could be similarly difficult but there was more control over choice of the work environment and achieving a match with personal strengths.

#### Experiencing the Demands of School and the Educational System

**Cormac** enjoyed primary school and did not find the academic demands becoming a strain until the transition to secondary school (“The distraction, for me it was a lot more noticeable in secondary school. Primary school was more of a doss. I enjoyed it”). **Rory** found the transition stressful (“I was just sitting there in the class staring into space, not learning anything, and just literally pulling my hair out. ... It was just a horrible time”). Similarly, **Conor** found that secondary school brought demands of focus and concentration that he had not experienced before and now struggled with:

Up to the age of twelve I really did very well. ... You don't really need to attend too much. ... there's no real need to focus and to spend prolonged amount of periods gathering data and information and all of this sort of stuff. ... when you get to secondary school, then you need to start knuckling down and applying yourself

**Conor** found that the secondary school experience went badly for him (“I had been flying. Now I was failing”). In response to these difficulties he started playing truant from maths class as he found it particularly difficult. This was not noted or picked up. He stopped doing homework. Finally he stopped going to school (“flunking out of the school system altogether”).

Several participants spoke about achieving well at secondary school, including **Brian**, **Daniel**, **William**, and **Rory**, although some experienced difficulty later when at college. Both **Patrick** and **Ethan** coped well with the academic demands of secondary school, due to the structure

there (**Patrick** attended a boarding school). Neither was able to cope with the learning environment in college, and both experienced considerable stress when they were unable to meet college demands:

I achieved because I found ways of getting around it in school, whereas when I came to college, because of a less structured environment, ... I just kind of fell off the track ... It was just that my coping mechanisms weren't enough (**Ethan**)

[secondary school] was a highly regimental regime, which benefitted me enormously, because there was only one option. You did this. You went to class. You had your mealtimes. You had your sports or outdoor activity. And then you had your study in the evening and then you slept. ... Very highly organised. Not of my making. ... And because of that, I did very well at school ... But the minute I went to college it was just... For the birds (**Patrick**)

**Brian** also found the transition from school to college very challenging. He was not prepared for the changed demands in college. Because he had performed well academically at school his problems with learning had not been picked up, thereby allowing him to prepare for later challenges:

the system is geared to accept school grades and things as triggers. Mismanaging your time is not, was not a red flag for mental health, so long as you hit your KPIs. ... you're handed work, you put your head down and just get on with it. No emphasis on life experience or thinking for yourself.

**William** shared **Brian's** view ("because I was doing relatively well, they didn't really give a shit. If I had have started doing really badly, then they would have started to care"). **Ciara** suggested that the teachers did not have an interest in identifying her ADD because she was a good, quiet student, ("they were happy. I wasn't disruptive"). **Conor** felt that it was imperative that the learning problems associated with ADHD are identified during the school career. He felt that, otherwise, the opportunity to provide support will be lost ("it becomes much more hidden actually for an adult ... You don't get that opportunity when you pass through the educational system"). He said that problems with focus and concentration at work would not be seen as an issue that the employer would need to deal with ("they're just going to sack you. They're not going to say, oh you might have ADD. Why don't you come into my office and we'll do a test"). The issue was that teachers might not have the awareness of the problem ("half the people don't even think it exists"). In addition, **Conor** felt, teachers are busy, have to deal with large classes, and have a tendency to focus on those children who excel rather than those who struggle at school.

**William** suggested that teachers needed to move on from simplistic explanations of disruptive behaviour in which the person is categorized as a “bad child ... this guy’s not hyperactive or being an arsehole. There’s something wrong with him. Give them the certain leeway that they deserve for somebody with a mental health difficulty”. Now in his 50s, **Declan** had certainly found the school environment to be unforgiving and harsh:

I could never concentrate at school. I was always told that I was a naughty child. I was forever getting a smack or sent out of the classroom because I couldn’t sit still. I couldn’t read anything or concentrate for any length of time. It was impossible. They just kept reinforcing it in terms of my mum, that ‘he’s a naughty child’. ‘You need to be firm with him’.

**Declan** described how his teachers had given up on him:

They just used to say to me ‘aw well, just do what you can do’. Well if you can’t read the board or write what’s on the board, and concentrate what’s on the board, you can’t sit still, you’re up against it straight away. ... You were just left. What I had was a tape recorder and you had earphones that used to read books. They used to say just sit at the back of the class. That’s the work they’d give you.

**Thomas** could not explain to himself at the time why he was having difficulty succeeding at school. His frustration mounted: “Why am I like this? You never talked about it. ... Kept it all inside, ... It led me to not going to school”. He got into trouble for missing school and got “a bad name in school”, which in turn knocked his confidence and self esteem. He was bullied by his peers (“boys your age saying that you were stupid ... He’ll not be able to do anything because he doesn’t learn”), and then adopted negative behaviours himself (“I became a bully because I got bullied”).

### Disruptive at School

One of the key aspects of the school experience was being seen as disruptive. Typically participants did not recall having the intention of being difficult. The behaviour was framed in terms of being ‘cheeky’ rather than ‘bad’, as seen here with **William**:

It was just seen as having a laugh you know. Nobody really gave a shite ... There’s **William**. He’ll come in, he’ll wind the teacher up. That’ll be funny ... I definitely wasn’t the worst in the year ... I was cheeky, but I was never violent ... I was never a bad child

Nevertheless his behaviour would have come across as challenging: “I was normally shouting at most of the teachers”. **Sinead**’s self-description of herself in first year of secondary school was also one of not being able to fit in with the system: “I couldn’t concentrate. I was sitting there fidgeting, trying to get other people’s attention. I was never bold, but I was always looking for something to do”. On the other hand, **Peter** did not frame his ‘giddiness’ as being exceptional “I think the giddiness might have been just... You might be talking a bit during class, so you’d get distracted with your friends or whatever”.

**Caroline**’s memory of school was of a time when she “would have been the boldest girl in school”. Her school reports said she had “little or no attention span” and she was “always” in trouble. School did not seem like a learning environment (“it didn’t even occur to me that I could or would be able to actually sit there and listen and take in what was being said”). She had felt different to the other students, and that she “had like a wildness to me ... I just would never really have had my homework done ... It would have been seen that I was cheeky and wild and bold, as opposed to having difficulty”.

Conflict with teachers was a prominent recollection for **Cathal** in recalling his school experience. These difficulties had played a role in his decision to leave school early (“school didn’t really work for me at all”). He had to move between different schools as a result of his behaviour and how it was perceived in the school environment (“I was always in trouble for nothing major. I mean I wasn’t burning down the school or anything. Just not sitting still, interrupting, that kind of stuff. Constantly. ... It was never to do with violence or vandalism or anything like that. An accumulation of stupid things”). Typically, things would escalate out of occasions of minor conflict (“Being thrown out of class for leaning back in your chair because the teacher told you three or four times not to lean back in your chair. Constantly interrupting”). He acquired a reputation among his peers (“infamous”) for not backing down and for seeing teachers as equals (“I had no problem looking a teacher in the eye and telling them yes or no. ... If I felt I did nothing wrong, ... To be sent to the principal’s office ... I would have no problem telling the principal that I was sent there because it was petty. ... there would have been other teachers that just couldn’t handle it at all”). He saw this as a management issue rather than an intention to be disruptive or disrespectful (“Open confrontation was not the way to go with me. Never was, and never is, or never will be probably”). From his adult perspective he could better understand his teachers’ position (“I can understand now as an adult that a teacher with 30 kids to educate, and one that’s upsetting the balance they’re trying to create in the corner can be very frustrating”).

#### Teachers

The attitude and teaching approach used in schools was an important influence on the school experience. One motivation for **William** to disrespect (“wind up”) teachers was because he saw some of them as “stuck up” (“I never dealt well with stuck up people”). For him, reacting against them was equitable (“if you treat me well, I’ll treat you well. But because some of these teachers were really stuck up f\*\*kers like, I treated them the same way”). **Caroline’s** recalled the school ethos as being based on discipline, with negative judgements if you were not able to perform well academically.

**William** found that his academic work improved in another school he attended, because in that school “the teachers cared more about the student than the actual results”. For **Ethan**, his experience at primary school was not positive. He did not like the style of teaching (“it was basically bullying”). He remembered the teachers in primary school describing him as “immature” and advising his mother that he should be held back to repeat a year. By comparison, the learning environment in secondary school was better. **Ethan** had younger teachers with better teaching methods there. He felt the teachers encouraged him and got him interested in learning.

To the teachers, **Cormac** felt that “I was just the clumsy kid, who lost interest in things”, and in respect of his experience with peers, “the bullying was quite vicious. . . . I never really got much physical bullying. It was much more psychological”. Several other participants spoke about similar experiences:

Getting slagged in school. Teachers mocking you. Making you out to be stupid like (**Jack**)

So all in all it never felt like a place of growth I suppose (**Caroline**)

Fear and humiliation, and that for me still is the best motivation. So that’s kind of my experience of school (**Daniel**)

#### Homework

Concentrating on schoolwork outside of the structured school environment was very hard for the participants. Completing homework was a challenge, even for those who were doing well in school overall (“If I could get away without doing my homework, I wouldn’t do it. And literally because. . . I just didn’t bother, and it would take me hours. . . . It was an absolute pain”, **Ethan**). Homework time typically included unproductive hours (“It was frustrating that I always had to work a lot harder than others, but I just had to deal with that. . . . there was

a lot of that time where you'd just be staring at the wall", **Peter**). **Shane** struggled for years on his school work, he felt ill equipped to complete what was asked of him. The school he had attended did not follow up on his obvious difficulty with this:

I was sent up to a room on my own, not knowing how to learn. Do you know what I mean? Just sitting there in front of a page and going 'what the fuck do I do with this page?' And that's the way it was for me. ... if it's not done, it's not done. Do you know what I mean? It's not 'why is it not done?', 'Do you need some support on why it's not done?' It's just, you're handing it in at this date and this time, and you get your result at the end of it.

### Poor School Performance

At age seven, **Aoife** was struggling a lot with literacy. She felt left behind as the school experience unfolded, and that she was judged by her peers to have academic problems which in turn impacted on their willingness to befriend her or sit beside her: "as time goes on in school, your friendships will, especially with girls it's very much about academic ability. ... They're like, going up here, and you're down there". She did not feel that teachers tried to work with her or support her, culminating in the perception that "you can lay dormant" in school, put into remedial classes, "the lowest alternative level of everything", with very low expectations for her achievement: "Sure **Aoife** might go off and be a cleaner or something. She probably doesn't even know. And that's it!"

She saw two ways out, neither of which were available to her, firstly of parents who would identify the issue and find the right supports, or of a teacher who connect with her: "But that didn't happen". She felt it was very important for lifelong development that problems with learning are identified as soon as possible in primary school, given that "If somebody isn't learning, there's nothing more important than that. Because learning doesn't stop ... Learning is in everything. It doesn't switch off. It doesn't stop".

She had been kept back a year and did catch up on her basic academic skills, but being kept back was dealt with insensitively. The memory had stuck with her:

they do the wonderful thing that they do in Ireland, they keep you back a year. Sure that was horrible. ... And you know why you're staying back. It's not because I was too young. ... I was 'thick'. Oh I still remember the teacher. ... I remember the teacher reading out people who were going into the next class. ... she kind of skipped over it. ... So I copped. I knew it. So then. I went up to her. I confronted her. ... I went up and she said, 'but you know you're doing so well now, I think you should stay back.'

#### ADHD Characteristics and School

In primary school, **Rory** knew that he was an intelligent child but that there was a problem with memorising material and retention of sequential learning: “It wasn’t embarrassing because I was bright. But it was... I didn’t understand the logic of it. Why are these other people, even the people who aren’t clever in the class are doing this better than me, ... when it came to repeating things, I just, I couldn’t do it”. Later, in secondary school, motivation was an issue as he was not stimulated by some of the subjects. He recalled a conversation with a teacher who remarked on his high level of general aptitude: “So why aren’t you getting A’s in everything?” And I said, ‘well you’re not teaching me anything interesting’”.

**Thomas** associated the problems he associated at school with key features of ADHD, including distraction, retention and high energy levels:

That’s why I didn’t like school, because you had to sit in a classroom all day or for a couple of hours. ... I hear people saying in the [support] group you know that when they were in school, they’re frustrated now because now they’re adults, they’re wishing they had have educated themselves more when they were at school. ... They couldn’t retain stuff in their heads. Or concentrate long enough to learn something you know. There’d always be a distraction. ... looking out windows when the teacher was talking, you know. Daydreaming.

**Conor** concurred that ADHD characteristics impacted on the ability to gain from the school experience:

I think it’s a problem for anyone who’s got it. Because you’re not going to be able to avail of education successfully. So that’s gonna really limit and hamper your opportunities. ... the educational system is completely geared for people who think in a linear way, rather than a lateral way. I think ADD thinkers think in a lateral way. ... My experience of the educational system has been very negative as a result of it. And I still struggle greatly to get qualifications and stuff like that. So it still impacts my life quite severely in that sense today.

#### Impact of ADHD Characteristics on Further Education

Nearly all of the participants who had studied at third level had struggled with adapting to the learning environment of oral lectures and assessment methods based on essays and exams. This difficulty could be traced back to the characteristic ways of thinking associated with ADHD. This link was summed up by Patrick:

It's the inability to process that's the problem. Or the inability to organise, to concentrate, you know. All of these symptoms, these ADD symptoms ... I have had five attempts to complete a college course of various kinds, and I've failed on all occasions. And it's not because I'm not intelligent, or that I don't have enough smarts to complete courses.

Other participants implicated a range of ADHD characteristics when they described why, despite their best efforts, they found it hard to succeed at college. **Peter** described distraction ("another person maybe would have been more focused and wouldn't have let the lingering doubts inside and the distractions take over"). **Cornac**'s note taking lacked organisation, it was "very confused ... My copybooks were... People would look and go, what??" **Daniel** found the technical, academic material to be unstimulating ("the blood just drained from my face when I realised I wouldn't be able to do it. ... it was just so tedious, so boring. ... it's just like there was a big steel curtain. And I'd try and I'd try").

This example from **John** shows a number of issues coinciding, including the inability to manage his money, at the same time as he was trying to manage with the academic demands, and a tendency to seek distraction:

That's where it really began unravelling a bit ... I got through by the skin of my teeth. ... I was fucking terrible with money. So that all became very apparent throughout uni. ... I thought I was pretty typical. Not so much, as it turns out ... I'd find a friend who wanted to do something at that point, and then when they went home to study, I'd find somebody who wanted to do something else.

Compared with **John**'s example of distracting himself through company, **Brian** talked about engaging in self-distraction, which led to long days spent in the library being wasted because he could not concentrate:

Time all goes down the plughole. ... There just wasn't any concentration. I would sit in a library all weekend. Literally you're talking about twelve hours each day, and get about a page written. A page. ... In the meantime I would do anything to get out of work. It could be go and buy a pizza, go

## Findings

### Impact of ADHD Characteristics on Further Education



and have a beer, go for a walk, read the Wikipedia article on how a Chinese dictionary works.

**Cathal** experienced a repeat in college of his earlier experiences in school when he had been challenging the teachers. He told the lecturer that he would be better off studying himself without attending class, but he was required to attend:

[I said] It's not going to work. I'll buy the book. I'll sit the exam. ... I was forced to attend. It didn't go well, and a week later they said 'it's okay, you don't have to attend'. ... She had a go at me, and I wouldn't let her. ... If a teacher didn't know what he was talking about, I'd pretty much point it out too, or ask some question that proved that he didn't know what he was talking about. Not always trying to be mean. Just trying to get as much as I could out of the class. ... I'd sit there with nothing in front of me and listen and answer.

### The Learning Environment

Learning at college was challenging for several reasons. For one, there was much less formal structure than had been the case at school. It was the responsibility of the student to attend class, to get assignments done, to organise a study routine, and so on. Without the 'scaffolding' of the school routine and close supervision by teachers, the characteristics of ADHD were doubly hard to work with. **Daniel** found this impacted severely on him ("I got further and further away from the structure of home, my results went down more and more and more. ... pure bluff and bullshit, and I don't know how, but I managed to get through and get the degree"). **Shane** was unable to function in this environment. Nothing had changed for him in his capacity to deal with information since he had been at school: "the same thing. I just found it difficult to learn, and didn't know how to learn". **Ethan** got a shock in his first year to find that this learning environment was considerably different to school:

I never failed anything in my entire life. And then I got my first year, my first semester results from Christmas, and that was... That was the hardest thing I think I've ever gone through. Getting back those results and seeing that I've failed all these exams ... It's just an unstructured environment. You need to basically motivate yourself or you're not going to do it. That's it.

### Forms of Assessment: Exams and Essays

The predominant forms of assessment used in college were not a good fit with the abilities of the participants. Exams required memorisation of large amounts of material, which were not very compatible with concentration problems and memory lapses ("I'd get the big picture. ... I never was big on dates or specifics ... answer it in a very vague, non-specific

way”, **Daniel**). Essays required extensive structuring of material and integration of varied sources, a process in which the participants could get lost. **Ethan** found that his approach of putting as much time in as possible was not fruitful: “I was doing fourteen, fifteen hour days in college every day ... I just got a pass in most of my exams. ... My mates and stuff like that, they didn’t go to college at all the whole year, and they were getting the same results as I was”. **Cormac** had to put large amounts of time into preparation, giving the sense of an all-consuming effort:

What I tended to do is, research in my own way, usually just spend hours and hours and hours endlessly browsing through topics and finding credible websites through the library or wherever. ... In that respect, there was a kind of organisation, but I could not take notes. Sitting in a class with a notebook, ... and it’s like, what’s relevant? What do I take note of?”

### A Wounding Experience

Completing his college course was obviously very important to **Patrick** but he was just not able to do it: “I got to second year. I went half way through second year, left for a year, came back and repeated second year, got through second year and then attempted third year twice. Couldn’t finish it. And I left the course then”. The impact of trying hard at college but either struggling or not being able to complete was damaging for self esteem and led to regret and self-recrimination. **Ethan** was not doing better at college, but still saw college as a challenge (“Once I basically crawl out of the stage of my life that I’m in, the college life, it should be fine”). **Daniel** gives the sense of personal failure at having left his course (“in the end I just like petered out and sort of slunk off”). **Conor** had to reconcile his view of himself as an intelligent person with the disappointment of finding himself unable to come up to his expectations in an academic environment (“I’ve had to drop out, because I couldn’t get the essays done”).

**Peter** saw the end of his studies as unfinished business (“I’ll always have that regret. ... I probably will end up doing it somewhere down the line”). **Cathal** felt his difficulty at third level had impaired his economic prospects (“I would be a higher achiever at the age of forty if I had a better education”). **Jack** described how he felt when he passed by the college where he found himself unable to succeed: “I loved it! This is it. I loved it! ... And it was a great experience. And yet... It came to the exams. And when did we do this? ... I was in bits for a long time. I think a couple of years afterwards. Really bad. If I ever cycle past that college, I be getting... Giving out to myself. Really bad”. **Shane** had struggled with college from the beginning of term. After having built up his expectation for being able to use the course to gain employment, his disappointment and upset is palpable: “it was just getting so overwhelmingly stressful ... But also it was a disappointment, because it was like another failure. You know. And I don’t think that’s right. I would get very... I felt as if I was wronged”.

## Not Knowing about ADHD

In retrospect, a crucial factor that impacted on the college experience for participants was that they were not able to place the difficulties in context by identifying that ADHD was a contributing factor. **Brian** identified two critical issues behind his experience at college of ‘Hell on earth’: “First of all, you don’t know what’s wrong with you. And second, you don’t have the tools to deal with it. ... You can’t fix a problem with the wrong tools. You can’t fix a problem if you don’t know what the problem is”. **Daniel** had adopted a negative personal explanation of why he avoided learning and struggled with the demands of the learning environment. For him, it meant that he was “scattered”, because he did not have knowledge of ADHD to explain what was happening: “I began to struggle straight away, because I wasn’t going to the lectures. ... then after that, computers came in and all of these... Everything became more technical, more difficult, and I really began to suffer with it. Not knowing what it was. Just thinking I was a fucking eejit. Or you know, scattered”. Later, on returning to college after finding out about ADHD, **Daniel** was able to take a more constructive approach: “I went up to my lecturer the very first day and said listen, I have ADHD. I don’t know if I’ll be able to do this, but I’d really love to. ... He just said don’t worry about that. We’ll work with you”.

## College Supports

While experiences at school often featured unsympathetic teachers and peers, these factors were not apparent in describing the college experience. For the most part, the interactions with academic staff were helpful: “my tutor at the time rang me up. ... And said, ‘hey look, I’ve got a certificate here with your name on it. And it says distinction. But you’re not gonna get it unless you hand me in this, this and this.’ So I kind of got my finger out and handed them in, so she did me a great favour actually” (**Conor**). **Cormac** found that lecturers were generous with their time: “They’d sit down and take their time. In that respect, college was, for me it was mind-blowing, because these people were there, and they were so amenable”. He also found the student support services were accessible to him: “it wasn’t a case of, you’re coping with it, go away. It was a case of, you’re coping with it, go away, but bear in mind I’m here, should there be any further problems. So it was supportive”.

Several specific supports were identified by participants as having been helpful. **Ethan** mentioned the audio pen recording technology (“to record my lectures. ... I can go back and actually listen to what my lecturers were saying, because I find listening ... it’s a far better way of actually me taking in the information rather than actually sitting down and reading out of my lecture notes”). He also availed of a low distraction venue for exams (“They have, is it the low distraction venue they call it, for my exams”). **Peter** referenced a space in the library that was also designated as low distraction (“it was a quiet space. ... there’s areas

where you're not allowed a mobile phone or anything. There's these super quiet zones. So stuff like that is great"). **Ciara** found there was support available to her in essay writing skills ("I was struggling with one of the essays, and I had a meeting with educational support, and that was really helpful. Just to get help with everything. Because I was worried about how I was... Like if I put this here, or that there or whatever"). However, **Shane's** experience was of seeking support was fruitless. Due to administrative issues he was not being able to avail of support in the crucial first semester, when he was trying to settle in to learning ("because you know when somebody says do a report or something like that there, I've never been taught how to do that. What structure or how to lay things out").

### Ways of Learning: Experiential, Practical, Conceptual

Traditional large, oral lectures and exam / essay assessment strategies were not effective for the participants. They did describe other forms of learning that they found successful. **Rory** learned to use mnemonics as a memory enhancement strategy, which had a dramatic effect on his ability to assimilate information ("that changed my life"). **Daniel** returned to study, but his course was more practical and experiential, and this suited him much better ("I didn't realise now that you can train in a very different way. ... So I've done two years now, and it's fuckin' hard going. ... Very much process. And that really suits me. ... I'm getting honours, which I never got in college. And I'm doing well, and I'm getting good feedback"). **Caroline** also found a subject area that matched her skills and aptitudes ("went back to study drama, which is what I've always wanted to do, and where I sort of feel I can listen and hear things and take them in"). **Cathal** took up a course that involved a minimum of classroom work ("it was much more practical ... there was a lot of activity involved. ... three days a week practical, and two days a week sit-down").

**Ethan** described small group tutorials as an excellent way for him to learn. It was far easier for him to concentrate. He would come out and know what happened, what he needed to learn, what he needed to revise, and what he had taken notes on. By comparison he would be "all day going to the ... lectures, and I still wouldn't learn anything". The topics covered in tutorials were more practical ("problem solving"). The set up in the room was better too ("it's all level tables and it's level in front of you as well. It's like a classroom set-up that would be in a secondary school. So it's a more focused environment ... there's ten to fifteen people in these tutorials"). For **Rory**, the key to success was not in rote learning, but in conceptual learning, learning a framework of information and ideas that can then be linked together in original ways ("It was like fun. It was like playing. It wasn't learning. Because learning to me was associated with not learning. ... You've to learn factoids which are interconnected, like nodes").

## Findings

Impact of ADHD Characteristics on Further Education: Ways of Learning



## Experiences of Employment

### Positive Experiences

The participants spoke about having had excellent and satisfying work experiences. These typically occurred when they felt stimulated and found a good match with their abilities (“There’s an air of responsibility there too which I enjoy, and I relish in. ... making a real difference you know. It’s good, because you can see sort of instant results”, **William**). **Daniel** spoke about the passion and satisfaction he found working with young people: “I absolutely loved it. ... I loved the psychological challenge of it. I loved the human challenge of it, of working with these young lads. ... it was all experiential. ... And there was supervision and support”.

**Peter** found that he could use his energy and positivity in his new job role (“People have given me feedback that I bring a lot of energy to the role. ... So you’ve got to be really bright and positive and optimistic. When I say bright I mean kind of, not intelligent, but not sounding like you don’t enjoy your job. ... I get into the extravert bit”). This was a great improvement on an earlier experience where he had coped through avoidance (“I don’t experience that at all with this. ... because you get a new project almost every day. It’s almost like your own desk, like your own little business. ... it’s just very dynamic”).

**Cathal** had difficulty in school with being told what to do, but found that he did not have that difficulty in the employment relationship, with the “guy ... who is paying me”. He left school at an early age (“school wasn’t working for me, whereas work was. I mean I was getting lots of praise when I was working”) and he earned good money. Unlike school, he could perform fine in the work environment (“If somebody asked me to do something I could do it you know. I would apply myself to the task at hand”). He felt that clear communication was an important part of working well: “I’ve never had a problem telling someone I couldn’t do something, or why I couldn’t do it, or ask why I had to do what I was doing. ... They’d prefer to have someone that knows what he’s doing and will just do it, rather than someone who just does what you tell them without thinking”.

**Cormac** had worked in a retail environment for some time (“I really, really enjoyed working in retail. ... Well there was job satisfaction. Retail was kind of my niche”). More recently he had moved into working in a caring role. He felt great satisfaction in this new role and that it fitted him very well (“making these people feel a part of the community ... I’ve never had so much job satisfaction”). **Patrick** felt that he had been able to succeed in his work life because he was self-employed and had a good deal of control available to him as a result:

I’ve never had a formal job. I mean that’s another one of my blessings in my life. I never had to work for somebody else ... this is part of the coping mechanism. ... if I had gone into an employment route, I think I would have been in and out quite a bit.

#### Moving Up and Progressing

Some of the participants had difficult experiences in school and college that had set back their occupational development. Nevertheless, several of these participants had used their determination to find their way back into the work environment and had progressed after initial confidence building experiences. **Aoife** “got the courage to go back into work” after a period of unemployment that arose when she had first become trained in areas that did not suit her. Over time she worked her way up through several jobs over several years before moving into jobs in more public roles. **Conor** had a similar experience of building up over time:

I discovered that actually I was really, really good at things that I thought I could never be good at. ... I was coming to the end of it. ... [later in another job] ... they actually said would you mind running it for a while, while we find a suitable replacement, and I ended up getting that job. I became the manager of that place ... I had to do like rosters, and that's fairly basic stuff as well. ... I was going to a lot of meetings ... running groups ... helping people to build plans about how they were gonna put their life back together

Clearly, it was possible to have good experiences at work. Yet a number of significant problems were also described. These focused around receiving good support from the employer, finding a job that suited the person, and being able to manage the challenge of administrative and organisational demands, especially paperwork.

#### Employer Attitudes

**Brian** remarked that employers did not have knowledge of adult ADHD. Their stereotype for a disability was in the physical or intellectual domain: “I think most of them have no clue where to start, but they will be open-minded. They expect a disabled employee to be physically disabled, blind, or possibly have a cognitive impairment, such as Downs’ or low functioning autism”. **William** concurred with this perspective, that employers had more experience of managing other conditions in the workplace: “They know how to deal with them, what they can do and what they can’t do, and they know where their strengths are. But there’s just not that with ADHD”. Among his employment experiences, **Brian** had found one boss who had made enquiries about what he was capable of: “the most ludicrous questions. ‘Is this man capable of understanding directions?’ ... I was too hurt to talk about it to anyone at work”. When he was going through stress at work **Daniel** had met with a manager who had a negative attitude and did not offer the kind of flexibility he needed: “It was humiliating initially. ... She just didn’t understand. Tried to feign empathy. ... I was suggesting maybe there’s different ways that I could work that would kind of help, and she was saying well not

in the current economic... She just didn't see the flexibility". The manager's attitude was an important issue, as **Aoife** attested: "Now I have an understanding area manager. I think if I had have been in a bigger firm with the same, I don't know would I still be in the job".

### Flexibility

Managers could show support to staff members with ADHD by engaging in clear, supportive communication and by endorsing a flexible approach. **Brian** spoke about this as having helped him:

The management model that I use is that I say what I need, and they provide me with the flexibility. ... I've been in my post less than six months, and therefore I'm not entitled to flexitime as a right. But I persuaded them to give it to me on the basis that it would help me manage my time. There's far more to be achieved than learning to cope without reasonable adjustments.

**William** found his employer to be flexible in accepting that he would have 'bad days' sometimes: "Now my employer knows that I have ADHD and is very good about it. If I'm a little bit late with a piece of work, he'll say 'look are you alright today?' And I'll go 'yeah, I'm just having an off day'. And he'll say, 'right okay. Just take your time. Get it done right instead of rushing through it and getting it wrong'". **Jack** felt this approach would be necessary for him to succeed in work in the future ("There has to be accommodations. ... 'don't worry, give yourself an extra half an hour with that job if that's what you need to do'"). **Rory** had found clear mentoring advice very helpful to him in framing his attitude to work: "he said 'don't change yourself'. Your core self. But just learn to... Because there's certain times where you need to pull in. ... That's one thing I've learned. I need to be in places where there's people who are like a mentor or creative, and then it's easier to go off and feel safe".

### Matching the Job to Your Interests

Experiencing stimulation and interest in work was critical in light of the characteristics of ADHD ("I found it very hard to keep churning out the work. I'd just nod off or want to go for coffees. It was just boring me", **John**). This was apparent in **William's** description of some of the jobs he had done before finding his present position:

I had no motivation to do anything. ... The jobs that I was doing were sort of mundane jobs you know. ... I quit them very quickly because it just wasn't interesting. There was nothing to challenge you. ... Just mind-numbing stuff you know. I find with the ADHD, if you're not doing something you're interested in, there's no point in doing it at all, because you'll just not concentrate.

#### Difficult Work Demands

Administration and paperwork were very significant problems for some of the participants. **Conor** said that he was “always falling down a little bit on report writing and all of the written tasks”. **Aoife** also found this (“I would have issues. Organisation. Paperwork issues”). This issue had caused a lot of difficulty for **Daniel**. Some years previously he had been delighted to get a job working in an area that he found very satisfying. His employers put trust in him because they could see he was able to do the job very effectively (“they just said ‘right, you know what you’re at, just do it’”). A problem arose over time because of growing expectations for administration and paperwork (“things became really standardised. ... a very, very rigid formalised standardised route ... Forms, reports, budgetary stuff”). This did not suit **Daniel** (“I really began to struggle”). He engaged in avoidance behaviours but felt the strain (“I was just going insane thinking like ‘what the fuck is wrong with me?’ ‘Why can’t I just sit down and do this?’ I know how to do it”). He had experienced similar management pressures in an earlier employment, and had tried to cope at that time through avoidance, with similar results (“That’s when I had my first kind of big breakdown. I just had this big ball of paperwork everywhere”). Things became very difficult for him (“I began to not turn up”). Eventually he was able to speak to his boss and work through some of the issues. However he still felt tension over the issue (“I still have a lot of fear and trepidation around it”).

**Declan** found himself unable to cope with assimilating instructions and requests (“If someone gives me instructions on the job that I’m doing, say ‘right can you ... do this and do that’, well it’s like I’ve forgotten what they’ve asked me. ... I’d remember either the first thing or the last thing, the other two things are completely gone”). He had always had to cope with this problem. When he started it was simple and straightforward (“There was no health and safety as such”). Over time a new problem came up, arising from increasing technical and administrative aspects of his job. He had difficulty with the move to technology (“I haven’t a clue what I’m doing”) and was unable to disclose that he had literacy difficulty (“I wouldn’t tell them that I couldn’t read or write, because I think I’d be a lesser person than what they were”). He could not cope with the changes (“Everything had a computer in it. Everything had to be by the board”). He tried to cover up his inability to perform in this environment but came to realise that “you can’t live your life like that. ... I’d have to ask someone and they’d say ‘fuckin’ hell, you should know how to use it by now’”. The problem “all sort of snowballed, and I couldn’t cope with it anymore. It just got too much”. As a result, he left the job, and latterly found that the physical exertions of physical labour over the years had taken a huge toll (“I’ve actually done so much damage to myself physically because of working in jobs that are the only jobs I could do. ... I’ve just worked myself to the ground). Now in his 50s, he felt like his employment options are more limited than he would like.

## Findings

Experiences of Employment: Difficult Work Demands





# Summary of the Study

This research study provides a novel perspective on the experience of ADHD among adults in Ireland, a topic that has not been extensively explored to date. It included a wide range of adults, across the Republic of Ireland and Northern Ireland, ranging in age from 18 to 53 years, including both genders and diverse occupational backgrounds. There was also diversity in the participants' background with ADHD, from those who were diagnosed with the condition as children, participants who had been diagnosed more than five years previously, recently diagnosed adults, and two who were yet to be officially diagnosed. The qualitative methodology allowed for an in depth exploration of each individual's experience with ADHD. This contributed to the study's main contribution, to give breadth and depth to our understanding of adult ADHD in Ireland. The main findings of the study correspond with experiences of adults with ADHD that have been described in international research in Europe, Australia, the UK and the U.S.

## Short Summary of the Study Findings

**The experiences associated with ADHD by the participants who took part in this study reflect the DSM 5 criteria (APA, 2013), with a greater emphasis on the ADD component of ADHD than on hyperactivity. These characteristics were the starting point of the ADHD experience for the participants. Having come to an understanding of ADHD only in adulthood (with the exception of three of the 19 participants), each person had assimilated the condition into the self concept in a unique manner – reflective of individual life history, personal circumstances and personality. Even those participants who had received a diagnosis in childhood had to develop their own adult understanding of the condition on reaching maturity.**

When coming to terms with the condition as adults, all participants had had to overcome negative social and self-judgements about ADHD characteristics that they had developed earlier in life. These characteristics had significant implications for personal adjustment and performance in social, academic and family domains of experience over a period of years or decades. Although the 'ADHD' label in itself attracted some stigmatising associations, it was easier to work with it as a clear understanding of their difficulties than the negative self-labeling as a person who was simply 'stupid', 'bad', or 'lazy'.

Self-management of ADHD and the use of specific coping strategies were evident in the findings. These adaptive aspects of the experience are not described in depth in earlier qualitative research literature on the condition. As an overall approach to self-management, the

## Summary of the Study

### Short Summary of the Study Findings

participants talked about taking personal responsibility for their behaviour. They seemed to have been empowered to do this by no longer feeling responsible for the disappointments and regrets attached to the past, when ADHD had not yet been available as an explanatory tool. Despite this determination to assert control, it was still acknowledged that ADHD was a challenging problem to manage and would always be a part of their lives.

Personal coping strategies fell into four main categories:

- Avoidance and alcohol / substance misuse. These had not been productive in achieving adaptation.
- Using aids for structure and completion. This included practical initiatives such as using organisers and other prompts, and employing personalised approaches to task management and completion.
- Positive lifestyle habits. These are efforts to maintain regular routines or habits that promote physical and mental wellness.
- A positive attitude centred on acceptance that ADHD has been, is, and will be part of the person's life story.

There were also social coping strategies based on support from family, friends, partners / spouses, and peers with ADHD. Access to peer support groups was rather restricted, but those who were involved spoke highly of the positive impact that group participation had for them.

There were three aspects to the medicalised experience of ADHD:

1. Getting a diagnosis and adapting to it. The participants were a community-based sample from varied backgrounds. Reflecting this, the participants had accessed a diagnosis using several different routes. These devolved into the private route achieved through consultants and clinics, and the public route based on multidisciplinary assessment. For most of the participants, the path leading to diagnosis started with becoming aware that the ADHD label might be applicable. This awareness was often reached as a result of encountering self-assessment tools on the Internet. Yet the participants also seemed to have reached a point in their lives when they were open to exploring this aspect of themselves. Some time usually elapsed between the initial recognition that ADHD could be relevant and the point of obtaining a formal diagnosis. This was partly due to the period involved finding (or waiting to access) the right forms of professional assessment. In addition, at a personal level, the participants tended to need time to work through concerns about ADHD as a stigmatised mental health

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condition. Although the initial diagnosis was met with ambivalent feelings, this tended to develop into a predominantly positive understanding as the participants achieved benefits linked to:

- a. A clearer understanding of the self.
  - b. A productive re-interpretation of the past, and
  - c. An acknowledgement of the need to take responsibility for developing a more positive future.
2. Contacts with health care professionals mainly involved General Practitioners in primary care and psychiatrists in mental health services. Most of these interactions were described in negative terms. This view was based on perceptions of doctors not listening to them or disbelieving the concept of adult ADHD. There was also a general impression that medical professionals had relatively little training and preparation in supporting adult patients with ADHD. Nevertheless, very positive experiences with doctors were referenced as well, the success of which was largely attributable to the doctor adopting a positive approach to communication and collaboration.
  3. The final component of the medical aspect of ADHD arose through experiences of medication use. There was considerable individual variation in medication experiences – in what forms of medication were used, patterns of use (steady, occasional, sporadic), experiences of side-effects, and attitudes to medication. Where medication worked well, it had a transformative effect in releasing the person from problems with concentration and attention. However there was also a sense of resisting medication too, due to enjoying some of the subjective aspects of ADHD characteristics such as lateral thinking and creativity.

Three applied areas were described in the findings, which referred to school, college and work:

1. The school environment. This represented the beginning point for most participants of experiencing negative implications and judgements as a consequence of displaying ADHD characteristics. Depending on the person, difficulties were particularly associated with primary school, in secondary school or at both stages of the educational experience. Only three participants had ADHD diagnosed during the school career. The vast majority of participants went through school facing difficulties with concentration, reading, sequential thinking and recall. Negative experiences at school posed great difficulty for later adjustment, sowing the seeds for low self-esteem and a feeling of personal failure.

## Summary of the Study

### Short Summary of the Study Findings



## Summary of the Study

### Short Summary of the Study Findings

2. Later educational experiences. Negative social judgements and peer bullying were not evident during third level education, but the same underlying issues with information processing and academic work continued. Indeed, the self-directed nature of academic engagement at third level contributed a new dimension to educational problems. Nearly all of the 14 participants with experience in higher education had either left an academic course before completion or had difficulty in completing coursework. Experiential learning and small tutorial-style learning environments worked best for participants studying at college. Although lecturers and student services were reported to be supportive, in many cases participation at this level of education had been a wounding experience.
3. Employment. The participants felt that the work environment was often unforgiving. There was a strong expectation in work for the person to stand independently without the supports that might be expected at school or college. The implications of ADHD characteristics at work were very stressful for several participants, creating quite profound levels of difficulty. Avoidance, procrastination, and lack of motivation were severe challenges for these participants, compounding problems with attention and retention. Yet some participants also found it possible to do well and to excel at work - ADHD characteristics could work in the participants' favour when matched with the right job context.

Taken together, the experience of ADHD for the adults in this study was one that undermined personal autonomy and empowerment to maximise personal potential in life. Yet on coming to terms with it as an underlying cause, the ADHD label provided the opportunity for a rich and insightful insight on the self and others, and a basis for effective adaptation. ADHD characteristics were not inherently disabling. Indeed they brought out original and innovative perspectives. However they did pose severe challenges when occurring in contexts where linear thinking and rote learning were favoured, as is often the case in school, higher education and work settings. The characteristics of ADHD were a fundamental challenge for individuals in conventional school and higher education systems.

Given limited access to peer support and care from suitably trained professionals, the participants were not well served by specialised supports when confronting these life challenges. Nor were families well supported or prepared to take on the challenges arising from having a family member experience the challenges of ADHD and its social consequences. The ill-prepared nature of systems, supports and structures relevant to ADHD was the critical issue, rather than the condition itself. As a result, the experience of adult ADHD was often linked to personal struggle and suffering, which the person was not well equipped to respond to or understand. Openness to self-exploration and diagnosis began a journey of personal empowerment to manage ADHD as a lifelong condition.

## Discussion of Findings

### ADHD Characteristics

The participants described characteristics of ADHD that map on to DSM 5 symptomology (APA, 2013). The inattentiveness component of ADHD was invoked more commonly than hyperactivity / impulsivity, reflecting the self-identification of most of the adults in the study with 'ADD' (five of the nineteen participants referred to hyperactivity). The impact of these characteristics on the personal experiences and daily life of adults with ADHD is still being understood by researchers. There are relatively few qualitative studies on the ADHD experience available at the present time. However the findings of this study are consistent with those international qualitative research studies that have been published on adult ADHD (Brod et al., 2012; Ek & Isaksson, 2013; Matheson et al., 2013; Young et al., 2008).

The main characteristics associated with ADHD were difficulties with:

- **Registering and perceiving information, especially when presented verbally.** These issues caused social embarrassment and had consequences such as problems at work. Participants wanted to address this but had difficulty openly acknowledging it in their dealings with other people.
- **Attentiveness to the external environment.** This led to others perceiving the participants as 'tuned out' or daydreaming. It was implicated in instances of bullying and being perceived as ineffective at work. It impacted on the ability to learn and the capacity to remain focused in situations that require high levels of monitoring.
- **Maintaining sustained concentration.** Depending on the context, such as the length of time that concentration was required, and on what kind of environment best suited the person, concentration problems had an impact on the ability to resist distraction when carrying out tasks such as studying or maintaining conversation.
- **Planning and sequencing.** Problems with planning, prioritising and sequencing impaired the ability to complete mental tasks and actions, or to adhere to choices. While conferring a benefit in some circumstances, through 'lateral thinking', this characteristic was perceived as reducing the ability to feel purposeful and in control.
- **Managing action tendencies.** The participants described the tendency to choose an action impulsively, without weighing up options or thinking through consequences. Framed positively, this contributed to a sense of spontaneity, but often had a negative impact. There were also problems with being active, due to difficulty choosing between options or in following through on responsibilities.

## Summary of the Study

### Discussion of Findings: ADHD Characteristics

- **Learning and memory.** Learning new information was difficult for many of the participants. This was exemplified by finding difficulty encoding and retaining the information in written material and in spoken communication. Short-term memory was a problem in daily tasks such as household and work tasks.
- **Motivation – energised, directed and persistent in task completion.** The critical issue for motivation was feeling interested and stimulated by a task. Most of the participants felt that they could achieve a high level of performance under the right conditions. However they found many tasks unstimulating and some participants described a general sense of low drive or motivation.
- **Energy, activity, and hyperactivity.** Many participants described having periods of high energy and activity that could be well directed and constructive (for example in the right work context). This could also be problematic in managing social interactions or in achieving persistence on one task. At the same time, high levels of energy could be tiring or wearing to the person. Reflecting the diversity of the sample, a small number of participants identified with sustained high activity levels linked to hyperactivity and others referred to having low energy overall.
- **Emotional responses.** A minority of the participants identified with experiencing anger, which they associated with interpersonal conflict or fighting with others. Anxiety was a more common experience, usually in reaction to other issues that arose such as work stress.
- **Organisation.** Problems with learning, sequential thinking, motivation and concentration came together with the impact of impairing day-to-day organisation. This resulted in specific issues such as procrastination and poor management of personal finances. The overall effect was in having problems with being (and remaining) organised at home, in education and in work. At its worst, this meant that things spiraled out of control and led to chaos.
- **Positive features of ADHD.** Depending on the context, several ADHD characteristics had positive dimensions. For instance, ADHD was seen as conferring a different perspective on problem solving and creative thinking. Not thinking in a linear fashion was also associated with curiosity and interests across a wide range of topics. Likewise, being energetic was associated with being good with people.

#### Personal Meaning of ADHD

ADHD had a deeper meaning to the participants than the sum total of the symptoms or features of the condition. The personal meaning of ADHD varied between participants but shared certain themes. These included:

- The impact of negative social stigma.
- The consequence of past labeling that used terms such as ‘lazy’ or ‘stupid’.
- The individual meaning of ADHD, as to whether it was seen as a disease, a health condition, or an integral part of the self concept.
- How ADHD was used as a means to forgive oneself for past mistakes and negative self judgements.

These factors have been described previously in qualitative research that relates to ADHD and the self. They have been discussed specifically with reference to how recently diagnosed adults with ADHD assimilate the condition to their self image (Fleishmann & Miller, 2013; Hansson Hallerod et al., 2015; Lebowitz, 2016; Schrevel et al., 2015; Young et al., 2008).

The participants had differing views on whether ADHD (a) simply represented a difference in how they process information, or (b) whether the features associated with it represented a deeper reflection of personality and self. Some regarded ADHD as a disruption or impairment in a particular cognitive function or ‘module’ dealing with attention and learning. This understanding kept it separate to their own self concept, whereas others saw it as a reflection of the inner self.

Taking on a self label as having a mental health condition was challenging for the participants who had received a diagnosis in adulthood. This is understandable given the negative stigma associated with having a psychiatric disorder in our society. Nevertheless, negative self labeling had already taken place for most participants over the years, through the use of terms (at least in certain contexts) such as ‘stupid’, a ‘messenger’, ‘lazy’, a ‘bad boy’, and so on. Describing oneself as ‘ADHD’ introduced a different label and an alternative explanation to that which had pertained to date. Seeing ADHD as a genetic and neurodevelopmental issue had offered a novel understanding of those characteristics now attributed to ADHD. It had brought a sense of self forgiveness, and a better way of being able to understand personal difficulties and the issues underlying them.

The process of getting the ADHD diagnosis occurred in a wider context of self-questioning. Often, having reached a point of maturity in life, the participants had set out on a search to better understand themselves and why they had felt different since childhood. In

this context, the label of ADHD was part of a general coming to terms with life issues. It signified a new openness that made personal exploration and labeling more acceptable as a developmental process.

Personal identification with ADHD was a complex process. For instance, individuals differed on how central ADHD was to their personal life narrative. For participants who had been diagnosed most recently, it was clear that this balancing of ADHD and self was still underway. In addition, the negative self-evaluations had developed over years, and were usually grounded in childhood experiences of negative feedback, extending to ridicule or even feeling that others had given up on the person. These expectations had fed forward into adjustment issues in adolescence and earlier adulthood, and had affected decisions about work, life plans and goals. ADHD had set a limit to the scope for personal achievement for some of the participants. There had been a price to pay for having certain ADHD characteristics, and it had usually taken time to understand how to cope with these characteristics or indeed to use them to good effect.

### Managing ADHD and Coping Strategies

The participants were not passive or lacking in insight when responding to ADHD. Although some recent work is available in this area, the topic of coping strategies used by adults with ADHD is not very well developed in the research literature (Brod et al., 2012; Ek & Isaksson, 2013). The coping responses made by participants fell into several categories. At a general level, the management of ADHD revolved around taking personal responsibility, to assert control in having an overall approach to establishing and maintaining routines. Alongside this clarity of direction there was an acknowledgement that ADHD is challenging to manage. It had a significant impact on all of the participants, leaving them feeling isolated at times and facing difficult adaptation issues on an ongoing process. Having a label to identify and help explain difficulties entailed an acceptance that ADHD is a lifelong condition, one that will always represent a challenge and require continuous efforts at adapting well to it.

At a more specific level, the participants identified a range of coping strategies that they were using or had used. These can be grouped into four categories. The first refers to coping strategies that are not productive in the long run, such as avoidance and use of alcohol / drugs. Several participants spoke about having had a problem with drinking or drug use in the past, to the level of a significant addiction. However for most participants addiction had not been a significant issue. It is also important to acknowledge that heavy drinking has been a normative behaviour in Ireland for some time, and that among young adults drug use has become partly normalised. Thus, for some people who did not identify as having a problem with addiction, it was hard for them to discriminate whether their substance use patterns might be attributable to 'ADHD' or to being a member of their local community.

The second coping category involved attempts to be structured and organised, in order to support task completion. The participants spoke about having a range of practical adaptations and coping strategies. These included adopting personal organisers, lists and diaries (including electronic diaries), as an effort to embed a more methodical approach to getting (and staying) organised. In response to the problem of having difficulty in receiving instructions or learning a new skill, participants described using more conscious ways of learning, such as breaking down various tasks and duties into smaller components to rehearse and assimilate. Task management was a significant focus for coping. Different strategies to this end included taking regular breaks in order to maintain task focus; doing multiple tasks simultaneously, switching between them to maintain motivation and interest; and self-regulation of task performance, by consciously monitoring task performance to stop distraction and encourage persistence.

Coping also occurred through positive lifestyle habits. This third category of coping strategies included ensuring or encouraging a daily structure and routine, for instance by treating third level education as a 9 to 5 job and by adopting regular habits of sleep and diet. Engaging in exercise and personal development were also referred to as positive actions. Exercise regimes differed in how structured or formalised they were, but the underlying link was the importance attributed to physical activity as an aid to manage ADHD. It was seen to promote a positive mental state and manage stress. Other forms of personal development were felt to have a similar outcome, such as learning skills like mindfulness. Being able to achieve a match between personal skills and the work environment also contributed to the ability to have positive experiences and achieve personal control. Another coping strategy was to seek and research information about ADHD, to achieve control and empowerment. The participants had skillfully used the Internet and library resources to find out about ADHD, possible treatments and medications.

The final category of personal coping strategies referred to developing a positive attitude to ADHD and striving for personal acceptance of the condition. This meant accepting that the condition has been and will be a part of the person's biographical life narrative, and accepting the need to adapt using practical strategies such as prompts, reminders, and having a positive attitude to change. Seeing oneself as an individual who is intelligent and capable was a positive step in working with ADHD on an ongoing basis.

Coping occurred with the support of others, such as family members, who could prompt the person to get help and adopt a constructive approach that enabled the person to feel supported. The findings on coping through the support of others demonstrated the importance of having a network of resources. However it should be noted that most of the references to family described non-supportive histories. Lacking the orientation and knowledge provided by understanding ADHD, it had been difficult for families to cope with undiagnosed ADHD,

## Summary of the Study

Discussion of Findings: Managing ADHD and Coping Strategies



both during school years and subsequently. In some cases the problems that arose within families were quite serious in their own right and contributed to negative self-evaluations that persisted for some time.

Nevertheless, the participants did identify effective ways of managing ADHD within families, such as a parent dealing with anger on the part of a teenager by remaining calm and separating the behaviour from the task or issue. Besides family, the support provided by friends was critical for younger adult participants. Similarly, spousal or partner support was very important for some participants. This took different forms depending on the person, from having a sense of partnership to needing the active support of a life partner on a practical level. In all cases it was important that both partners in the relationship were on the same path of positive development and were able to achieve open communication.

The other channel for social support was through peer support from other adults who were experiencing ADHD. Some participants were regularly involved in mutual support groups and spoke about this as an important coping strategy. Being with other people who experienced the same issues led feelings of isolation to diminish. It was a form of validation, whether the group took place in a community setting or through online groups. By meeting other adults with ADHD, the person gained valuable information and ongoing support. Groups had the potential to provide opportunities for learning useful self-management skills and fostering a constructive community environment.

### ADHD Diagnosis

Several recent qualitative studies have explored the impact of a diagnosis of ADHD as an adult (Fleishmann & Miller, 2013; Hansson Hallerod et al., 2015; Matheson et al., 2013; Schrevel et al., 2015; Young et al., 2008). The diagnosis itself was the end point of a process for the participants, which began with the openness to search for an explanation for their experiences. They had reached a point where they felt able to look at personal characteristics in a new light and to re-consider the past. For several participants, the trigger for considering ADHD was coming across or finding self-assessment tools online. Such tools resonated with participants as offering a very close match with their own experiences. These events were reflective of a general tendency to become informed through doing personal research. In some instances this led to the participant presenting a doctor with a very clear understanding of their condition. Subsequent to making an initial connection with ADHD there was a period of time in which further information was sought or where concerns about having a diagnosis were processed.

Three participants received a diagnosis of ADHD during childhood, and each one had a unique experience of this. Two of them spoke about the importance of medication in allowing them to do well at school. Participants who had received an early diagnosis did not want to feel different from their peers. The participants who were diagnosed as adults described several

different routes to diagnosis. The principal methods were (a) to pay an expert consultant or clinic privately, and (b) multidisciplinary assessment accessible through the public health care system. Practitioner expertise and the building of trust were important in ensuring that the diagnosis provided a route toward effective management and adaptation. Two participants had yet to engage with formal assessment and diagnosis. Their account of the concerns and issues they faced prior to getting a diagnosis matched very well with the retrospective pre-diagnosis accounts given by participants who had already been through that process.

Diagnosis raised numerous issues to work through. These included uncertainty over what to do next to manage ADHD, concerns about medication use, and the lack of availability of specialised treatments or psychosocial therapies. Besides these management concerns, the participants also had to work through their own preconceptions about adult ADHD, from the starting point of social stereotypes of ADHD as a U.S. phenomenon of hyperactive and overmedicated children. The initial phase after receiving a diagnosis could be difficult due to self-stigma and prior associations with mental disorders. Over time, identifying as having ADHD was seen as a positive development, a proactive response to the real difficulties that the participants had been encountering. Given that the adults in this study had, on average, received a diagnosis within the past five years at the age of 40, there was regret over not having had an earlier diagnosis and a belief that this would have made a big difference to the person's life. Now that it was comprehended, it was puzzling to think of having gone through life without recognising something that was now so obvious. Diagnosis prompted, and was part of, a wider and deeper rethinking of the past and self exploration. The benefits of having received a diagnosis included the new explanations and self narrative that arose, in which ADHD played a part, and the feeling that direct personal responsibility for past mistakes and actions was now reduced. These realisations supported the individual to take greater personal responsibility for present and future actions, founded on an improved understanding of how personal control can be asserted in the context of having ADHD.

### Support from Health Service Professionals

The participants spoke of most of the health care contacts they had in negative terms, similar to the findings described by other qualitative studies (Matheson et al., 2013; Swift, Sayal, & Hollis, 2013; Swift et al., 2013; Young et al., 2008). Breaking down these negative interactions, the participants described problems with doctors being:

- Dismissive of the concept of adult ADHD
- Tending not to listen to the person
- Having a limited insight on marginalisation, and
- Lacking training and professional preparation in managing ADHD.

Given the low knowledge base pertaining about adult ADHD, several participants said it was necessary to be very well prepared beforehand as a patient with knowledge and understanding of the condition. Those participants who expressed the greatest degree of empowerment in their health care were highly proactive in identifying what care path was an appropriate fit for them, to the point of identifying and contacting certain specialists or services. This tended to entail having to source private care at a high financial cost.

Positive and rewarding interactions with health care practitioners were characterised by professional relationships that featured trust, open communication, and an openness to a collaborative approach on the part of a doctor. It was important for the patient to trust that the professional has expertise, but in addition the relationship benefited from getting a sense of the doctor's commitment to the patient. Overall, there was limited scope and availability of specialised services and expertise. The participants were dependent on the level of service development for adult ADHD in a particular area. As a related issue, two individuals diagnosed with ADHD as children talked about the transition to adult mental health services as being problematic. Transition to the adult service at the age of 18 was not handled well by the health service in these instances. In one case the person described having been told that he had now matured out of ADHD, which was not the case. Several years of difficulty ensued before he was able to get grounded again with appropriate support. In the other case, the transition had only recently occurred. That person felt very out of place in the adult mental health service and felt unsupported to make the transition by the health care professionals there.

### Medication Use

Diagnosis was a precedent or trigger for managing ADHD using medication. Those who had not taken medication expressed a hesitancy and caution about taking this step, especially in relation to whether it would alter personality or have negative side effects. For others medication was seen as unnecessary at this point. Medication did have difficult side effects for some participants, often requiring changes in dosage or in changing medication type. Few participants had reached a point of stability and continuous use of medications. Descriptions given by participants who had recently started on treatment captured the positive impact that medication could have on the issues faced around concentration and focus. This had consequences for personal confidence levels, the capacity to engage effectively in paid work, taking part in conversations, daily tasks, and college study. Several participants who were taking short acting (as opposed to slow release) medication did not see themselves as continuous users of ADHD medication. In certain contexts or for particular tasks it was attractive for them to take a break from the linear thinking associated with medication use.

#### Applied Contexts – School, Later Education, and Work

Three applied contexts were studied in the participant accounts: School, college, and work. The school environment has been described as challenging for people with ADHD (Lebowitz, 2016). Even recently, teachers have been described as having limited formal knowledge or preparedness for managing ADHD in the classroom (Russell, Moore, & Ford, 2016). The participants in this study described difficulties in making transitions from one level of education to the next. This was the case among participants who had recently attended school or college, as well as those who were older. Secondary school academic demands were recalled as a step up from primary school. For some participants, this marked the beginning of academic and behavioural problems associated with school, while others described difficulties at both primary and secondary school.

In some instances the structure and routine of secondary school was a protective factor, and it was the transition to the relatively unstructured and self-determined nature of college education that led to problems. Two of the three participants who had been diagnosed in childhood used medication and described it as enabling them to perform well at school. This left the vast majority of participants as having gone through school facing difficulties with concentration, reading, sequential thinking and recall. Homework completion was a particularly severe problem. Although school was the obvious point to notice ADHD and initiate appropriate reactions like assessment, teachers were felt to label children who did not conform to their expectations. In some cases this extended to a memory of teachers having given up on children who were not performing well academically. Those participants who performed well at school also critiqued the school system. They recalled little interest by teachers at the time in picking up on or understanding the non-academic issues that they experienced. Some of the difficulties at school were associated with disruptive behaviour at school, and this in turn compounded academic problems. In the absence of teacher preparation for recognising ADHD the participants' actions were labeled as 'bold'.

The experience of managing ADHD in third level education has been described elsewhere as challenging (Lefler et al., 2016; Brod et al., 2012). The participants who had attended university or Institutes of Technology struggled with comprehending and retaining information delivered through lectures and with exam and essay-based assessment formats. The possibilities for distraction, procrastination and avoidance were much greater than at school. Given the self-directed nature of much learning at third level this posed very significant problems. Fourteen of the participants had studied at third level or were doing a course at the time of the interview. Half of these participants had the experience of leaving a college programme before completion. Most of the remaining participants had experienced significant difficulty before completing the programme.

**Summary of the Study**  
Discussion of Findings



A block in learning at third level was described, with numerous examples of self-recrimination from not completing courses or not performing up to personal potential. Strategies to enhance the chance of successful completion included finding a good fit to the person's learning style, with a focus on experiential learning, small group practical learning sessions and peer study groups. Not knowing about ADHD as a student was an obstacle. It led to negative self-labeling and attributions of personal responsibility for struggle and lack of academic success. College student service supports were described as helpful and lecturers were responsive when assistance was requested. However in a number of instances the participants described college as having been a wounding experience that ended in leaving without completion or a sense of underachievement.

Compared with children or youth, one key distinction for adults with ADHD is the need to manage the condition in a work environment (Brod et al., 2012; Ek & Isaksson, 2013; Lasky et al., 2016; Schrevel et al., 2016). Although there was considerably more personal responsibility required at third level than at school, at least there were support services available and academic staff were described as understanding and flexible. By comparison, work was seen as a life domain in which levels of individual accountability and responsibility were raised further again. There was no obligation for employers to exhibit the same level of support as at college and school.

There were positive experiences of the work environment, especially where the work was stimulating and challenging. Energy and positivity could be advantages in these settings, and likewise thinking conceptually or creatively could be assets. The participants took personal meaning and satisfaction from work. They were resilient and determined to succeed, but had to overcome characteristics such as avoidance, distraction and memory difficulties. Organisation, planning and paperwork were particularly challenging for the adults who took part in the study. Offering support through flexibility was an effective employer strategy. However some of the employer attitudes to ADHD were not conducive to adjustment to the work environment. There was a knowledge gap in understanding what ADHD is, what implications arose for work performance, and how employees can be supported to succeed at work.

## Generalisability and Limitations

Clearly the resonance with international research highlights the plausibility of the findings and supports the external validity of the study. However the purpose of a qualitative study is not to generalise outside of the study itself. The objective of the study was not to identify findings relevant to all adults with ADHD in Ireland. The study has been useful in identifying the need for further research on specific issues that were raised in the findings, in particular to explore particular aspects of the ADHD experience, the support needs and self-management practices identified in the study, and applied features of ADHD experiences in specific contexts such as the family environment, schools and colleges, health care services and the workplace.

The scope of the research was limited in certain respects. These limitations should be acknowledged as they have implications for topics that should be developed in future research. For instance, particular demographic groups were not well represented in the study, particularly young men and women who were not studying at college, and young adults experiencing significant adjustment difficulties (e.g., through problematic interactions with health care, addiction issues, or engagement with probation services). Addiction and substance abuse regularly feature in ADHD research as key non-adaptive strategies and responses; although these phenomena were noted and discussed in several interviews it may be that self-selection biases led to people with addiction problems being under represented in the sample. In addition women were underrepresented among the participants, and most of the participants associated with ADD as opposed to hyperactivity.

A large proportion of the sample had experience of third level study, which may indicate a socio-economic self-selection bias. There were many examples of occupational difficulties, but taken together, the participants provide a perspective primarily on those adults with ADHD who are striving to adapt to the condition. A final point of consideration in respect of self-selection is that the participants were highly verbal and articulate in relation to their experiences, supported in doing this by their point of adjustment to ADHD.

The findings are especially useful in showing how adaptation has developed over time for adults in mid-life. This is consistent with a life span approach in which adjustment to different life tasks proceeds over a long period. Nevertheless the experiences ranged across a wide age span, and from those with a childhood diagnosis to two participants who had not yet had a diagnosis. Recruitment to the study took place through two principal mechanisms – contacts from two community groups (INCADDS, ADHD NI) and individuals who responded to a newspaper advertisement. The participants represent a community sample, with varied symptoms, experiences of assessment and treatment, not restricted to a particular clinic and spread out across the island of Ireland.

#### Future Research

There is considerable scope for future research in Ireland on adult ADHD. Several discrete issues were noted in the participants' experience of health care and treatments, including the transition of youth into adult mental health services, experiences of medication use, and attitudes of teachers, medical personnel and employers to adult ADHD. At a personal level, there is scope to pilot the introduction of an information support package to support adults to explore ADHD and assist with later adjustment to the diagnosis. Taking a person-centred approach, this could include case study examples of adjustment and adaptation to ADHD. Further to this, a future research study should focus on identifying the coping strategies that adults use to manage ADHD. This research explored a number of coping strategies but the topic has been given little coverage in the international literature.

People with ADHD need more explicit support structures to be put in place in the health care, school and college learning environments. For instance, knowledge and awareness of ADHD is limited among professionals due to lack of opportunity. A support package for third level students with ADHD could assist in sharing positive tips and peer experiences. In the occupational context there is also a need to develop and assess information and practical resources that will empower employers to support workers who have ADHD.

At a group level, best practice in running successful peer support groups should be disseminated and resources provided to enable groups to meet the potential for self help and learning about ADHD in a supportive environment. Such groups can meet locally or be developed using an online platform. Finally, carer and parent support needs have not been well documented or met. Life partners, family members, friends and parents provide much of the supportive network that enables adults with ADHD to assimilate the condition and move on with their lives. There is scope to build on existing local support groups that already incorporate parents. To summarise, given that there has been little focused research on experiences of adult ADHD and how best to support adaptation and thriving, a significant programme of work remains to be done, to be guided by research prioritisation. Further work is required to identify priorities for research and should adopt participatory strategies that include people with the condition when doing so.



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