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COMMENTARY

FALLING THROUGH THE CRACKS

The toll of mis- and missed diagnosis in FASD and ADHD: A call to action

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Abstract

This commentary examines the widespread issue of mis- and missed diagnosis of fetal alcohol spectrum disorder (FASD) and attention-deficit/hyperactivity disorder (ADHD), with a particular focus on the disproportionate impact on Māori individuals and their whānau. Grounded in a Kaupapa Māori approach, this research integrates mātauranga Māori and lived experience to critically analyse the systemic barriers that prevent accurate identification and timely support for neurodivergent individuals. Drawing on academic literature and the lived experience of advocate and researcher Deb Cole, the report highlights the severe consequences of the mis- and missed diagnosis of FASD and ADHD, including increased vulnerability to mental health challenges, justice system involvement, and lack of access to essential services. The overlap in symptomatology between these conditions contributes to frequent diagnostic confusion, exacerbated by institutional inequities, under-resourced services, and the absence of culturally responsive assessment tools. This report issues an urgent call to action directed at policymakers, health professionals, educators, and the wider community. It demands the formal recognition of FASD as a disability in Aotearoa New Zealand and advocates for Kaupapa Māori-led diagnostic pathways and support systems. Furthermore, it calls for investment in Māori-led solutions that prioritise whānau-centred, culturally appropriate care. Without immediate systemic reform, individuals with FASD and ADHD—and their caregivers—will continue to fall through the cracks, perpetuating cycles of disadvantage and marginalisation. The time for change is now.

Keywords

ADHD, Arorereretini, FASD, Kanorau-ā-roro, misdiagnosis,
neurodivergence, neurodiversity, Te Iho Tātai-ā-Rongo

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Introduction

This commentary emerges from the findings of a summer student internship programme funded by Unitec's Tūāpapa Rangahau | Research and Postgraduate Office and supervised by its Ngā Wai a Te Tūī | Māori and Indigenous Research Centre. Grounded in Kaupapa Māori methodology, the research critically examined the mis- and missed diagnosis of fetal alcohol spectrum disorder (FASD) and attention-deficit/hyperactivity disorder (ADHD), highlighting the impact on individuals, whānau, and the broader socio-political landscape of health, education, and social services in Aotearoa New Zealand. The findings contribute to the growing discourse on neurodevelopmental conditions, particularly in the context of systemic inequities affecting Māori.

At the core of this research is Deb Cole (Ngāti Hine, Ngāti Kahu, Te Rarawa, Ngāi Takoto), a dedicated advocate, researcher, and caregiver with lived experience of the challenges surrounding FASD. A mother of five and kuia to 20 mokopuna, Deb's academic and advocacy work is deeply informed by her personal journey. More than two decades ago, four of her mokopuna arrived on her doorstep in a state of severe neglect. Two were later diagnosed with FASD—an experience that reshaped Deb's life and set her on a path of relentless advocacy for tamariki, whānau, and caregivers affected by the condition (Cole, 2021).

Deb's master's research, which examines the intergenerational impact of FASD on Māori whānau, has been instrumental in framing this study. Her work challenges systemic failures in the health, education, and justice sectors, where Māori with FASD are frequently misdiagnosed, underdiagnosed, or overlooked entirely. Through legal action and advocacy, Deb has successfully held health institutions accountable, ensuring that whānau voices are recognised as central to FASD care and decision-making. She has spoken at national forums, Waitangi Tribunal hearings (WAI 2575 and 2624; see Cole, 2021), and before community advocacy groups, sharing both her personal experiences and research-driven insights.

FASD and ADHD are prevalent neurodevelopmental conditions, yet many individuals remain undiagnosed or misdiagnosed, leading to inappropriate or insufficient support. It is estimated that between 3% and 9% of the general population live with FASD, and over 5% of the general population have ADHD (Clark et al., 2024; Popova et al., 2019; Young et al., 2016; Yousefi & Chaufan, 2022). It is estimated that between 45% and 75% of those diagnosed with FASD have a co-occurring diagnosis of ADHD (Chasnoff et al., 2015; Clark et al., 2024; Ehlert, 2017; FASD United, 2016; Ware et al., 2014) and that 86.5% of those with FASD are either misdiagnosed or underdiagnosed (Chasnoff et al., 2015). A study of youth in a youth detention centre, the first study of its kind, found an FASD prevalence rate of 36%, and 89% of those youth had one severe neurodevelopmental domain impairment (Bower et al., 2018). The overlap in symptoms between these conditions contributes to frequent diagnostic confusion, particularly in health and education settings that lack awareness and understanding of neurodiversity. For Māori, these issues are compounded by systemic inequities, including institutional racism, under-resourced services, and a lack of culturally informed diagnostic tools.

The research reported here was framed within a Kaupapa Māori approach, which positions whānau, whakapapa, and tino rangatiratanga as central to understanding and addressing FASD and ADHD. The study advocates for Māori-led solutions that integrate mātauranga Māori, ensuring that tamariki and rangatahi receive timely, culturally appropriate diagnosis and support. By foregrounding lived experience, this research highlights the urgent need for systemic change, focusing on equitable access to resources, policy reform, and whānau-driven models of care.

This report is primarily authored by Deb, with structural and editorial support from Dr Byron Rangiwai, an experienced Kaupapa Māori researcher. His role in this study has been to support the development of the introduction and conclusion and prepare the research for publication. However, the essence of this work remains deeply personal—it reflects Deb's lived realities, her academic journey, and her unwavering commitment to advocating for those affected by FASD and ADHD. Furthermore, Byron lives with ADHD and has published a paper that seeks to reframe ADHD from a Māori perspective through the metaphor of the pīwakawaka, an energetic and playful bird that is significant in Māori society (Rangiwai, 2024). Through our research, we call for a fundamental shift in policy and practice, ensuring that Māori with neurodevelopmental conditions, and their whānau, are no longer left navigating these challenges alone.

How does mis- and missed diagnosis of FASD and ADHD affect individuals and their caregivers?

Misdiagnosis occurs when someone presents with symptoms but is incorrectly diagnosed with a condition; missed diagnosis is when the symptoms are missed altogether (Crowe & Harris, LLP, 2022). Mis- and missed diagnosis can profoundly impact quality of life, leaving many individuals with significant functional challenges without access to essential, coordinated, multidisciplinary support such as daily living assistance, housing, employment, and mental healthcare (Crawford et al., 2020; McLachlan et al., 2020; Olson & Sparrow, 2021). This lack of support places a significant burden on whānau and caregivers, often leading to strained relationships and increasing the vulnerability of individuals with FASD to mental health issues, interactions with the justice system, and incarceration (Disability Rights Commissioner and Children's Commissioner to the Prime Minister, 2021; Gibbs, 2022; Jonsson, 2019). Caregivers frequently experience grief, isolation, inadequate support and information, difficulties in accessing resources, and financial strain (Crawford et al., 2020; Harding et al., 2022; Mukherjee et al., 2013; Popova et al., 2023). Additionally, they often find themselves in an ongoing battle to secure essential services while facing misunderstanding, stigma, and blame (Flannigan et al., 2022; Hamilton et al., 2020).

What is the relationship between FASD and ADHD?

FASD and ADHD are two distinct neurodevelopmental conditions with overlapping symptoms. Research suggests that approximately 73% of individuals with FASD may also meet the criteria for ADHD; however, the disorders differ in their underlying causes, behavioural patterns, symptom profiles, and treatment approaches (Copley, 2023; Ehlert, 2017; FASD United, 2016; Young et al., 2016). Due to their shared characteristics, such as difficulties with attention and impulse control, they are often mistaken for one another. These challenges frequently contribute to struggles in academic and social settings, as well as in diagnostic settings.

What is FASD?

FASD is a broad term encompassing a spectrum of negative effects resulting from prenatal alcohol exposure (PAE; Espiner et al., 2022; Mattson et al., 2019). These effects are lifelong conditions resulting in significant neurobehavioral and cognitive impairments, as well as challenges with adaptive behaviour, executive functioning, memory, attention, and language (Mattson et al., 2019). Awareness and understanding of the disorder remains limited among professionals, service providers, and the public (Flannigan et al., 2020). FASD is also called the "invisible disability" as over 80% of those with the condition have no discernible facial abnormalities (Bashista, 2022) and, as such, is one of the most underdiagnosed and misdiagnosed conditions (Chasnoff et al., 2015; Chudley, 2022; Clark et al., 2024; Rockhold et al., 2024; Young et al., 2016).

FASD can be separated into two classifications: primary disabilities and secondary disabilities. Primary disabilities refer to those conditions that a child is born with as a consequence of PAE. These conditions cause permanent brain damage that results in impaired neurocognitive and adaptive functioning accompanied by significant developmental and behavioural challenges. Secondary disabilities, meanwhile, are not present at birth but occur as a result of the primary disabilities (Bagshawe et al., 2023). These include mental health problems and can lead to incarceration, poor academic achievement, addictions, and unemployment (Streissguth et al., 1996).

In their seminal paper on the secondary disabilities of those who live with FASD, Streissguth et al. (1996) describe a set of important protective factors to mitigate the onset of secondary disabilities, which is still quoted today. The most important protective factor is an early and accurate diagnosis, preferably before age six. This is followed with immediate appropriate resources and support structures for the individual and their carers. Finally, the individual needs to have a stable long-term home that is free from violence and substance abuse.

What is ADHD?

ADHD is a common neurodevelopmental disorder affecting over 5% of children and adolescents (Salari et al., 2023; Shah & Suresh, 2024; Young et al., 2016) and characterised by patterns of age-inappropriate levels of inattention, hyperactivity, and impulsivity that interfere with development and functioning (FASD United, 2016; Rosso et al., 2023). The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; American Psychiatric Association [APA], 2013) outlines the criteria for an ADHD diagnosis, which include a persistent pattern of inattention and/or hyperactivity-impulsivity (six or more symptoms for <17 yrs; five or more for ≥17 yrs) for at least six months, present in multiple settings (home, school, work), interfering with the quality of school work and social interactions (see also FASD United, 2016; Shah & Suresh, 2024). ADHD often emerges in childhood and significantly impacts cognitive, academic, behavioural, emotional, and social functioning. It is also associated with a high risk of comorbid psychiatric conditions and severe functional impairments (Shah & Suresh, 2024; Young et al., 2016).

Overlapping symptoms

FASD and ADHD share overlapping symptoms but are distinct conditions. About 73% of those diagnosed with FASD may also have ADHD, and the shared symptoms contribute to frequent diagnostic confusion (Copley, 2023; Ehlert, 2017; FASD United, 2016; Young et al., 2016). Both disorders are characterised by difficulties in attention and impulse control, often leading to poor academic and social performance.

Children with either condition may struggle with sustained attention, exhibit impulsive behaviour, and experience challenges in task completion. These shared traits frequently result in children with FASD being misdiagnosed with ADHD, particularly since ADHD is more widely recognised and understood by clinicians and educators.

Behavioural issues such as emotional dysregulation, inattentiveness, daydreaming, and hyperactivity are hallmark features of both disorders, contributing to functional difficulties in school and social settings. Additionally, studies have shown significant overlap in diagnostic criteria, with many children with FASD meeting the criteria for ADHD (Chasnoff et al., 2015; Ehlert, 2017). Understanding these differences is crucial for ensuring accurate diagnosis and appropriate interventions. Mis- and missed diagnosis of these conditions can have profound implications for individuals, families, and society, often resulting in inadequate support, stigmatisation, and poor long-term outcomes.

Differences between FASD and ADHD

FASD and ADHD differ significantly in their causes, cognitive profiles, behavioural phenotypes, and responses to stimuli, despite sharing some overlapping features. FASD is caused by PAE, making it an environmentally driven condition (Popova et al., 2023). In contrast, ADHD is a neurodevelopmental disorder with many causes, including genetic and environmental factors, but it is not directly linked to PAE. Unlike ADHD, which has well-established diagnostic criteria and extensive treatment guidelines (APA, 2013; Ergun et al., 2021; Ware et al., 2014; Young et al., 2016), FASD lacks a unified diagnostic framework.

The cognitive impairments associated with FASD are broader and more severe than those typically observed in ADHD (Popova et al., 2023). FASD often results in deficits in verbal abilities, perceptual reasoning, working memory, processing speed, and overall adaptive functioning. Children with FASD also struggle to switch attention between tasks and can become overwhelmed in environments with multiple stimuli.

ADHD is the most common psychiatric disorder diagnosed in children with PAE worldwide, at a rate of 48% (Young et al., 2016). ADHD is associated with deficits in executive functioning, such as inattention, hyperactivity, and impulsivity, but the cognitive impairments are generally narrower in scope (Mattson et al., 2019). Additionally, children with FASD often daydream due to overstimulation, whereas children with ADHD tend to daydream due to understimulation, reflecting distinct cognitive challenges in each condition (Kooistra et al., 2010).

Behaviourally, individuals with FASD or ADHD exhibit different patterns. Children with FASD are more vulnerable to social difficulties, such as susceptibility to peer pressure, confabulation, stealing, and challenges recognising social cues (Chasnoff et al., 2015). They often display poor social judgement, struggle to predict consequences, and face challenges forming positive peer relationships. These behaviours stem from neurodevelopmental impairments and are less common in ADHD. On the other hand, ADHD is primarily characterised by inattention, hyperactivity, and impulsivity without the broader spectrum of behavioural issues seen in FASD.

There are significant gaps in the screening and assessment tools available for FASD (Chasnoff et al., 2015). For instance, existing screening tests often fail to differentiate FASD from ADHD, leading to misdiagnoses. While children with ADHD typically have the potential to develop adaptive skills (everyday life functioning) over time, children with FASD face greater challenges in this area and require intensive, tailored support to make progress (Lambie, 2020). In their study, Kooistra et al. (2010) found that rather than being a form of ADHD, FASD has behavioural traits that are distinct from it.

Another key distinction lies in how children with FASD and ADHD respond to stimuli. Children with FASD are particularly susceptible to overstimulation, showing significant variability in performance in fast-paced environments. Conversely, children with ADHD tend to struggle in understimulated settings, driven by a need for higher levels of stimulation. These differences in responses to stimuli can help clinicians differentiate between the two conditions and guide tailored approaches to diagnosis and treatment (Kooistra et al., 2010).

Discussion

The quality of life of individuals with FASD and/or ADHD is significantly impacted by misdiagnosis, missed diagnosis, and the availability of support services. Popova et al. (2023) report that longitudinal studies consistently show that adverse outcomes are more likely when such services are lacking. Addressing postnatal environmental exposures and opportunities can mitigate secondary disabilities (Streissguth et al., 1996). According to Flannigan et al. (2020), "There is a critical and timely need for increased research and targeted service delivery during this life stage and to provide wraparound supports for individuals with FASD who may otherwise lack resources and supports to promote healthy outcomes" (p. 2425).

Regarding mortality, Thanh and Jonsson (2016) found the average life expectancy for individuals with FASD to be 34 years, with 44% of deaths attributed to external causes, including suicide (15%) and accidents (14%). Those also diagnosed with ADHD have a higher mortality than their non-ADHD counterparts due to unnatural causes like suicide, injury, and poisoning (Catalá-López et al., 2022; Li et al., 2024).

Mis- and missed diagnosis further exacerbates the problem, leaving many individuals with significant functional deficits without the benefits of coordinated, multidisciplinary support like daily living assistance, housing, employment, and mental healthcare (Crawford et al., 2020; McLachlan et al., 2020; Olson & Sparrow, 2021). This places an immense burden on whānau and caregivers, often resulting in relationship breakdowns and leaving individuals with FASD more vulnerable to mental health issues, encounters with the justice system, and incarceration (Disability Rights Commissioner and Children's Commissioner to the Prime Minister, 2021; Gibbs, 2022; Jonsson, 2019).

Finally, mis- and missed diagnosis not only impacts the person living with FASD—their caregivers are also significant victims, along with the wider society. Caregivers often experience loss and grief, isolation, a lack of support and accurate information, difficulty accessing resources, and financial stress (Crawford et al., 2020; Harding et al., 2022; Mukherjee et al., 2013; Popova et al., 2023). They often have to constantly advocate for essential services while facing misunderstanding and blame (Flannigan et al., 2022; Hamilton et al., 2020).

These challenges negatively impact caregivers' and families' functioning and quality of life (Harding et al., 2022; Popova et al., 2023) and create additional stress from navigating interpersonal relationships and systemic barriers (Harding et al., 2022; Petrenko et al., 2019). Furthermore, caregivers of individuals with FASD experience stressors that are often more severe compared to those caring for other disability populations (Flannigan et al., 2022).

In June 2024, the New Zealand Institute of Economic Research (NZIER, 2024) estimated the cost of alcohol harm to the New Zealand economy to be $9.1 billion, with over half of that, $4.8b, associated with FASD. NZIER concluded that "the true cost of alcohol harm may be considerably higher than existing evidence can show" (p. vii). Successive governments have continued to ignore the enormity of alcohol harm and the FASD epidemic, refusing to categorise FASD as a disability and failing to dedicate funding and resourced pathways for lifetime support for those who live with FASD and their whānau/caregivers. Currently, over 80% of those diagnosed with FASD and those who care for them are disqualified from receiving vital, immediate, and comprehensive support. This must change—now.

While there are no figures for the estimated cost to the New Zealand economy of harms associated with ADHD, imagine the savings if the government took these harms seriously and worked to address them. A recent US study found the annual costs associated with ADHD to be US$19.4 billion among children (5–11) and US$13.8 billion among adolescents (12–17) (Schein et al., 2022).

Conclusion and call to action

The mis- and missed diagnosis of FASD and ADHD creates profound and lasting consequences for individuals with the conditions, their caregivers, and society. Without timely and accurate identification, those affected are denied essential resources, leading to severe functional impairments, mental health challenges, and increased interactions with the justice system. Caregivers, too, bear the weight of these failures, often facing financial strain, emotional exhaustion, and systemic barriers in their advocacy for support.

For Māori, these challenges are further compounded by institutional inequities, a lack of culturally responsive diagnostic frameworks, and an ongoing struggle for recognition within the health, education, and social service systems. The research reported here was grounded in a Kaupapa Māori approach and highlights the urgent need for a shift in thinking—one that prioritises Māori-led, whānau-centred solutions, integrating mātauranga Māori to ensure culturally appropriate, timely, and effective interventions.

The economic burden of these conditions is staggering. The estimated cost of FASD-related harm in New Zealand alone is $4.8 billion annually. Despite the overwhelming evidence supporting early diagnosis and comprehensive support as protective factors, the government has still not categorised FASD as a disability, denying individuals and their whānau access to vital services. This leaves families to navigate complex and indifferent bureaucratic structures with minimal assistance. The emotional, financial, and social toll on caregivers is immense, highlighting the urgent need for systemic change. Addressing these issues proactively—through better screening, diagnosis, intervention, education, and wraparound support—would not only reduce this financial strain but, more importantly, improve countless lives.

Our call to action is clear. Māori communities and leaders must continue demanding the formal recognition of FASD as a disability and work towards strengthening Kaupapa Māori-informed education and diagnostic pathways. Developing Māori-led wraparound services will ensure culturally grounded care that meets the needs of individuals and their whānau. Policymakers must take immediate steps to officially recognise FASD as a disability and implement policies co-designed with Māori experts, those who live with FASD, and those who support and care for them, to ensure culturally safe diagnosis, treatment, and support. Urgent funding must be allocated towards Kaupapa Māori health models to address the specific needs of neurodivergent individuals. Researchers and academics must prioritise Māori-led research on FASD and its impact within Māori communities while also investigating the long-term consequences of mis- and missed diagnosis. Decolonising diagnostic frameworks in mental health and neurodevelopmental research is essential to achieving more equitable outcomes.

The wider public also has a role to play in addressing stigma and misinformation surrounding FASD and ADHD. Understanding that the societal impacts of FASD and ADHD are not due to "bad parenting" but rather systemic failure is crucial in shifting public perceptions. Advocating for equitable access to diagnosis, treatment, and lifelong support will ensure that individuals and their caregivers are no longer excluded, ignored, or dismissed. Supporting whānau and caregivers through increased awareness, community engagement, and advocacy will create a society of tolerance and kindness where those with neurodevelopmental conditions receive the respect and support they deserve, and whānau are strengthened.

The failure to properly diagnose and support individuals with FASD and ADHD is not just a medical oversight—it is a human rights issue. Ensuring accurate diagnosis, appropriate intervention, and culturally responsive care is essential for the well-being of individuals, families, and future generations. The time for change is now.

Glossary

Kaupapa Māori	research approach that is informed by Māori philosophy and principles and is by Māori for Māori
kuia	grandmother
Māori	Indigenous peoples of New Zealand
mātauranga Māori	Māori knowledge
mokopuna	grandchildren
pīwakawaka	New Zealand fantail, *Rhipidura fuliginosa*
rangatahi	youth
tamariki	children
tino rangatiratanga	self-determination
whakapapa	genealogy
whānau	family

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