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Essay topic - 'Seeing the whole person beyond the diagnosis'

Beyond the Diagnosis: A Bridge to Care or a Pathway to Punishment?

By Dr Mahatia Minniecon

To go beyond the diagnosis is to ask what it does in the world. A diagnostic label is never neutral; it shapes how a child is seen, managed, and responded to by systems of health, education, welfare, and justice. This reflective essay draws on lived experience to consider the ethical consequences of diagnosis for Aboriginal children and families. For Aboriginal families, this ethical weight cannot be separated from history. If our history is understood as a nervous system shaped by sustained threat: by dispossession, forced child removal, and repeated loss of safety, then intergenerational trauma is not inherited pathology, but unresolved activation carried forward when repair was never possible. Diagnoses such as Fetal Alcohol Spectrum Disorder (FASD) do not arise in isolation, but within bodies, families, and communities already shaped by cumulative stress. Beyond the diagnosis lies a responsibility to ensure that naming difference becomes the beginning of care, not another mechanism of exclusion.

When I hear the words *"suspected Fetal Alcohol Spectrum Disorder,"* my body responds before my mind does.

There is a tightening in my chest, a heaviness behind my eyes, a recognition that these words carry far more than clinical meaning. FASD is never just a medical term. It holds stories about how a child came to be, what their brain has survived, and how the world is likely to respond to them next.

For me, this diagnosis echoes through generations.

I am Aboriginal, and like many Aboriginal families, my own family story is shaped by the enduring impacts of child removal, foster care, and kinship responsibility. This is not unusual where I come from; it is how our families have survived when systems fractured us. My responsibility is to interrupt a cycle of systemic, transgenerational trauma and to keep mob together when institutions have repeatedly failed.

So when I hear the words *"suspected FASD,"* I do not just hear a diagnosis. I hear history speaking through one small child.

I see a grandmother shaped by trauma.
I see a mother shaped by survival.
I see a pregnancy lived inside stress and instability.
And I see a developing brain doing everything it could to adapt.

FASD does not begin with alcohol. It arises within lives shaped by colonisation, racism, poverty, and unresolved grief, conditions that make substance use a means of coping rather than moral failure. Stripped of this context, the diagnosis risks turning injury into blame.

Once the child is born, the narrative narrows.

The mother is judged.
The baby is measured.
The brain is assessed.
The history disappears.

What remains is clinical language, *executive dysfunction, impulsivity, emotional dysregulation*. These terms describe behaviour, but not meaning. Beneath them is a nervous system that learned early how to survive in an unpredictable world.

The behaviour of a child close to me tells a story words cannot yet tell.

When he melts down, his nervous system is overwhelmed.
When he reacts quickly, his brain struggles to slow itself.
When he cannot remember instructions or consequences, it is not because he does not care, it is because memory, sequencing, and impulse control are precisely the domains most affected by prenatal injury.

Seen this way, behaviour is not something to correct.
It is something to understand.

Yet systems do not speak the language of nervous systems.
They speak the language of rules.

Children like the one close to me are placed into environments that demand compliance from brains that cannot always provide it, classrooms that are loud and unpredictable, routines that

shift without warning, responses that escalate rather than soothe. When these children fail to meet expectations, they are punished for the very adaptations that once helped them survive.

This is how trauma becomes criminalised.

The evidence confirms what families already know. In a representative study of adolescents in youth detention in Western Australia, 36% were diagnosed with FASD, and 89% had severe impairment in at least one neurodevelopmental domain, despite most never having been diagnosed previously (Peadon et al. 2018). Seventy-four per cent of those assessed identified as Aboriginal, highlighting how deeply this pathway intersects with colonisation, poverty, and systemic inequity (Peadon et al. 2018).

These young people were not born destined for prison.
They were born with brains that needed understanding, and grew up in systems that offered control instead.

Even access to diagnosis is often blocked.

In Australia, many FASD diagnostic pathways require documented evidence of alcohol exposure during pregnancy. For children separated from their birth families, including adopted children and those in kinship or foster care — this evidence may never exist. Mothers may be unavailable, traumatised, or fearful of disclosure; records may be incomplete or absent. As a result, many children with neurodevelopmental profiles consistent with FASD are excluded from diagnosis, disability funding, and early intervention (NACCHO 2024).

No documentation means no diagnosis.
No diagnosis means no support.
No support means behaviour is treated as choice rather than disability.

This is how children fall through the gaps.

Before applying a diagnostic label to any marginalised child, we must ask harder questions.

How will this diagnosis improve this child's life?
What doors will it open and which might it quietly close?
Will it bring protection, or will it mark the child as a problem in systems already primed to exclude them?

A diagnosis should be a bridge to care, not a pathway to punishment.

Beyond the diagnosis, the child close to me is not a list of deficits. He is a body learning how to feel safe and a brain still making sense of the world. He is a child whose story began long before anyone wrote his name in a file.

Families who open their hearts and homes to children shaped by trauma and prenatal injury are doing extraordinary work. They are co-regulating nervous systems wired for danger, often with limited respite and inadequate support. They need schools that adapt rather than exclude, services that collaborate rather than blame, and systems that recognise lifelong need rather than responding only in crisis.

To go beyond the diagnosis is to return to the ethical question with which we began: what does this label do in the world? If our collective history has functioned like a nervous system held in survival for generations, ethical care requires more than naming injury. It requires creating the conditions for safety, regulation, and repair.

The child close to me does not need to be fixed.
His brain is not broken, it is shaped by what it has endured.
What he needs is consistency, protection, and environments that adjust to him as a whole person, rather than expecting him to adapt to systems that were never designed for his brain to thrive.

That is what it truly means to go beyond the diagnosis.
And that is the future I am fighting for — for this child, and for every Indigenous child whose story is bigger than a label.

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