



ADHDadultUK

Appendix II

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ADHDadultUK 2024 ‘State of the Nation’ Survey: Appendix II: Full Thematic Analysis

Thematic analysis of open-ended responses was performed using ‘Framework Analysis’ on the ‘any other comment’ section of the survey) which was provided by 756 respondents out of 1440 responses).

The following themes were identified.

1. Healthcare

1.1 Access to Diagnosis

Key Insight: Lengthy NHS wait times, and the fragmented integration of private diagnoses are creating significant hurdles for individuals seeking timely and effective ADHD care.

Findings:

- **NHS Delays:** Respondents widely reported extensive wait times for NHS ADHD assessments, often spanning multiple years. For many, these delays led to prolonged struggles with untreated symptoms, negatively impacting their mental health, relationships, and employment. Several respondents noted that they felt "lost in the system," with limited communication or updates on their referral status.
- **Private Diagnosis Concerns:** To circumvent NHS delays, many individuals sought private diagnoses. However, these were often perceived as less valid within NHS pathways, creating obstacles to accessing follow-up care or medication. Respondents described feeling penalized for pursuing private assessments, especially given the financial sacrifices often required to do so.
- **Lack of Knowledge Among GPs:** General practitioners (GPs), often the first point of contact for individuals seeking help, were frequently described as dismissive or ill-informed about ADHD. Many respondents reported being told ADHD was not a legitimate condition for adults or being referred to inappropriate services that did not address their needs.

Direct Quotes:

- *“I waited three years for an NHS appointment, only to be told I didn’t meet the criteria because my symptoms weren’t ‘severe enough.’”*
- *“I had to borrow money to go private, but now my GP refuses to prescribe medication based on that diagnosis. It’s devastating.”*
- *“My doctor told me ADHD doesn’t really exist in adults and that I just needed to ‘get more organised.’”*

Implications:

- Prolonged delays exacerbate symptoms and contribute to secondary issues, such as anxiety, depression, and financial instability.
- The lack of recognition for private diagnoses creates a two-tiered system that disadvantages individuals who cannot afford private assessments.
- Insufficient ADHD training for GPs limits their ability to identify ADHD symptoms and provide appropriate referrals, further delaying care.

1.2 Post-Diagnosis Support

Key Insight: The absence of structured, consistent post-diagnostic care leaves individuals feeling unsupported and uncertain about managing their condition.

Findings:

- **Lack of Continuity:** Many respondents reported a sharp decline in support after receiving their diagnosis. Once an initial medication plan was established, follow-up care was often non-existent. Respondents described being left to navigate their treatment and coping strategies independently, with little guidance or access to ongoing resources.
- **Inadequate Resources for Life Skills:** Respondents highlighted a need for holistic care that extends beyond medication, including access to therapy, coaching, and ADHD-specific strategies for managing daily life. Many expressed frustrations at being unable to access such resources through the NHS.
- **Confusion About Care Pathways:** A common theme was a lack of clarity about how to access support after diagnosis. Respondents described being passed between mental health services and primary care providers, with neither taking responsibility for ongoing care.

Direct Quotes:

- *“It felt like the system gave up on me after my diagnosis. They said, ‘Here’s your prescription, good luck,’ and that was it.”*
- *“I’ve had to figure everything out on my own—what to read, what tools to use, how to explain ADHD to my employer. There’s no roadmap.”*
- *“The lack of follow-up is shocking. I was diagnosed two years ago, and I haven’t seen a specialist since.”*

Implications:

- The lack of post-diagnosis support increases the burden on individuals, particularly those with co-occurring mental health conditions or complex life challenges.
- Without structured care, individuals are more likely to experience treatment noncompliance, unmanaged symptoms, and reduced quality of life.

1.3 Medication Availability

Key Insight: Disruptions in medication supply have a profound impact on individuals' ability to manage ADHD symptoms and maintain stability in their lives.

Findings:

- **Medication Shortages:** Respondents frequently mentioned difficulty accessing their prescribed ADHD medications, with many describing how shortages left them unable to function effectively. Some had to switch medications abruptly, leading to destabilizing side effects and reduced symptom control.
- **Communication Failures:** Many respondents reported a lack of transparency from pharmacies and healthcare providers about medication availability. This left individuals scrambling to find alternatives, often at their own expense.
- **Medication as a Lifeline:** For many, medication was described as a critical tool for maintaining employment, managing relationships, and fulfilling daily responsibilities. The disruptions caused by shortages were not only practical but also deeply emotional, as they undermined the stability that medication had provided.

Direct Quotes:

- *“Without my medication, I feel like my life is unravelling. I can’t concentrate, and I’m constantly overwhelmed.”*
- *“I’ve had to call five different pharmacies to find my prescription—it’s humiliating and exhausting.”*
- *“When my medication isn’t available, I can’t work. It’s as simple as that.”*

Implications:

- Medication shortages disrupt individuals' ability to function in critical areas of life, from work to family responsibilities.
- The lack of clear communication about supply issues creates unnecessary stress and forces individuals to navigate an already strained system.

2. Workplace and Educational Support

Workplace and educational challenges were a central theme in the survey.

Respondents highlighted significant struggles in environments where ADHD is often poorly understood, with insufficient accommodations and a lack of empathy for ADHD-specific needs. These challenges were particularly evident in two key areas: **Workplace Challenges** and **Education System Support**.

2.1 Workplace Challenges

Key Insight: Rigid workplace policies and the absence of ADHD accommodations contribute to job instability, increased stress, and lower productivity for individuals with ADHD.

Findings:

- **Lack of Accommodations:** Respondents frequently described workplaces as “ADHD-unfriendly,” with rigid schedules, strict deadlines, and minimal flexibility for adjustments. Commonly requested accommodations—such as quiet workspaces, flexible hours, or structured task support—were rarely provided.
- **Fear of Disclosure:** Many respondents reported reluctance to disclose their ADHD diagnosis due to fears of stigma or retaliation. Some described being dismissed or treated unfairly after disclosure, leading to mistrust of employers.
- **Burnout and Masking:** A recurring theme was the exhaustion caused by “masking” ADHD symptoms to meet neurotypical expectations. This led to burnout, reduced mental health, and job turnover.
- **Disciplinary Actions and Job Loss:** Several respondents recounted losing their jobs or facing disciplinary measures directly linked to their ADHD symptoms, such as missed deadlines or perceived disorganisation.

Direct Quotes:

- *“My boss didn’t understand why I needed flexible hours, even though ADHD makes mornings almost impossible for me.”*
- *“After I told my employer about my ADHD, I noticed I was being given fewer responsibilities as if I wasn’t capable.”*
- *“I work twice as hard as everyone else to hide my ADHD, but it’s exhausting and unsustainable.”*

Implications:

- The absence of accommodations exacerbates difficulties in navigating workplace expectations, leading to diminished job satisfaction, higher turnover, and poorer mental health.
- Fear of disclosure perpetuates stigma and prevents individuals from advocating for their needs, creating a cycle of unmet challenges.

- A lack of awareness among employers leaves many ADHD workers unsupported, negatively impacting productivity and morale.

2.2 Education System Support

Key Insight: Support for ADHD students in higher education is inconsistent, with postgraduate students facing significant gaps in accommodations.

Findings:

- **Inconsistent Accommodations:** While some undergraduate respondents described receiving support, such as extra time for exams or access to note-taking services, postgraduate students felt underserved. The structure of postgraduate education - characterised by long-term research and independent study - makes traditional accommodations insufficient.
- **Barriers to Success:** Respondents highlighted challenges in managing large, unstructured projects, such as dissertations or thesis research, due to difficulties with executive functioning, time management, and focus. Many noted that their academic institutions lacked the flexibility or resources to address these unique needs.
- **Stigma in Academia:** Several respondents shared experiences of being dismissed or misunderstood by academic staff, who often perceived their struggles as laziness or lack of discipline. This perpetuated feelings of inadequacy and alienation.
- **Impact on Mental Health:** The lack of effective accommodations and support systems contributed to heightened stress, anxiety, and, in some cases, academic withdrawal.

Direct Quotes:

- *“Undergrad support is okay, but PhD students are just left to sink or swim. There’s no recognition of how ADHD impacts long-term research.”*
- *“I need deadlines to stay on track, but my supervisors just expect me to figure it out on my own—it’s overwhelming.”*
- *“I was told that ADHD wasn’t a valid reason for an extension because it’s not a ‘real disability.’”*

Implications:

- Inadequate support in higher education, particularly at the postgraduate level, creates significant barriers to academic success for students with ADHD.
- A lack of understanding from academic staff contributes to stigma and mental health challenges, discouraging students from seeking help.
- The disconnect between ADHD needs and existing support systems limits opportunities for neurodiverse students to thrive in academia.

2.3 Intersection of Work and Education

Key Insight: Respondents transitioning from education to the workforce often face compounded challenges due to the lack of preparation and support in both environments.

Findings:

- **Workplace Readiness:** Students with ADHD often graduate without the skills or confidence needed to succeed in traditional work environments. This stems from insufficient preparation during their education, where accommodations are often removed upon entering the workforce.
- **Inadequate Career Support:** Many respondents felt that career services within educational institutions were not equipped to help neurodiverse individuals find ADHD-friendly workplaces or navigate disclosure and accommodation requests.
- **Lack of Transition Resources:** The abrupt shift from academia to employment left many individuals struggling to adjust, particularly as they faced environments that were less accommodating than their universities.

Direct Quotes:

- *“When I finished university, it was like the safety net disappeared. I had no idea how to cope in a workplace.”*
- *“Career services don’t talk about finding jobs where ADHD is accepted—they just tell you to practice interviews and apply.”*
- *“The transition from university to work was brutal. Everything was rigid, and I felt like I didn’t belong.”*

Implications:

- A lack of preparation for workplace environments increases the risk of job dissatisfaction and turnover for ADHD graduates.
- Career services that fail to address neurodiversity contribute to the cycle of underemployment among individuals with ADHD.

3. Social Stigma and Public Perception

Social stigma and public perception were central themes in the ADHDadultUK 2024 State of the Nation survey. Respondents reported experiencing stigma and misunderstanding in various settings, including healthcare, workplaces, educational institutions, and personal relationships. The lack of societal awareness about ADHD's complexity exacerbated these challenges, impacting individuals' mental health, self-esteem, and willingness to seek help. This section explores two critical sub-themes: **Misunderstanding and Dismissal** and **Need for Awareness**.

3.1 Misunderstanding and Dismissal

Key Insight: Dismissal and invalidation in social and healthcare settings lead to isolation, reduced self-confidence, and reluctance to seek support.

Findings:

- **Healthcare Setting Misunderstanding:** Respondents frequently reported that healthcare providers lacked understanding of ADHD, often dismissing their symptoms as personality traits, laziness, or a lack of willpower. Adults seeking diagnosis and treatment were particularly affected, as ADHD is still widely perceived as a childhood condition.
- **Social and Workplace Dismissal:** Many participants recounted instances where friends, family, or colleagues downplayed their struggles, accusing them of using ADHD as an excuse or exaggerating their challenges. Such attitudes fostered feelings of invisibility and frustration.
- **Impact on Self-Esteem:** The constant need to justify their condition to others negatively impacted respondents' self-worth and confidence. For some, the fear of being judged or dismissed prevented them from discussing their ADHD openly, perpetuating cycles of isolation and unmet needs.

Direct Quotes:

- *“Even my GP told me ADHD isn’t a real issue for adults—it was incredibly disheartening.”*
- *“People think I’m just lazy or forgetful, but they don’t understand how much effort it takes to get through the day.”*
- *“It’s exhausting having to prove my struggles are real when everyone assumes ADHD is just an excuse for being disorganised.”*

Implications:

- Misunderstanding and dismissal in healthcare settings delay access to diagnosis and treatment, leaving symptoms unmanaged.
- Social stigma prevents individuals from advocating for themselves, creating barriers to accommodations and support.

- A lack of recognition for the seriousness of ADHD leads to mental health deterioration, including increased anxiety and depression.

3.2 Need for Awareness

Key Insight: Public education campaigns could reduce stigma, dispel myths, and foster greater understanding of ADHD as a lifelong condition.

Findings:

- **Prevalence of Myths:** Respondents highlighted the persistence of stereotypes about ADHD, such as the belief that it is primarily a childhood disorder, that it only affects hyperactive boys, or that it is overdiagnosed. These misconceptions often trivialize the experiences of those living with ADHD.
- **ADHD as a Serious Condition:** Many participants felt that ADHD is not seen as a legitimate condition, particularly in adults. Respondents advocated for public awareness campaigns to highlight ADHD's complexity, including its impact on mental health, relationships, and employment.
- **Media Representation:** Several respondents noted that ADHD is often portrayed inaccurately in media, either as a minor inconvenience or as a personality quirk. They called for more authentic depictions to help normalize the condition and challenge harmful stereotypes.

Direct Quotes:

- *“People think ADHD is just about being hyper, but it affects every part of my life—work, relationships, even how I manage my emotions.”*
- *“I wish there were more public campaigns to show ADHD as a serious condition, not just something kids grow out of.”*
- *“The media needs to stop portraying ADHD as a joke—it’s a real condition with real consequences.”*

Implications:

- Persistent myths and stereotypes about ADHD perpetuate stigma, leading to a lack of empathy and support for individuals with the condition.
- Misrepresentation in media and public discourse undermines efforts to raise awareness and secure necessary accommodations in workplaces and educational settings.
- A lack of public understanding hinders advocacy for systemic changes, such as improved healthcare pathways and workplace policies.

3.3 The Ripple Effect of Stigma

Key Insight: The stigma surrounding ADHD has far-reaching consequences, impacting not only individuals but also the broader community.

Findings:

- **Impact on Relationships:** Respondents described how stigma strained relationships, as family members or partners often failed to understand the challenges posed by ADHD. This lack of support left individuals feeling isolated, even within their closest social circles.
- **Barriers to Advocacy:** The stigma attached to ADHD hindered collective advocacy efforts, as individuals were often reluctant to disclose their condition or participate in campaigns due to fear of judgment.
- **Intersection with Other Challenges:** For many, stigma compounded other issues, such as difficulties in accessing healthcare or securing workplace accommodations, creating a cycle of marginalization.

Direct Quotes:

- *“My partner still doesn’t understand how ADHD affects me—it’s like I’m fighting this battle alone.”*
- *“I want to advocate for better ADHD support, but I’m scared people will judge me if I speak out.”*
- *“Stigma makes everything harder—getting help, talking to your employer, even just explaining it to your family.”*

Implications:

- Stigma not only isolates individuals but also weakens broader efforts to improve ADHD support systems and societal understanding.
- Relationships suffer when loved ones dismiss ADHD-related struggles, further eroding mental health and resilience.
- Advocacy efforts require a united front, but stigma discourages individuals from participating, slowing progress toward systemic change.

4. Mental Health and Co-Occurring Conditions

Mental health challenges and co-occurring conditions were consistently highlighted in the ADHDadultUK 2024 State of the Nation survey. Respondents described how untreated ADHD exacerbates mental health struggles and contributes to the development of other conditions, such as anxiety, depression, and substance use disorders. These issues are explored in two critical sub-themes: **Mental Health Struggles** and **Substance Use and Other Comorbidities**.

4.1 Mental Health Struggles

Key Insight: Untreated or inadequately managed ADHD often leads to significant mental health challenges, including anxiety, depression, and suicidal ideation.

Findings:

- **Impact of Delayed Diagnosis:** Respondents frequently mentioned that delays in ADHD diagnosis left them dealing with untreated symptoms for years, contributing to chronic stress, anxiety, and depression. The lack of recognition for ADHD's role in these struggles resulted in misdiagnoses and ineffective treatment.
- **Emotional Toll of ADHD Symptoms:** Many participants highlighted how core ADHD symptoms, such as difficulty with focus, emotional regulation, and impulsivity, directly impact their mental health. The frustration of feeling "different" or "broken" often led to cycles of low self-esteem and self-doubt.
- **Inadequate Mental Health Services:** Respondents reported that traditional mental health services often failed to address the underlying ADHD that drives many of their struggles. General mental health professionals were perceived as lacking the training or expertise to identify and treat ADHD effectively.

Direct Quotes:

- *"I've spent years being treated for depression, but it wasn't until I was diagnosed with ADHD that everything made sense."*
- *"The constant struggle to meet basic expectations left me feeling like a failure—I was drowning in anxiety before my diagnosis."*
- *"Therapists didn't understand ADHD—they just told me to 'focus more' or 'try harder,' which only made things worse."*

Implications:

- The lack of timely ADHD diagnosis and specialized mental health care perpetuates cycles of untreated symptoms and worsening mental health.
- Misdiagnoses, such as depression or anxiety without addressing the underlying ADHD, lead to ineffective interventions, wasted resources, and prolonged suffering.

- Low self-esteem resulting from ADHD symptoms diminishes individuals' ability to advocate for themselves or seek further help.

4.2 Substance Use and Other Comorbidities

Key Insight: The presence of ADHD significantly increases vulnerability to substance use disorders, eating disorders, and self-harm, exacerbating the challenges faced by individuals.

Findings:

- **Substance Use as Coping Mechanism:** Respondents frequently described using alcohol, recreational drugs, or other substances to manage ADHD symptoms, such as hyperactivity, impulsivity, or emotional dysregulation. While some found temporary relief, these behaviours often led to additional health and social challenges.
- **Eating Disorders and Self-Harm:** For some, untreated ADHD symptoms manifest in harmful coping behaviours, such as binge eating or self-harm. These issues were often compounded by poor access to ADHD-informed care, leaving respondents without effective support.
- **Economic and Social Impact:** The financial and social consequences of these comorbidities were also noted, with respondents citing job losses, strained relationships, and financial instability as secondary effects of unmanaged ADHD and associated behaviours.

Direct Quotes:

- *"I started drinking just to quiet my thoughts—it was the only way I could get through the day before my diagnosis."*
- *"I didn't know why I was binge eating all the time until I realized it was my way of coping with ADHD."*
- *"Self-harm became my outlet for the frustration I felt because I couldn't control my impulses or emotions."*

Implications:

- Substance use and other harmful behaviours often develop as a direct result of untreated ADHD, highlighting the need for holistic care that addresses underlying conditions.
- Poor management of ADHD symptoms increases the likelihood of these behaviours escalating, creating additional barriers to stable employment, financial security, and personal well-being.

4.3 Broader Impacts of ADHD on Mental Health

Key Insight: The mental health consequences of untreated ADHD extend beyond individuals to their families, workplaces, and communities.

Findings:

- **Family Strain:** Respondents described how their struggles with emotional regulation, forgetfulness, or impulsivity created tension in relationships, often leading to feelings of guilt and shame.
- **Workplace Impacts:** Poorly managed ADHD symptoms, coupled with mental health challenges, led to job instability, with many respondents reporting frequent job changes or difficulties maintaining employment.
- **Community and Healthcare Costs:** Unaddressed ADHD and its associated mental health challenges contribute to broader societal costs, including increased reliance on healthcare systems and reduced workforce participation.

Direct Quotes:

- *“I feel like a burden on my family because they have to deal with the fallout of my ADHD.”*
- *“I’ve had to quit jobs because I couldn’t manage my symptoms, and it’s taken a toll on my mental health.”*
- *“The cost of not treating ADHD properly is huge—not just for individuals but for society as a whole.”*

Implications:

- Untreated ADHD has ripple effects that extend far beyond the individual, impacting families, workplaces, and broader communities.
- Addressing these challenges requires a systemic approach that recognizes the interconnectedness of ADHD, mental health, and societal outcomes.

5. Lack of Affordable ADHD Management Resources

The survey revealed that affordability is a significant barrier to effective ADHD management. Respondents highlighted the prohibitive costs of coaching, therapy, and other professional support, as well as their reliance on community-driven resources to fill gaps in formal services. This section explores two critical sub-themes: **Cost of Support Services** and **Reliance on Community Support**.

5.1 Cost of Support Services

Key Insight: High costs of ADHD-related services make effective management inaccessible for many individuals, particularly those on lower incomes.

Findings:

- **Financial Barriers:** Respondents frequently described the high cost of essential services, such as coaching, therapy, and specialized counselling. Many reported that these services were critical to their well-being but out of reach due to financial constraints, leaving them to navigate ADHD without adequate support.
- **Insurance Gaps:** Several participants noted that private health insurance often does not cover ADHD-related services, further limiting access. For those reliant on public healthcare, the lack of affordable options created a stark divide between those who could afford private care and those who could not.
- **Economic Inequality:** The financial burden disproportionately affected individuals from lower-income backgrounds, creating inequities in ADHD care. Respondents expressed frustration that effective management seemed to be a privilege reserved for wealthier individuals.

Direct Quotes:

- *“I know ADHD coaching would help me, but I just can’t afford it—it feels like only the rich get to thrive.”*
- *“Therapy is too expensive, and the NHS doesn’t offer anything beyond medication, so I’m stuck.”*
- *“I feel like I’m being punished for not being able to pay for the support I need.”*

Implications:

- The high cost of support services creates a two-tiered system where individuals with financial means access better care, while those without remain underserved.
- Without affordable options, individuals are more likely to experience unmanaged symptoms, reduced productivity, and poorer mental health outcomes.

5.2 Reliance on Community Support

Key Insight: In the absence of affordable formal services, individuals rely heavily on peer-led and community-driven resources, which offer valuable support but lack professional guidance.

Findings:

- **Online Communities as Lifelines:** Respondents described online forums, social media groups, and peer networks as vital sources of advice, solidarity, and coping strategies. These communities filled gaps left by inaccessible formal services, providing practical tips and emotional support.
- **Limitations of Peer Support:** While beneficial, community-driven resources often lack the personalized, evidence-based guidance that professional services can provide. Respondents noted that peer support was helpful for sharing experiences but insufficient for addressing complex or severe challenges.
- **Unregulated Information:** Some participants expressed concerns about the quality of advice in online communities, noting that misinformation or harmful practices could sometimes proliferate in unmoderated spaces.

Direct Quotes:

- *“The ADHD community on Facebook has been my lifeline, but it’s not a substitute for real help.”*
- *“I’ve learned more from Reddit than from any professional service I’ve been able to access.”*
- *“While the advice online is helpful, I still wish I could talk to an expert who understands ADHD.”*

Implications:

- The reliance on community support underscores the urgent need for accessible professional resources that can provide tailored, evidence-based care.
- While peer-led initiatives are valuable, their limitations highlight the importance of integrating professional oversight and guidance.



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**A charity for adults with
ADHD, run by adults with
ADHD.**

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