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

RESEARCH STUDY SUMMARY

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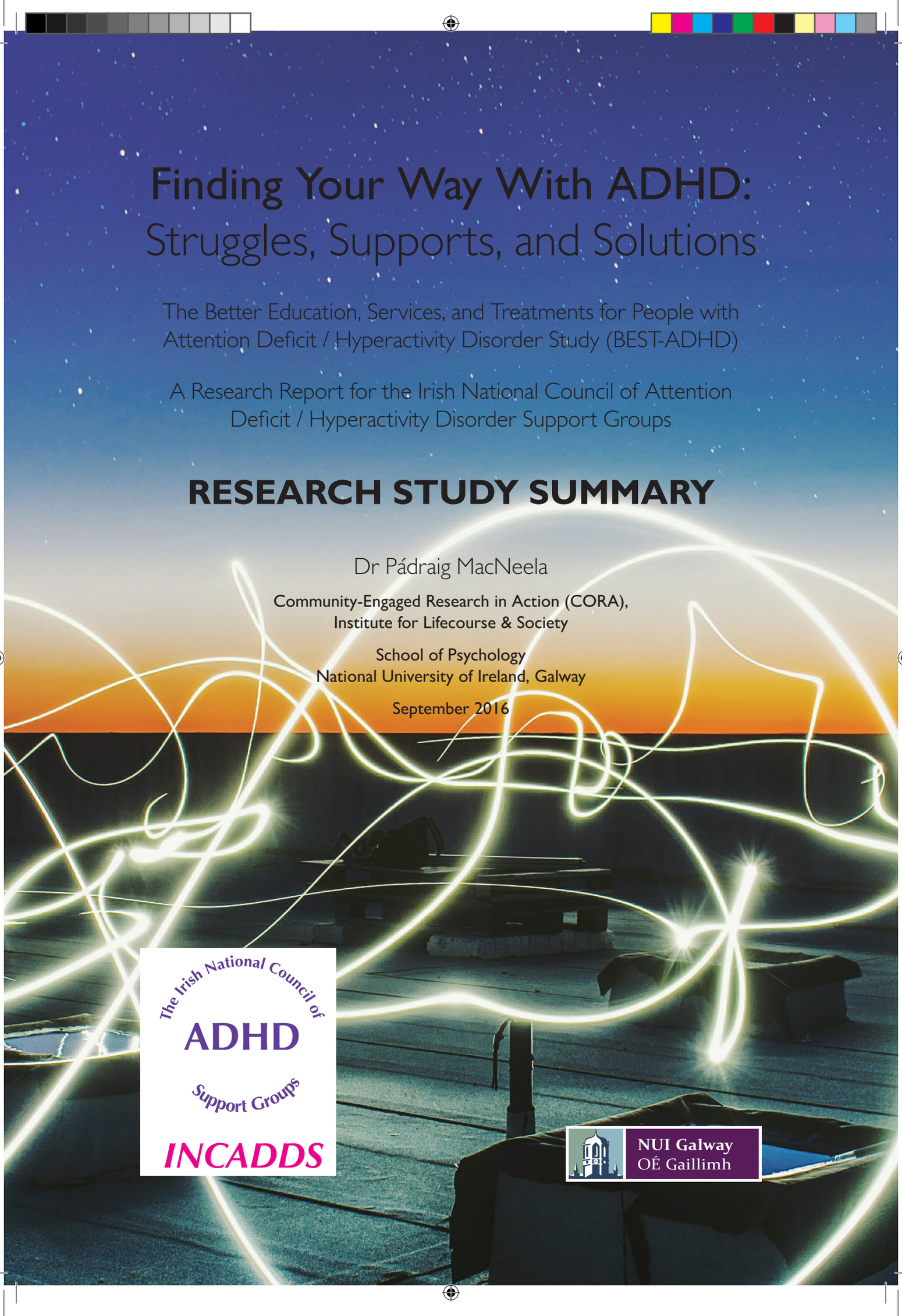


The Irish National Council of ADHD Support Groups

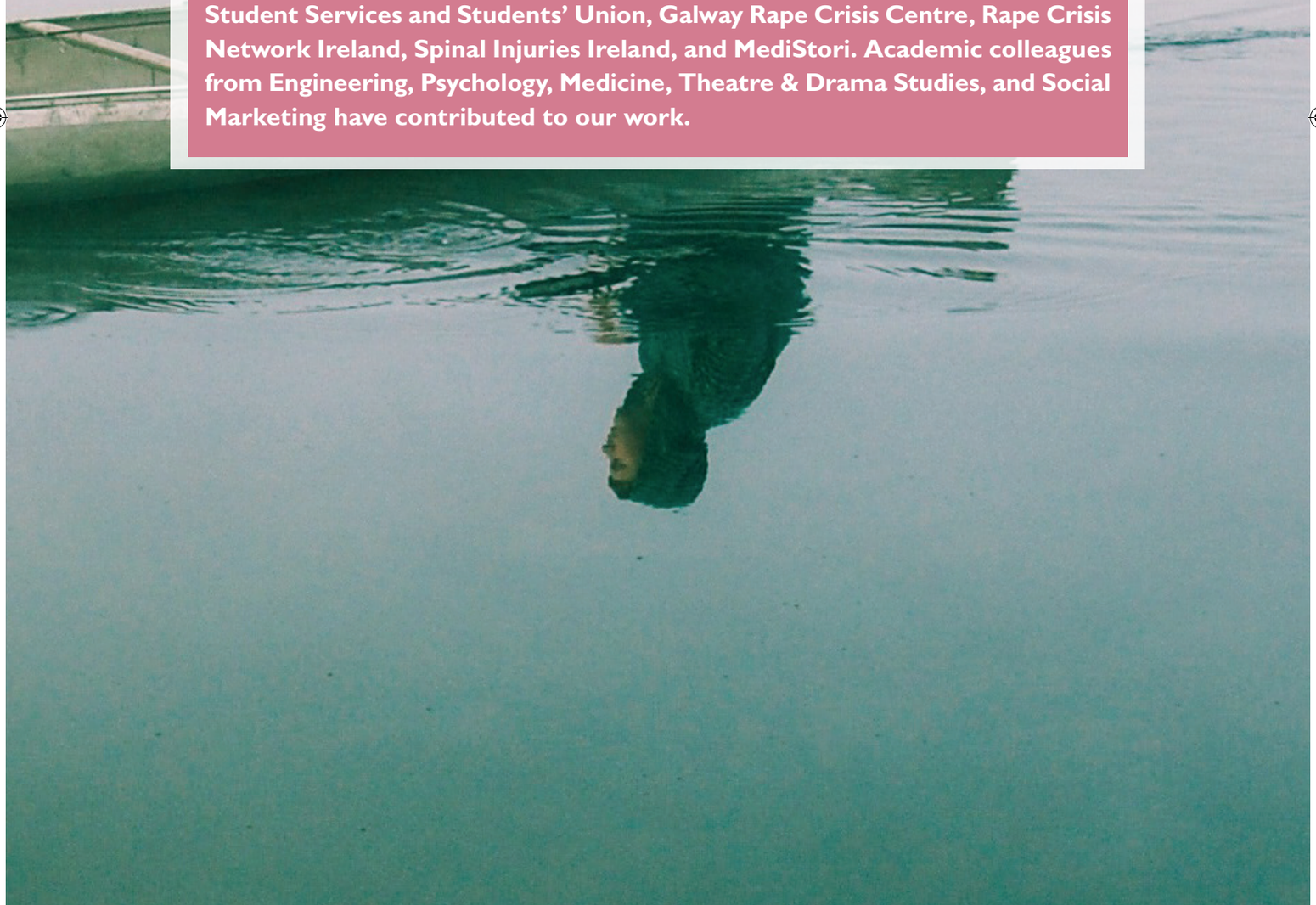
INCADDS

NUI Galway
OÉ Gaillimh

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.



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

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

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.

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.

- **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 'messer', '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,

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.

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 conductive 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.

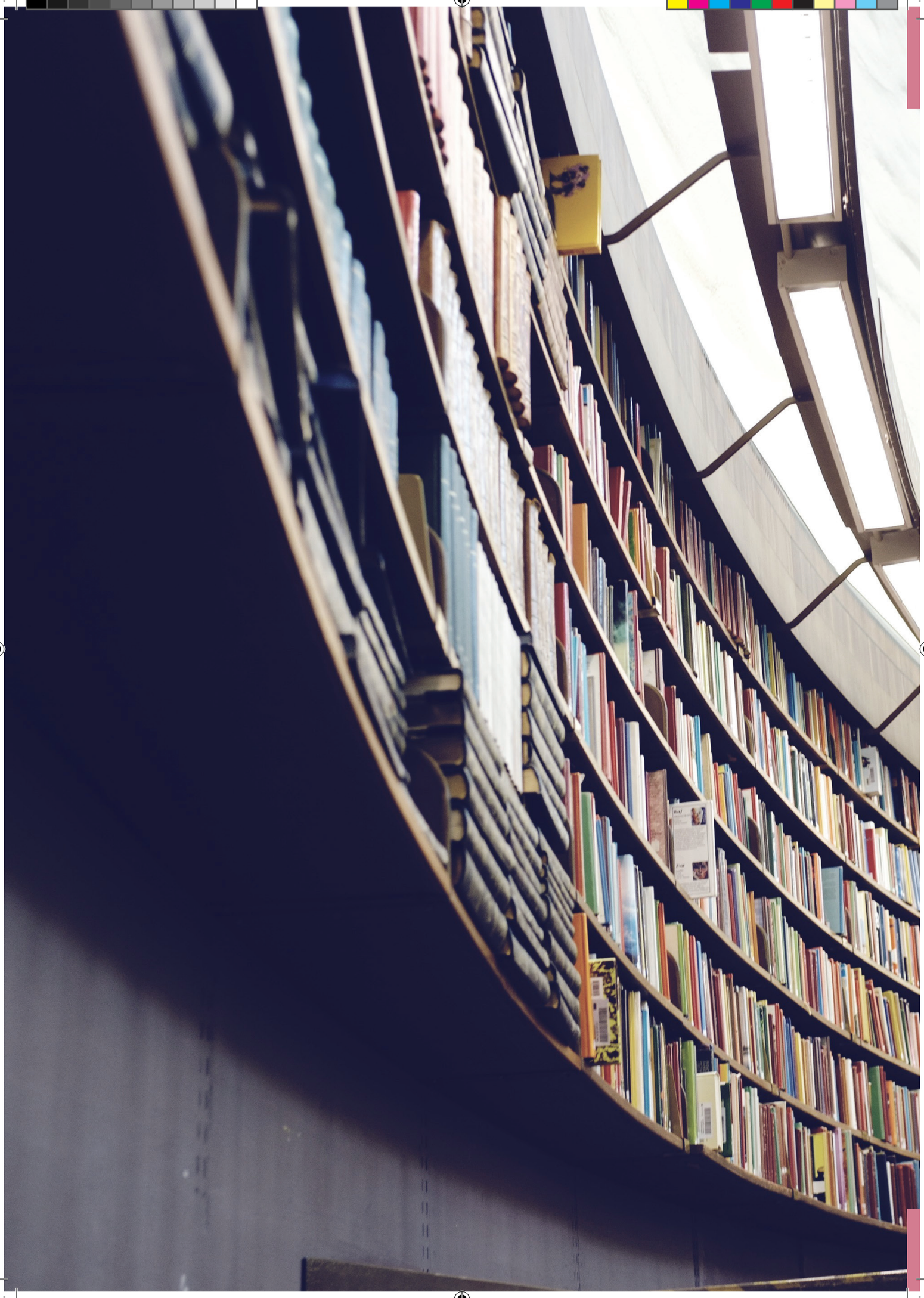
The findings are especially useful in showing how adaptation has developed over time for adults in mid-life. This is consistent with a life span approach in which adjustment to different life tasks proceeds over a long period. Nevertheless the experiences ranged across a wide age span, and from those 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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