The Paediatric Society of New Zealand
Te Kāhui Mātai Arotamariki o Aotearoa

NZCYCN
New Zealand Child & Youth Clinical Network

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PSNZ Paediatric Neurodevelopment Network's Submission on the Revitalised FASD Strategic Action Plan

Te Kāhui Mātai Arotamariki o Aotearoa | The Paediatric Society of New Zealand's Paediatric Neurodevelopment Network welcomes the Ministry's renewed focus on addressing Fetal Alcohol Spectrum Disorder (FASD) and acknowledges the progress made in recent years. We support the intent, kaupapa, and vision underpinning the draft Strategic Action Plan, especially its whole-of-life course approach, commitment to a joined-up cross-agency response, and acknowledgement of the lived experience of whānau.

One central concern from our members is that developing a disease-specific diagnostic pathway for FASD could unintentionally overshadow other neurodevelopmental conditions with equally complex and pressing needs. While early and accurate diagnosis is important — both for understanding and validating a child's experience — the group strongly reinforced that **access to services and support must be guided by functional need, not diagnosis alone**. There was a shared view that resourcing and system design should reflect the real-world challenges whānau face, regardless of the diagnostic label attached.

However overall, the plan's intent and the values of our clinical community are aligned, and this submission brings together feedback from members of the Paediatric Neurodevelopment Network, a cross-disciplinary group of clinicians from across Aotearoa.

While the vision and direction are well supported, the plan lacks clarity in key areas and requires more operational detail to give confidence it can be realistically delivered. We believe **workforce capacity and system resourcing** will be critical in ensuring its success.

The following sections provide structured feedback on each outcome area, highlighting what's positive, where the gaps are, and what changes would help make the plan truly impactful.

Outcome one: Prevention

The Network supports the overall intent of this outcome and welcomes the emphasis on reducing alcohol-exposed pregnancies and tackling stigma. However, members felt the

approach needs to go further – focusing less on awareness alone and more on sustained behaviour change, system-level enablers, and equitable access to prevention tools.

Key gaps and suggestions:

- **Behavioural change focus *(Related to Priority Action 1.1)*:**
  The language in this section would benefit from refinement to ensure it avoids stigma and individual blame. If the term "screening" is used, it should be clearly defined as a supportive, consent-based process, and not imply judgement or surveillance of pregnant individuals. Rather than focusing solely on awareness, prevention efforts should aim for measurable, population-level shifts in alcohol use, achieved through long-term, inclusive campaigns that promote **alcohol-free pregnancies as a shared responsibility** — supported by whānau, communities, and systems.
- **Broader scope for alcohol reduction policy *(Related to Priority Action 1.2)*:**
  Policy efforts to reduce alcohol harm should target not just children's exposure but community-wide exposure to alcohol marketing, which normalises consumption and undermines prevention efforts at every level.
- **Contraceptive access and education *(Related to Priority Action 1.3)*:**
  The high rate of unplanned pregnancies in Aotearoa (compared to Australia and the UK) contributes significantly to unintentional alcohol exposure. Prevention efforts must include **universal, equitable access to contraception**, sexual health services, and inclusive, trauma-informed, culturally appropriate education – especially in high-risk communities.
- **Action point 1.4: Aotearoa New Zealand FASD messaging and branding:**
  Needs more clarity – members were unaware of what this means.
- **The role of social determinants:**
  Members highlighted that effective prevention must go beyond individual behaviour change and acknowledge the broader **social determinants of health** — including poverty, housing, access to healthcare, and systemic inequities. Preventing alcohol-exposed pregnancies is a **collective responsibility**, requiring action at whānau, community, and policy levels.

Outcome two: Early Intervention

This outcome is critical, and the Network strongly supports early access to assessment and support. However, the current wording is vague and lacks the detail needed to give confidence that delivery will be achievable, equitable, or consistent nationwide.

Key gaps and suggestions:

- **Terminology clarity:**
  The term 'screening' in the vision statement is problematic and causes concern. We recommend reframing this as "identification of prenatal alcohol exposure and

neurodevelopmental risk" to better reflect clinical practice and avoid unintended consequences of inappropriate screening.

- **Pilot clarity and scaling (Related to Priority Action 2.1):**
  The NASP pilot and other initiatives referenced are not clearly described. The plan should clarify where pilots are located, what models are being tested, and how learning will inform national rollout. Many of our members have seen pilots come and go and are keen to clarify how this pilot will be funded and resourced for ongoing impact. Any pilot programme must be integrated within the broader neurodevelopmental assessment ecosystem to avoid fragmentation or inequity of access.
- **Broaden the support structure (Related to Priority Action 2.3):**
  Appropriate interventions need to be supported through a multi-agency approach as this reaches further than health services alone, e.g. education, midwifery, child protection, housing, and social services.
- **Referral and diagnostic pathways (Related to Priority Action 2.2 and 2.4):**
  The plan references pathway redesign but lacks concrete actions. Existing CDS and Gateway pathways vary significantly. Diagnostic pathways should be standardised and supported by regional hubs or telehealth models to provide access to specialist advice.
- **Workforce and capability (Linked to Outcome 6, Workforce):**
  Assessment requires high clinical skill, training, and interdisciplinary collaboration. Significant investment is needed in workforce development to make this a reality.
- **Integration with other neurodevelopmental conditions**
  Members emphasised that **FASD should not be siloed** from other neurodevelopmental conditions. A tiered diagnostic and support framework that allows FASD to sit alongside ADHD, ASD, and other developmental differences will better reflect the real-world complexity of tamariki needs, avoid duplication, and help to reduce access inequities.

Outcome three: Life Transitions

The Network supports the intention to better support transitions across the life course, particularly between services, settings, and life stages. However, the actions under this outcome are somewhat high-level and underdeveloped. To support this section, members need more specific information and clear outlines of what's involved.

Key gaps and suggestions:

- **Lead agency appropriateness (Related to Priority Action 3.1):**
  Currently, the Ministry of Health is listed as lead, but in many cases transitions are more appropriately led by Education, Oranga Tamariki, or Whaikaha. We recommend a **cross-agency** lead structure.
- **Clarify transitions scope and resourcing (Related to Priority Action 3.2):**
  Transition is not just a health issue. Clear milestones and funding to support

successful transitions between school, employment, health and justice services are needed.

Outcome four: Life Course Support

This outcome is essential to a genuine life-course approach, and the Network supports the vision of wraparound, sustained support for individuals and whānau affected by FASD. However, current diagnostic and funding structures do not reflect this aspiration.

Key gaps and suggestions:

- **Formal recognition of FASD as a disability (Related to Priority Action 4.1 and 4.2):** Without this, many families remain unable to access the Disability Allowance or relevant support. FASD should be recognised as a standalone disability, with funding and service eligibility following functional needs. This would support access to Ministry of Health-funded disability support and alignment with Whaikaha policy settings.
- **Collaborating on child mental health and addiction pathways (Related to Priority Action 4.5):**
  Members noted the draft plan references mental health and addiction pathways, but it's unclear if this includes children. The Network emphasised the need to clarify this, given that tamariki with FASD often face inconsistent access due to service contracts and eligibility criteria. Members expressed strong interest in being involved in any work on **shaping pathways to improve access** for the paediatric population.
- **Whānau navigation and advocacy (Related to Priority Action 4.2 - 4.4):**
  Accessing services is often complex. The plan should invest in funded whānau navigators or key workers to help families manage support across agencies.
- **Future thinking for pilot programmes (Related to Priority Action 4.7):**
  All pilot programmes need to be viable and future-fit; members stressed the point that running a pilot that isn't likely to be funded or supported for ongoing use is a waste of time and resources.

Outcome five: Prevalence

Understanding the scale of FASD in Aotearoa is essential for service planning and resource allocation. The Network supports this goal but notes that the data cited is not robust and more accurate measurement is needed.

Key gaps and suggestions:

- **Data quality and source:**
  The claim that only 5% of individuals with FASD are diagnosed is not well-referenced and should not guide policy without stronger evidence.
- **Checking the correct agency has been highlighted (Related to Priority Action 5.2):**
  Members raised the point that the prevalence study is actually being led by the University of Auckland, not Oranga Tamariki, as mentioned in the priority actions table.
- **Call for national prevalence study (Related to Priority Action 5.3):**
  Including a stock take of current research, members recommend a national prevalence study (not one only focused on high-risk locations) using internationally validated methodologies. This research should be undertaken by expert independent researchers and clinicians.

Outcome six: Workforce

The Network supports the focus on building workforce capability, recognising it as a critical enabler across all outcome areas. Members emphasised that improving outcomes for people with FASD requires **widespread and increasing knowledge across the entire health system and broader sectors**, not just within specialist services. This includes frontline staff, educators, mental health practitioners, and social services — all of whom interact with tamariki and whānau affected by neurodevelopmental conditions.

While there is agreement on the importance of upskilling, members noted that the scale of the challenge is significant, and efforts must be well-resourced, sustained, and tiered to reflect different levels of responsibility and expertise.

Key gaps and suggestions:

- **Tiered workforce development (Related to Priority Actions 6.1 and 6.2):**
  Establish a national training programme with tiered levels of competency – from awareness to diagnostic expertise.
- **Support and retention (Related to Priority Action 6.3):**
  Provide adequate time, supervision, and funding for clinicians involved in FASD-related work. Preventing burnout is essential.
- **Interdisciplinary practice and referral support (Related to Priority Action 6.4 and 6.5):**
  Encourage collaborative practice through referral pathways, second-opinion models, and telehealth access to experts.
- **Clarity required (Related to Priority Action 6.6):**
  More clear guidance on what 'Government FASD awareness and capability activities' relates to and how this is rolled out.
- **Recognising the role of allied health:**
  Allied health professionals play a vital role in the assessment, support, and long-term care of tamariki with FASD. Members highlighted that these roles are often under-

recognised and underfunded despite being essential to functional support and whānau engagement. The Network recommends that **all workforce development and service funding include allied health** and that these professions be involved in the design and delivery of cross-sector training and services**.**

Equity considerations

Network members strongly emphasise the importance of embedding equity throughout the Strategic Action Plan. The discussion highlighted that Māori and Pacific tamariki and whānau are disproportionately affected by FASD and face greater barriers to diagnosis and support. Without deliberate, sustained focus, the plan risks reinforcing existing inequities.

Key points raised by members:

- **Māori and Pacific communities are over-represented:**
  Members noted that the burden of FASD is higher in these communities, yet access to diagnostic services is poorer, and support is often less culturally appropriate or coordinated.
- **Need for culturally responsive approaches:**
  Participants stressed that **whānau voice** must be prioritised, and that care must be culturally safe and responsive. Members noted that one-size-fits-all models do not work.
- **Equity must be embedded in service design:**
  Several members highlighted that achieving equity means services need to be intentionally designed for the needs of Māori and Pacific whānau, not retrofitted after the fact. This includes ensuring whānau are supported across transitions and that navigation support is available.
- **Health literacy and communication styles matter:**
  It was noted that we must be able to communicate information in **multiple ways** to suit the needs of diverse families – some may need written materials, and others need face-to-face conversations.

Recommendations:

- Strengthen the visibility of equity throughout the plan – particularly in resourcing, workforce actions, and access to diagnosis.
- Ensure any national training or service development is co-designed with Māori and Pacific clinicians and communities.
- Invest in whānau-facing roles (e.g. navigators or key workers) that help ensure families are heard, understood, and supported across agencies.
- Prioritise equity in how workforce development, pilots, and service rollout are staged – starting where the gaps are greatest.

Other comments

In addition to feedback aligned with the six outcome areas, Network members raised several broader issues that are critical to the success of the FASD Strategic Action Plan:

- **Recognition of FASD as a disability:**
  There is a strong call for formal recognition of FASD as a disability in its own right. Currently, tamariki and whānau are often unable to access appropriate supports unless the child meets criteria for another diagnosis (e.g. intellectual disability or ASD). Recognising FASD functionally within funding and support systems (e.g. Child Disability Allowance) is essential to addressing unmet need.
- **Operational definitions and terminology:**
  Terms such as "screening" and "centre of excellence" require clearer definitions. Screening implies a universal process, which is not currently supported by evidence or capacity. Members recommend the use of "identification" or "targeted assessment" to reduce confusion. Likewise, clarification is needed around what constitutes a centre of excellence and how these will be staffed, funded, and accessed.
- **Equity of access and regional variation:**
  Significant inequities exist across the motu in terms of diagnostic services, trained clinicians, and support systems. Rural and regional areas are particularly under-resourced. The final plan must address these disparities through targeted investment and workforce support.
- **Reframing prevention language to avoid stigmatising:**
  Members emphasised the need to avoid moralistic or blame-based messaging in prevention efforts. Rather than focusing on individual behaviour (e.g. "encouraging mothers not to drink"), the language should highlight **collective social responsibility** — creating environments where alcohol-free pregnancies are supported by partners, whānau, and society. Messaging should be strengths-based, inclusive, and avoid reinforcing stigma.
- **Workforce development across all levels:**
  While Outcome Six addresses workforce, members noted the need for tiered training – from basic awareness for frontline staff to advanced diagnostic skills for specialists. Upskilling alone is not enough – it must be supported by adequate time, funding, and system-wide changes to allow interdisciplinary teams to collaborate effectively.
- **Focus on the first 1000 days:**
  Members strongly emphasised the importance of intervening during the first 1000 days of a child's life, noting this period as "absolutely critical" to long-term development and well-being. They stressed that support during this window must be proactive, not just responsive and that systems should focus on early identification and wraparound support for whānau well before a formal diagnosis.
- **Diagnosis must not drive access to support:**

Members raised concerns about creating a disease-specific diagnostic pathway for FASD that risks overshadowing other neurodevelopmental conditions with similar needs. While early and accurate diagnosis is important, it was noted that support should be based on functional needs, not diagnosis alone. Members highlighted the importance of designing a system that is fair, sustainable, and responsive across the full neurodevelopmental spectrum.

- **Suggested strategic principle:**
  Members recommended the plan adopt a clear strategic principle that commits to a **trauma-informed, non-stigmatising approach** across all FASD-related prevention and intervention activities. This should include explicit recognition of the role colonisation, social inequality, and community-wide alcohol culture play in shaping risk and outcomes. Embedding this principle would help ensure that all actions are grounded in equity, compassion, and systemic understanding.

We appreciate the opportunity to provide feedback on the draft FASD Strategic Action Plan. The Network is committed to supporting its development and implementation, and we remain eager to contribute our clinical expertise to ensure the plan delivers meaningful, equitable outcomes for all tamariki, rangatahi, and their whānau.

Ngā mihi nui,

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