

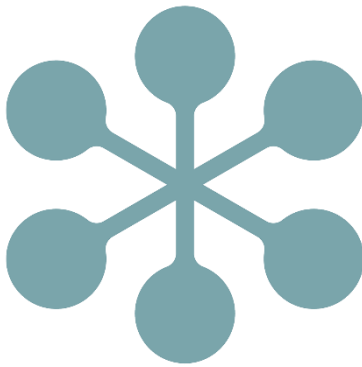
Litmus

Research to inform the FASD Action Plan

Phase 1: Research on the whole-of-system response to children/tamariki aged 0–10 years with diagnosed and suspected Fetal Alcohol Spectrum Disorder (FASD) in Aotearoa New Zealand

03 April 2023





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Mā pango, mā whero, ka oti te mahi
With black and with red the work is completed.

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Report glossary

| Term | Explanation |
|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Aotearoa | Te reo Māori name for New Zealand. |
| Babies | Refers generically to babies of families. |
| Children | Refers generically to children of families. |
| Child and Adolescent Mental Health Services (CAMHS) | Mental health services for children and youth aged up to 18 years with moderate to severe mental health issues. |
| Child Development Services (CDS) | Child Development Services is a team of allied health professionals. CDS provides community-based support and will work with families to support their achievement of development goals. |
| Disability Support Services (DSS) | Disability Support Services are for people who have one or more physical, intellectual or sensory disability, which 1) is likely to continue for at least six months, and 2) is likely to result in a reduction of independent function to the extent that ongoing support is required. |
| District Health Boards (DHBs) | Before July 2022, District Health Boards were organisations that funded and provided health services in their region of New Zealand. There were 20 in total. |
| Early Intervention Service (EIS) | Specialist support for children with additional needs from birth (e.g., a developmental or learning delay, a disability, a behaviour difficulty or a communication difficulty) until they transition to school. |
| Families | Refers generically to families and caregivers interviewed for the research or were referred to by stakeholders interviewed. |
| FASD | Fetal Alcohol Spectrum Disorder |
| <u>Fetal Alcohol Spectrum Disorder Care Action Network (FASD-CAN)</u> | A registered charity in New Zealand that aims to unite caregivers, support whānau and individuals, strengthen communities, and educate about FASD across Aotearoa New Zealand. |
| Gateway assessment | An inter-agency process that identifies ways to address the health and education needs of children entering or at risk of entering care. |
| GPs | General Practitioners |
| High and Complex Needs (HCN) | An inter-agency approach that works with children and young people who have high and complex needs to help families find positive solutions. |
| Intensive Wraparound Service (IWS) | A support programme for young people aged 5–14 years who: 1) have behaviour, social and/or learning needs that are highly complex and challenging, and 2) require support at school, at home and in the community. |
| Kaupapa Māori | Māori approach, Māori institution, Māori ideology— a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society. |
| Learning Support Coordinator (LSC) | Seeks to build the capability of teachers, identify support needs for children with additional needs, and be available to support learners and their families. |
| Mana motuhake | The right for Māori to be Māori (Māori self-determination); to exercise their authority over their lives, and to live on Māori terms and according to Māori philosophies, values and practices including tikanga Māori. |
| Needs Assessment Service Coordination (NASCs) | Needs Assessment Service Coordination agencies (NASCs) assess people to identify services and supports they are eligible for and which are funded. |
| Ola Manuia | Pacific Health and Wellbeing Action Plan 2020–2025 |

| Term | Explanation |
|-----------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Oranga Tamariki | Ministry of Children dedicated to supporting any child whose wellbeing is at significant risk of harm now, or in the future. 'Oranga' is the wellbeing Oranga Tamariki wants to help the children they work with to have. 'Tamariki' reminds them that children are descended from greatness. They are born with an inherent mana that can be damaged by abuse and neglect. |
| Ongoing Resourcing Scheme (ORS) | Provides support for students with the highest ongoing levels of need for specialist support. |
| Pae Ora (Healthy Futures) Act 2022 | Established three new entities: Te Aka Whai Ora – Māori Health Authority, Te Whatu Ora – Health New Zealand, and the Public Health Agency within Manatū Hauora – Ministry of Health. The Act provides for Iwi-Māori Partnership Boards to represent local Māori perspectives on the needs and aspirations of Māori with respect to the planning, design, and delivery of health services at the local level. |
| Pēpi | Māori babies |
| Pregnancy and Parenting Service (PPS) | Intensive case coordination services for parents of children under three years old, and pregnant women experiencing problems with alcohol and other drugs, and who are poorly connected to health and social services. |
| Primary health care | Primary health care relates to the professional health care provided in the community, usually from a general practitioner (GP), practice nurse, nurse practitioner, pharmacist or other health professional working within a general practice. |
| Rangatahi | Māori young people |
| Resource Teachers: Learning and Behaviour (RTLBs) | Specialist teachers who work with and upskill teachers and schools to make interventions for students with learning and/or behavioural difficulties. |
| Tamariki | Māori children |
| <u>Te Aka Whai Ora – Māori Health Authority</u> | An independent statutory authority to drive improvement in hauora Māori. Established in July 2022. |
| Te Tiriti o Waitangi (Te Tiriti, The Treaty of Waitangi) | The founding document of Aotearoa New Zealand that represents an agreement between Māori chiefs and the British Crown. Te Tiriti is accepted as a constitutional document that establishes and guides the relationship between Māori and the Crown (embodied by the Government). |
| <u>Te Whatu Ora - Health New Zealand</u> | The national organisation to lead and coordinate delivery of health services across the country. Established in July 2022. |
| Tino rangatiratanga | Māori self-determination and mana motuhake. Māori are key decision-makers in the design, delivery, and monitoring of health and disability services. |
| Well Child Tamariki Ora (WCTO) services | A universal programme for all children aged 0–5 years to identify growth, development, parenting or wellbeing difficulties and to develop a plan for support or referral. |
| <u>Whaikaha – Ministry of Disabled People</u> | A Ministry that provides a wider lens on disability across Government and drives transformation of the disability support system. Established in July 2022. |
| Whānau-centred approach | A culturally grounded, holistic approach focused on improving the wellbeing of whānau and addressing individual needs within a whānau context (Te Puni Kokiri, 2015). |
| Whānau Māori | Māori families interviewed for the research or referred to by stakeholders interviewed. |
| Whānau ora | A whānau-centred approach to support whānau wellbeing and development. |

| Term | Explanation |
|---------------------|-------------------------------------|
| Whakamaaua | Māori Health Action Plan 2020–2025 |
| Young people | Refers generically to young people. |

Executive summary

Research rationale

Fetal Alcohol Spectrum Disorder (FASD) is the diagnostic term for a neurodevelopmental disorder caused by prenatal alcohol exposure. FASD is a lifelong disability. Individuals with FASD are unique and have both strengths and challenges. Individuals with FASD can experience challenges in their daily living and may need support with motor skills, physical health, learning, memory, attention, communication, emotion regulation, and social skills. FASD is often labelled an invisible disability as it can be undiagnosed, underdiagnosed, and misdiagnosed. Families and individuals living with FASD or suspected FASD are often marginalised and stigmatised.

Since 2016, an inter-agency approach has been used in Aotearoa New Zealand to prevent FASD and ensure people with FASD and their families live the best possible lives. The FASD Action Plan 2016–2019 guides this work and focuses on making the current system more responsive to the needs of individuals, families, whānau, and communities. This research will inform this work and decisions related to service planning for people living with FASD to improve outcomes for babies, pēpi, children, tamariki, young people, rangatahi, families, whānau Māori, and caregivers.

Research purpose and method

The research purpose is to describe and understand the current whole-of-system response to individuals with FASD or suspected FASD. This report is Phase 1 of the research (2021–2022), which is focused on babies/pēpi and children/tamariki aged 0 to 10 years (primary school age). Phase 2 (2022–2023) will focus on older children and young people/rangatahi aged 11 to 18 (intermediate and secondary school) and include the youth justice sector.

The research addressed three key questions:

1. How does the FASD system work across government and other agencies at the two life stages?
2. How does the design and delivery of services and supports for people living with FASD meet Te Tiriti o Waitangi obligations?
3. What improvements are needed to strengthen the FASD system across agencies to better support children and families living with FASD?

We used qualitative research methods to understand the system response to FASD. The research was carried out in Hawke's Bay and Hutt Valley as their respective Child Development Services have a diagnostic pathway for children with suspected FASD within their existing neurodevelopmental diagnosis and assessment pathways.

The fieldwork was completed in June and July 2022. It included:

- a desktop review of policies and practice documents
- interviews and workshops with 87 stakeholders across the health and disability, education, and care and protection sectors; NGOs; and Māori and Iwi providers
- interviews with eight families with a child (or children) living with FASD aged under 10 years.

Research findings

Families want a joined-up and regionally consistent whole-of-system response

Different government agencies fund health, disability, education, and other services to support families and children living with FASD. Figure 1 summarises the services available. The services offer different intensities and levels of support based on level of need.

Figure 1. Government-Funded Services Available for Children with Suspected and Diagnosed FASD Across Age Groups (*eligibility criteria apply)

| 0–2 years | 3–4 years | 5–6 years | 7–8 years | 9–10 years |
|--------------------------------------------------------------------------------------|-----------|-----------|-----------|------------|
| Health and disability | | | | |
| Primary health care | | | | |
| Child Development Services (CDS) | | | | |
| *Disability Support Services, including Needs Assessment Service Coordination (NASC) | | | | |
| *Child and Adolescent Mental Health Services (ICAHS/CAMHS) | | | | |
| Private psychological services | | | | |
| Well Child Tamariki Ora (WCTO) services | | | | |
| *Pregnancy and parenting services (PPS; pilot) | | | | |
| Education | | | | |
| *Early Intervention Service (EIS) | | | | |
| *Teacher support e.g., teacher aides, RTLBs | | | | |
| *Behaviour Support | | | | |
| *Intensive Wraparound Service (IWS) | | | | |
| *Ongoing Resourcing Scheme (ORS) | | | | |
| Care and Protection | | | | |
| National Care Standards and associated entitlements | | | | |
| *Gateway Assessment | | | | |
| Financial support | | | | |
| *Supported Living Payment | | | | |
| *Child Disability Allowance | | | | |
| Inter-agency | | | | |
| *High and Complex Needs (HCN) | | | | |

While services exist, families interviewed do not know about them, or are unable to or struggle to access diagnostic and support services. Further, they noted services across health, disability, and education are not joined up (e.g., FASD assessments from health are not always used to guide education support received). As a result, families are stressed due to the lack of certainty about the FASD assessment and support pathway for their child, and the need to prove and advocate on an ongoing basis for help.

Sector reforms in health, education, and Oranga Tamariki present opportunities to create a more joined-up and nationally consistent whole-of-system response for families and children living with FASD. However, the risk exists that FASD may be overlooked without strong leadership, governance, and accountability.

FASD system improvements need to better meet Te Tiriti o Waitangi obligations

Whānau Māori interviewed want support based on culturally led and culturally responsive services that are FASD-informed and embedded in their whānau, hapu and Iwi. Whānau Māori require strong cultural connectedness and support to ensure good outcomes for the tamariki with an FASD diagnosis or suspected FASD. Feedback from Iwi and Māori providers interviewed highlight they do not have a defined role in the system response.

Enhancing the FASD system response needs to lead with strengthening tino rangatiratanga for whānau Māori. Māori leadership and governance are needed to inform decision-making about enhancing the FASD system response nationally and regionally. Iwi and Māori providers are uniquely placed to walk alongside whānau Māori and tamariki living with FASD, and need to determine their role in the FASD system response.

Families interviewed want an early and non-judgemental assessment process that informs interventions and support received

Families interviewed want an early and non-judgemental assessment process to diagnose the strengths and challenges of their children aged under 10 with suspected FASD. Families want assessment and diagnostic pathways for FASD to be consistent across Aotearoa New Zealand.

Hutt Valley and Hawke's Bay Child Development Services have developed an FASD diagnosis and assessment pathway based on international best practice nested in their wider neurodevelopmental assessment process to ensure appropriate diagnosis. They use multi-disciplinary and sector meetings to ensure families and their children are correctly assigned to the appropriate assessment pathway. They also work to increase both their own and sector-wide understanding of FASD and try to link to education services to ensure assessment reports inform classroom practice for children with an FASD diagnosis.

These Child Development Services have worked to improve their assessment pathways and cross-sector links. However, feedback from families shows their experiences do not align with their aspirations of receiving an early diagnosis and support. Due to a lack of health workforce capacity, access to assessment and diagnosis is delayed for children to around 10 to 12 years old.

Aotearoa New Zealand's FASD diagnostic and assessment guidelines are currently being developed to ensure processes are culturally and clinically safe. However, stakeholders indicated a lack of capacity and FASD-informed capability in the Child Development Services workforce across Aotearoa New Zealand. Implementing the national guidelines may require a workforce strategy to build the capacity and capability in the neurodevelopmental and FASD assessment and diagnosis pathway. The workforce strategy would need to contribute to the priority leadership and workforce actions in Whakamaua: Māori Health Action Plan 2020–2025 (Whakamaua) and Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025 (Ola Manuia) (Ministry of Health, 2020a; Ministry of Health, 2020b).

Families interviewed want early access to FASD-informed interventions to support their child to live their best possible life

Families interviewed want Early Intervention Services and the education system to work with their children to be their best as they grow. They fear, without these services, their children will face adverse outcomes and significant challenges at key transitional points (e.g., going to or changing schools). Families want to be listened to and work with professionals to develop solutions to meet their child's and family's needs. Families were exhausted from caring and advocating to prove their entitlement to support and resources.

When a diagnosis is reached (and before), families and stakeholders note few FASD-informed services are available to support the child with FASD or their family. The challenges of accessing support services were particularly marked for families of children with a sole diagnosis of FASD or moderate needs who do not meet the criteria for Disability Support Services.

While the education system does not require a confirmed FASD diagnosis, families struggle to receive support in primary schools. Many described their child with FASD as being sidelined. One-off exceptions were noted where primary schools created a positive FASD-informed learning environment. No families received support through Early Intervention Services in early childhood centres, although some were encouraged to seek assessments for their child's behaviour.

Families want access to respite care. Currently, many families cannot access respite care as a sole diagnosis of FASD does not meet NASC's eligibility criteria for disability support services.

Families interviewed want an FASD-informed community and workforce

Families interviewed highlighted their wider family's and community's lack of FASD understanding. Families shared many examples of stigma, shame, and stress when engaging with their own families and wider communities. Families also shared instances where knowledge of FASD was limited across frontline staff (who do not specialise in FASD) in health, education, Oranga Tamariki, NGOs, and Māori providers. The lack of FASD knowledge created access barriers to assessment pathways and FASD-informed support, particularly in the classroom. Negotiating this adverse environment is exhausting for families. As a result, some withdraw from their families and services and feel isolated in their communities. Māori and Pacific whānau also highlighted racism and systemic bias. As a result, a few withdrew from engaging with the system until reaching crisis point.

Regional stakeholders (particularly professionals who do not specialise in FASD) also acknowledged a need to strengthen their FASD-informed practice and their willingness to learn. Inter-agency initiatives related to the FASD Action Plan have created training and resources on FASD, and on appropriately supporting families and children living with FASD. However, frontline staff in health, education, and care and protection highlighted barriers to engaging with the resources, specifically a lack of awareness, capacity, budget, and other pressing priorities.

Creating an FASD-informed workforce requires FASD training to be incorporated into professional training and continuing education, supported by existing online FASD resources. Some steps have been taken to do this (e.g., the Postgraduate Diploma in Specialist Teaching supports neurodiverse learners woven into the course content).

A summary of improvement opportunities¹

The following opportunities were identified across the feedback from families and stakeholders on improving outcomes for families and children aged 0–10 living with FASD.

Whole-of-system opportunities

- Develop a whole-of-system strategy for neurodiversity generally and FASD specifically to foster a nationally consistent and joined-up cross-sector response for families living with FASD, linked to wider system reforms.
- Ensure strong cross-agency governance (embedded into wider system reforms) and review the implementation.

Opportunities to meet Te Tiriti o Waitangi obligations

- Ensure appropriate national and regional level cross-agency governance includes Māori leadership and whānau Māori living with FASD.
- Ensure whānau Māori living with FASD are respected, listened to, have choices and resources, and are actively involved in the solution to support their tamariki.
- Invest in Māori providers to build their workforce's understanding of FASD.
- Engage with Iwi and Māori providers so they can determine their role in the FASD system response.

Assessment, diagnosis and support opportunities

- Ensure families living with FASD are respected, listened to, have choices and resources, and are actively involved in the solutions to support their children.
- Have an assessment and diagnosis pathway for FASD nested in a wider neurodevelopmental assessment process based on Aotearoa New Zealand's diagnostic guidelines (when released).
- Develop and implement a workforce strategy, drawing on Whakamaui and Ola Manuia, to build multidisciplinary and cultural capability in the neurodevelopmental and FASD assessment.
- Consider the opportunity for a sole diagnosis of FASD to qualify for Disability Support Services so children with more moderate needs can access disability support services.
- Enable access to evidence-informed early interventions that address systemic influences (e.g., psychoeducation and support for the family, environmental accommodation, child-focused interventions, and integrated case management) (McLean, 2020).
- Continue work to create an FASD-informed education system that supports children with FASD based on their needs to support their learning and connection with peers.
- Establish localised FASD or neurodiverse community hubs to enable cross-sector and family collaboration.
- Have FASD coordinators to support families in accessing services and offering advice.
- Have access to FASD-informed respite options.

Community and workforce capacity and capability opportunities

- Increase the focus on prevention activities and messages to the public.
- Increase public awareness and understanding of FASD and create a dialogue shift from blame and stigma to strengths-based and enabling.
- Continue to build FASD training in frontline professionals' training.

¹ Some opportunities are being addressed by relevant government agencies (e.g., work on workforce capability and capacity in the health sector through the health reforms).

- Actively promote existing online resources and create enabling learning and practice environments for professionals to prioritise their use and apply in their practice.
- Continue to support and promote FASD-CAN in providing training to families and professionals.
- Have dedicated FASD-informed specialists in a community hub to offer capability building and advice to families and professionals working with them.

Research context

FASD is a health challenge contributing to inequitable outcomes in Aotearoa New Zealand

Alcohol use is common before recognition of pregnancy. The 2012/13 New Zealand Health Survey on alcohol use found 76% of female respondents had drunk alcohol in the past 12 months (Ministry of Health, 2015a). About one in five drank alcohol at some point during their most recent pregnancy. The Growing Up in New Zealand study found a quarter of women (23%) reported drinking during the first trimester, particularly European and Māori (Rossen et al., 2018).

FASD is a diagnostic term for a neurodevelopmental disorder caused by prenatal alcohol exposure. Not all babies exposed prenatally to alcohol will have FASD. The prevalence of FASD is not known in New Zealand. Estimates are between 3–5% of the school-aged population is affected (around 1,800 to 3,000 children born with FASD per year) (Minister of Health, 2016).

FASD is often termed an ‘invisible disability’ as it is often undiagnosed, underdiagnosed, and misdiagnosed (Chasnoff et al., 2015). Only a very small portion of children with FASD (around 4%) present with the three sentinel facial features (Clarren et al., 2015). An FASD diagnosis provides families and professionals supporting families with a framework for understanding an individual’s strengths and challenges (Andrew, 2010; Looock et al., 2020). In addition, international studies show early diagnosis and interventions for FASD are linked to better long-term outcomes for the child and their family (Reid et al., 2015; Novak and Morgan, 2019).

FASD is a lifelong disability. Individuals with FASD may experience some degree of challenges in their daily living. They may need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to live their best possible lives. Each individual with FASD is unique and has areas of both strengths and challenges (FASD-CAN, 2022a).

FASD is stigmatised. Individuals with FASD and their families are marginalised, face negative stereotypes and misperceptions, and have lower self-esteem. Shame and blame are often targeted at women and mothers (Flannigan et al., 2021). FASD is often misperceived as an ‘indigenous issue’ which creates substantial harm through cultural stigma and perpetuating negative stereotypes (Flannigan et al., 2021).

The FASD Action Plan 2016–2019 guides cross-agency collaborative action and this research

In 2016, the FASD Action Plan² sets out an inter-agency approach to prevent FASD and ensure people with FASD and their families live the best possible lives (Ministry of Health, 2015b). The FASD Action Plan focuses on making the current system more responsive to the needs of individuals, families, whānau, and communities. The FASD Action Plan does not establish new FASD-specific services (FASD Working Group, 2016).

² The full name of the action plan is ‘Taking Action on Fetal Alcohol Spectrum Disorder: 2016–2019: An action plan’.

The FASD Action Plan outlines four priorities to achieve its aims: prevention, early identification, support, and evidence. The Action Plan also identified 10 action areas with associated activities that central government agencies have worked on and reported against (Ministry of Health, 2021). The principles and action areas are outlined in [Appendix 1](#).

Before July 2022, the Ministry of Health was the lead agency for the FASD Action Plan working with the Ministry of Education, the Health Promotion Agency, Oranga Tamariki – Ministry for Children, the Ministry of Justice, the New Zealand Police, the Department of Corrections, and the Ministry for Primary Industries.

The FASD Coordination Group enables collaboration across these government agencies and provides recommendations to the cross-agency FASD Governance Group. The FASD Governance Group provides strategic oversight and governance to implement the FASD Action Plan.

Since July 2022, the health system changes have refined the structure of health agencies working on the FASD Action Plan. On 1 July 2022, the [Pae Ora \(Healthy Futures\) Act](#) took effect, establishing three new entities, in addition to the Ministry of Health. Together, these entities are:

- [Manatū Hauora](#) – the Ministry of Health remains the policy, strategic, and regulatory arm of New Zealand’s health system
- a new [Public Health Agency](#) within the Ministry of Health to lead and strengthen public health
- [Te Whatu Ora – Health New Zealand](#) as the national organisation to lead and coordinate the delivery of health services across the country (the operational arm)
- [Te Aka Whai Ora – Māori Health Authority](#) as an independent statutory authority to drive improvement in hauora Māori.

The Pae Ora Act recognises the role of Iwi-Māori Partnership Boards to act as a vehicle for Māori to exercise tino rangatiratanga and mana motuhake with respect to the planning, design, and delivery of health services at the local level. In this new environment, a new lead agency for the FASD Action Plan is to be appointed.

[Whaikaha – Ministry of Disabled People](#) was also established in 2022 to provide a wider lens on disability across Government and drive transformation of the disability support system.

In 2021, the Ministry of Health³ commissioned Litmus to complete research to inform Action 9 and activity 33: commission research to identify what an effective system-wide approach to responding to FASD and neurodevelopment disorders would look like. This research is one of six projects to inform future work (i.e., piloting enhanced maternal addiction and child development services and developing new diagnostic guidelines).

³ The Ministry of Health commissioned this research. In June 2022, the contract was moved to Te Whatu Ora/Health New Zealand.

Research method

Research purpose

The research purpose is to describe and understand the current whole-of-system response⁴ to individuals with FASD or suspected FASD. This report presents Phase 1 of the research (2021–2022), which is focused on babies/pēpi and children/tamariki aged 0 to 10 years (primary school age). Phase 2 (2022–2023) will focus on older children and young people/rangatahi aged 11 to 18 (intermediate and secondary school) and include the youth justice sector.

The research findings will inform decisions related to service planning for responding to people living with FASD to improve outcomes for babies, pēpi, children, tamariki, young people, rangatahi, families, whānau Māori, and caregivers. The research identifies system gaps and opportunities for improvement.

This research was approved by the New Zealand Ethics Committee (project number: NZEC22_04).

Key research questions

The research addressed three key questions.

1. How does the FASD system work across government and other agencies at the two life stages?
2. How does design and delivery of services and supports for people living with FASD meet the obligations of the Crown as a Treaty partner as defined by Whakamaua: Māori Health Action Plan?
3. What improvements are needed to strengthen the FASD system across agencies to better support children and families living with FASD?

Research method

We summarise below an overview of the research approach. We used qualitative methods to understand the system response to FASD. We established a multidisciplinary Research Advisory Group to guide the research team on the design, analysis, and reporting.

To explore regional responses to FASD for children aged 0–10 years, the research was carried out in Hawke's Bay and Hutt Valley District Health Boards (DHBs) regions. We selected these regions as their respective Child Development Services⁵ had a diagnostic pathway for children with suspected FASD within their existing neurodevelopmental diagnosis and assessment pathways. From July 2021, the two DHBs were rebranded as Te Whatu Ora Te Matau a Māui, Hawke's Bay and Te Whatu Ora Hutt Valley.

⁴ In this research, the 'whole-of-system response' refers to the policies and services available to people living with FASD at national, regional, and local levels and across all relevant sectors.

⁵ More information on the role of Child Development Services is [here](#).

We selected the two Child Development Services to gain insights into their learnings from implementing a diagnostic pathway for children with suspected FASD. These locations also have high Māori populations and a mix of urban and rural locations.

Fieldwork was completed in June and July 2022. We completed:

- a desktop review of national strategies, policies and practice documents at a national and regional level.
- qualitative interviews and hui with 87 stakeholders across the health and disability, education, and care and protection sectors; NGOs; and Māori and Iwi providers offering early identification, assessment and diagnosis, support, and interventions.
- qualitative interviews with eight families with a child (or children) living with FASD (five living in Hawke's Bay and three living in Hutt Valley) aged under 10 years.^{6,7}

[Appendix 2](#) presents the Research Advisory Group's members, the detailed research questions, data collection methods, sample description, research limitations, and research tools.

Analysis and reporting

Most interviews were audio-recorded and transcribed verbatim, with participants' permission. We systematically coded all interview transcripts and hui notes based on key themes in an Excel spreadsheet.

We undertook regular debriefs and internal analysis workshops with the research team. We held a sense-making session with the Research Advisory Group and Te Whatu Ora, where we presented the preliminary findings and discussed their implications.

We used an integrated analysis approach drawing across the data streams to identify key insights that address the research questions. To answer research question 2, we drew on an analysis of families' needs and experiences and service availability against the framing of Whakamaui to identify key insights and opportunities for improvements. We also used the framing of the FASD Action Plan and Whakamaui to identify key insights and recommendations for research questions 1 and 3, drawing from families' and key stakeholder feedback.

Report structure

Each section starts with the key insights and opportunities to strengthen the current whole-of-system response, followed by the supporting evidence.

The Research Advisory Group, Dr Aria Graham (kaupapa Māori researcher), Child Development Services teams at Hawke's Bay and Hutt Valley, Te Whatu Ora, Oranga Tamariki, and the Ministry of Education reviewed the draft report. Before finalising the report, we considered and incorporated their feedback as appropriate to the evidence.

⁶ While families focused on their service experience for their child aged 0–10 living with FASD, they also reflected on the services and support they wanted as their child aged beyond 10. To respect families, we have included this feedback in the report.

⁷ One family's child was older than 10 years. This family reflected on their and their child's experience before they were 10.

Research limitations

We are confident the report reflects the feedback from families and key stakeholders interviewed. We acknowledge the report's limitations:

- The findings are based on the system response in two areas with an established FASD diagnostic pathway for children aged 0–10. We acknowledge FASD services are likely to vary across Aotearoa New Zealand. Therefore, families in other regions may have different service experiences.
- We only talked to families willing to be interviewed about their journey living with FASD. Several families approached by community connectors did not want to talk about their experiences due to experiences of stigma from services, whakamā, and other personal reasons.
- We interviewed eight families. The families interviewed had similar service experiences and their feedback reflected regional stakeholders' feedback on services. However, given the varied presentation and experiences of FASD, the research does not represent the full diversity of people's experiences.
- The interview sample of families reflects a caregiver perspective, not biological parents. The sample also reflects those connected to services and care for children who have received a diagnosis.
- We have limited insight into the experiences of families who live rurally.
- Families mainly reflected on their primary school experience as this tended to be when their child's neurodevelopmental difficulties became more noted or when they knew their child had FASD and wanted FASD-informed support. No families mentioned receiving support through early childhood services. We have limited insight into the role of early childhood education in supporting children under five with suspected FASD.

Research findings



Understanding the policies influencing service availability and access

This section provides key insights and opportunities for the national government agency roles, strategies and policies that influence the services and supports available, and the experience of families and children aged 0 to 10 living with FASD.

Government agencies fund a range of services to support families and children living with FASD

Government agencies have different approaches and funding criteria to support people living with disabilities, reflecting their role within the public service system. Government agencies' policy perspectives are summarised below, along with services funded to demonstrate how national-level policy impacts regional services and support for families and children aged 0–10 with suspected and diagnosed FASD. Figure 1 in the Executive Summary gives an overview of the government-funded services for children aged 0–10 with suspected and diagnosed FASD.

Tables 1 to 5 offer a detailed service description, eligibility criteria (if any exist), and the referral pathway or application process.

Whaikaha (Ministry of Disabled People) funds a range of disability support services using eligibility criteria

In July 2022, Whaikaha was set up in partnership with the disabled community, Māori, and the Government to transform the disability system in line with the Enabling Good Lives approach.⁸ Whaikaha funds disability services for those who meet the eligibility criteria.

In July 2022, funding for Child Development Services now lies with Whaikaha⁹. Child Development Services are a team of allied health professionals, with expertise in physiotherapy, speech-language therapy, occupational therapy, and psychology. They provide community-based support and will work with families and children to support the achievement of the child's development goals. They provide specialist assessments and therapy-based support, and work with other agencies to support children. Families and children with suspected FASD are referred to Child Development Services by GPs, Well Child Tamariki Ora nurses, or other health or education specialists.

Child Development Services are a key entry point for families and children with suspected FASD to gain assessment and support when they have concerns about their child's development or behaviour. Across Aotearoa, around 30 Child Development Services exist. Before July 2022, some were in DHBs and the rest were in NGOs. In 2019, new funding was invested in Child Development Services as part of the Child Development Service Improvement Programme. Assessment and diagnosis processes for FASD varies across Child Development Services.

Disability Support Services funded by Whaikaha are services and support for disabled people delivered by various organisations around the country. People can self-refer or be referred by health professionals to the Needs Assessment and Service Coordination (NASC) to assess their eligibility for

⁸ [Enabling Good Lives](#) is an initiative to support disabled people by offering greater choice and control over the support they receive.

⁹ While organisation names and funding streams have changed, the services offered by the Child Development Services have not.

different funded disability services and support. If eligible, people can access support such as community day services, respite care, home and community support services, individualised funding, and supported living. Disability Information Advisory Services provides free independent information and advice to disabled people and their families.

In 2022, a sole diagnosis of FASD¹⁰ does not meet the eligibility criteria for Disability Support Services, despite meeting the Whaikaha's definition of 'disability'.¹¹ However, children with FASD who have an eligible physical, sensory, or intellectual disability or Autistic Spectrum Disorder (ASD) are eligible for consideration to access Disability Support Services. Children solely diagnosed with FASD do not meet NASC's eligibility criteria for services and support.

Table 1. Service Descriptions of Health and Disability Services Available for Children Aged 0–10 with Suspected and Diagnosed FASD

| Health and disability sector | Service description | Eligibility criteria | Referral pathway |
|--------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|
| <u>Child Development Services (CDS)</u> Now funded by Whaikaha (previously the Ministry of Health) | <p>CDS comprises multidisciplinary allied health and community-based services. The purpose is to promote and facilitate a child's developmental pathway through assessment, intervention, and support services from birth to 16 years.</p> <p>In Hawke's Bay, the Developmental Assessment Programme (DAP) is based in CDS in Hawke's Bay, which offers a specific FASD assessment pathway.</p> | All children from birth can access CDS if there is an identified disability, developmental delay, Autism Spectrum Disorder, or a possibility of these. Children with suspected FASD qualify for this service. | Through a general practitioner (GP), Well Child Tamariki Ora nurse, health specialist, education professionals, and other service providers. |
| <u>Disability Support Services and NASC</u> Now funded by Whaikaha (previously the Ministry of Health and DHBs) | NASC services assess people to identify services and supports they are eligible for and which are funded. They then facilitate access to supports and services, such as home help, personal care, respite, etc. | Disability Support Services are for people who have one or more physical, intellectual or sensory disabilities, which 1) are likely to continue for at least six months, and 2) need ongoing support to live independently. Children with FASD need another eligible condition (e.g., intellectual disability) to qualify for this service. | Anyone can apply for a needs assessment, either in person or by referral from another person or organisation, such as a GP. |

¹⁰ Under the Canadian diagnostic guidelines (Cook et al., 2015), a diagnosis of FASD requires evidence of alcohol exposure before birth, and severe impairment in at least three out of 10 domains of central nervous system structure or function (e.g., motor skills, neuroanatomy, language, attention, executive function).

¹¹ For the purpose of eligibility for many Whaikaha-funded Disability Support Services, disability is defined as "a person with a disability is someone who has been assessed as having a physical, intellectual or sensory disability (or a combination of these) or autism spectrum disorder that is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that on-going support is required."

| Health and disability sector | Service description | Eligibility criteria | Referral pathway |
|-----------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|
| Child and Adolescent Mental Health Services (CAMHS) Now funded by Te Whatu Ora (previously the Ministry of Health) | Mental health services are aimed for children and youth aged up to 18 years with moderate to severe mental health problems. They might also run acute and crisis services. Service names differ by region e.g., ICAFS/Infant, Child, Adolescent & Family Mental Health Service in Hutt Valley. | Children qualify if they have moderate to severe mental health issues and CAMHS are the best service to help (following referral and an initial appointment). Children with suspected FASD qualify, if they meet criteria. | A referral can be made by a child or young person, their parents or caregivers, a GP, or the child's or young person's school. |
| Private psychological services Might hold contracts with DHBs or Oranga Tamariki | Private clinical psychologists assess the needs of children with challenging behaviours, developmental delay, and other issues. | All people qualify for private psychological services, if they can pay for it or are funded by Oranga Tamariki or another source. Children with suspected FASD qualify, if their families can afford it. | Referral is by CDS if through the public health system or Oranga Tamariki for children in care. People can also self-refer if paying privately. |
| <u>Well Child Tamariki Ora (WCTO) services</u> Now funded by Te Whatu Ora (previously the Ministry of Health) | WCTO's programme is to ensure all families are supported to maximise their child's developmental potential and health status to establish a strong foundation. Thirteen core contacts are available to all children aged 0–5 years to identify growth, development, parenting or wellbeing difficulties, and to develop a plan for support or referral. | Universal programme available to all children from six weeks to five years of age. Checks and visits occur regularly at key points during this time e.g., B4 School checks for children at age four. Children with suspected FASD qualify. | The midwife will sign families up shortly after the child is born. |
| Pregnancy and Parenting Services (PPS) Now funded by Te Whatu Ora (previously the Ministry of Health) | PPS are intensive, assertive outreach case coordination services for parents of children under three years old and pregnant women experiencing problems with alcohol and other drugs, and who are poorly connected to health and social services. PPS was piloted in three regions, including Hawke's Bay (Te Ara Manapou). | PPS are for parents who are: 1) pregnant and/or have children under three years of age, 2) experiencing difficulties with alcohol or other drugs, and 3) poorly connected to services. PPS clients are at an increased risk of FASD, and PPS teams may link children with suspected FASD to specialist support for speech and other delays. | Main referrals to Te Ara Manapou were from the DHB. Other sources included self and family referrals and community services. |

The Ministry of Education bases service access on need

The Ministry of Education takes an inclusive approach and does not require children to have a diagnosis to qualify for support. The Ministry of Education recognises variability across learners and seeks to provide flexible, universal, targeted and tailored supports that respond to the level of individual need. Needs may relate to physical, behavioural, communication, learning, and wellbeing needs. Supports and services may include Learning Support practitioners (e.g., early intervention teachers, speech-language therapists, learning support advisors, occupational therapists,

psychologists, and physiotherapists), teacher aides, specialist teachers (Resource Teachers: Learning and Behaviour/RTLBS; Learning Support Coordinators), training resources, and programmes.

The Ministry of Education is implementing a new model for delivering learning support. The [Learning Support Delivery Model](#) was developed by parents, whānau, staff, and disability and education groups. The model has six elements:

1. known point of contact for learning support
2. an individualised support plan with agreed goals and tailored support
3. a collective way of working across an agreed cluster of schools, kura, early learning services and kōhanga reo to identify community needs and agree resource allocation
4. better facilitation to bring supports and services together
5. more flexible decision-making to meet local needs and priorities rather than using rigid criteria
6. shared data to create understanding and enable planning.

[Te Tūāpapa o He Pikorua](#) guides the work of the Ministry of Education and RTLBS. Te Tūāpapa is an evidence-informed approach for identifying supports that increase in intensity depending on the needs and the context. The levels are universal, targeted, and tailored. Te Tūāpapa enables practitioners to:

- intervene early
- support developing universal, systemic responses within clusters, schools, kura, and early learning services
- support developing individualised approaches within educational contexts where a specific need has been identified
- use adaptation and differentiation for groups and individuals within settings.

More intensive funding and programmes, such as the [Ongoing Resourcing Scheme](#) (ORS) funding and the [Intensive Wraparound Service](#) are available for children with high levels of need. The Ongoing Resourcing Scheme provides direct support to individual students with the highest needs to enable them to be present, participate and learn. The Ongoing Resourcing Scheme provides support through additional teacher time, specialists, teacher's aide support, and a Consumables Grant.

Table 2. Service Descriptions of Education Services Available for Children Aged 0–10 with Suspected and Diagnosed FASD

| Education sector ^{12,13} | Service description | Eligibility criteria | Referral pathway |
|-----------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|
| Early Intervention Service (EIS) Funded by the Ministry of Education | EIS provides specialist support for children with additional needs from birth (e.g., a developmental or learning delay, a disability, a behaviour difficulty or a communication difficulty), until they transition to school. | Children with additional needs qualify and do not need a diagnosis to access EIS. Waitlists exist. Children with suspected FASD qualify for this support. | Parents can contact EIS directly to request support. With parental consent, educators or other professionals (e.g., doctor) can also request support. |

¹² The Ministry of Education has a range of student supports available and not all are covered here. See [here](#) for a full list of available supports.

¹³ The Ministry of Education has an Inclusive Education policy that means all children can access services with a diagnosis. There is also an online resource available for schools and families (see [here](#)).

| Education sector ^{12,13} | Service description | Eligibility criteria | Referral pathway |
|------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <u>Teacher support – teacher aides</u> Funded by the Ministry of Education | Teacher aides assist teachers in helping with the child's learning, including managing their behaviour and working with other children. Support is offered from Year 1 onwards. | Children qualify if they receive funding from ORS, the School High Health Needs Fund, In-Class Support, Behaviour Services, or Communication Services. Children with suspected FASD may fit these criteria. | Children are allocated teacher aide funding (based on support needs) after qualifying for eligible funding categories. |
| <u>Teacher support – Learning Support Coordinators (LSCs)</u> Funded by the Ministry of Education | LSCs are a relatively new role that seeks to build the capability of teachers, identify support needs for children with additional needs, and be available to support learners and their families. | At this early stage, LSCs are allocated to school clusters that are further ahead in implementing the Learning Support Delivery Model and other factors e.g., proportions of rural schools, Māori and Pacific students, number of Māori medium ¹⁴ , and number of students. ¹⁵ | LSCs work with schools, and clusters make decisions about what the LSC role entails. The guiding allocation is a ratio of one LSC to 500 students within a cluster. |
| <u>Teacher support – RTLBs</u> Funded by the Ministry of Education | RTLBs are specialist teachers who work with and upskill teachers and schools to make interventions for students with learning and/or behavioural difficulties. RTLBs work across multiple schools, from Year 1 to 10. | Students with learning and/or behavioural difficulties qualify for support. Children with suspected FASD may fit these criteria. | Schools can request RTLB support for students having difficulties. Families can talk to the child's teacher to request additional support for their child. RTLB clusters (regional groups) have their processes for managing requests. |
| <u>Behaviour support</u> Funded by the Ministry of Education | The Behaviour Support service is for students in Years 1–10 who have extreme and ongoing behavioural challenges in a way that: 1) significantly affects their learning, 2) risks their safety or the safety of other people, and 3) gets in the way of positive relationships with other people. A Ministry of Education representative will work with the school, child, family, and specialists to assess the child's needs and co-design tailored support for them. | Students with significant behavioural difficulties qualify for an assessment for support. Children with suspected FASD may fit these criteria. | Support can be requested by contacting the local Ministry of Education office. |
| <u>Intensive Wraparound Service (IWS), Te Kahu Tōi</u> Funded by the Ministry of Education | IWS is a support programme for young people aged 5–14 years who: 1) have behaviour, social and/or learning needs that are highly complex and challenging, and 2) require support at school, at home and in the community. IWS takes a bespoke, comprehensive, holistic, and youth and family-driven approach. | IWS has two key criteria: 1) there has to be a need in the school, home, and community, and 2) every other intervention has been used or attempted and was unable to meet needs. A panel reviews all referrals and decides if the child is accepted. Children with suspected FASD qualify if they meet criteria. | Applications are made by Ministry of Education Learning Support staff, RTLB and day specialist schools, or fund-holder (ORS) schools. |

¹⁴ Māori medium schools refer to schools where all or some students are taught in the Māori language for at least 51% of the time.

¹⁵ Allocation rationale and other information about LSCs can be found [here](#).

| Education sector ^{12,13} | Service description | Eligibility criteria | Referral pathway |
|-------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <u>Ongoing Resourcing Scheme (ORS)</u> Funded by the Ministry of Education | The Ongoing Resourcing Scheme (ORS) provides support for students with the highest ongoing levels of need for specialist support. ORS provides support for specialists, specialist teachers, teacher aides, and consumables. Once a child is accepted for ORS, they retain it for the rest of their schooling. | To meet ORS criteria, students must have: 1) ongoing extreme or severe difficulty with one or more of the five areas of need (learning, hearing, vision, physical, language), or 2) ongoing moderate to high difficulty with learning, combined with two other areas of need at a moderate to high level. Children with suspected FASD qualify if they meet criteria. | Educators or key workers apply for ORS funding on behalf of high-needs students and their families. The application process is a collaborative effort between the parents/family, educators, and the team around the child. |

Many children in care are eligible for a Gateway assessment to identify their needs

The Oranga Tamariki vision is to ensure all tamariki or children in Aotearoa New Zealand are in loving whānau or family and communities where oranga tamariki can be upheld. An estimated 50% of children and young people in Oranga Tamariki care could be affected by FASD (FASD Working Group, 2016).

Children in the care of Oranga Tamariki are eligible for a comprehensive Gateway assessment working with education and health providers. Through a multidisciplinary team, recommendations are put forward to support the child. If appropriate, available, and accessible in their area, the child may receive an FASD assessment. However, while children are eligible for a Gateway assessment, referral rates for the assessment vary across Aotearoa New Zealand. Some children in care, usually those who are older, may receive Tuituia¹⁶ assessment instead of a Gateway assessment.

Table 3. Service Descriptions of Services Available for Children aged 0–10 with Suspected and Diagnosed FASD Through Oranga Tamariki

| Care and protection | Service description | Eligibility criteria | Referral pathway |
|-----------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------|
| <u>National Care Standards and associated entitlements</u> Funded by Oranga Tamariki | The National Care Standards set out standards for children to do well and be well, and support caregivers. They cover: 1) need assessments and plans for children, 2) meeting needs of children (cultural, recreational, education, health, etc.), 3) assessments, plans and support for caregivers, 4) supporting children to express their views, 5) supporting children during care transitions, and 6) monitoring and reporting on compliance. | All children in Oranga Tamariki care are entitled to the standards of care and associated entitlements. Children with suspected FASD are eligible if they are in care. | The care standards are expected when a child enters care. |
| <u>Gateway assessment</u> | A Gateway assessment is an inter-agency process that identifies ways to address the health and education | Gateway assessments are for children entering care, already in care, or at risk of | Social workers make a Gateway assessment referral: 1) when a referral |

¹⁶ The Tuituia framework is used by social workers, working with other professionals, to assess the areas of need, strength and risk for the child, and their parents or caregivers.

| | | | |
|----------------------------------|----------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Funded by Oranga Tamariki | needs of children entering or at risk of entering care. An inter-agency plan is then developed to follow up on identified needs. | going into care. Children with suspected FASD qualify if they meet criteria. | for a care and protection family group conference is made, or following it if appropriate, 2) within 10 working days of entering care, or 3) when the child is already in care if it would be beneficial. |
|----------------------------------|----------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

The Ministry of Social Development provides financial support if eligibility is met

The Ministry of Social Development uses a social model of disability. This model identifies systemic and social barriers which make it difficult or impossible for individuals with impairments to navigate their world. Policies focus on providing financial support based on need. Children with FASD and their families may be eligible for the Child Disability Allowance, Supported Living Payment, and the Extraordinary Care Fund. Children with an FASD diagnosis are eligible for financial support if they have a diagnosis noted on a medical certificate and meet other criteria (e.g., income level).

Table 4. Funding Available for Children Aged 0–10 with Suspected and Diagnosed FASD Through the Ministry of Social Development

| The Ministry of Social Development | Service description | Eligibility criteria | Application process |
|-----------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------|
| <u>Supported Living Payment</u> Funded by the Ministry of Social Development | The Supported Living Payment is a weekly payment to help if people have, or are caring for someone with, a significant health condition, injury, or disability. | Parents and caregivers are eligible if they are caring full-time for someone. The amount depends on the situation and how much they and their partner earn. Caregivers and family of children with FASD qualify if they are full-time carers. | Parents/caregivers can apply through Work and Income. |
| <u>Child Disability Allowance</u> Funded by the Ministry of Social Development | The Child Disability Allowance is a fortnightly payment made to the main carer of a child with a serious disability. | Parents/caregivers are eligible if: 1) they are the main carer of the child, 2) a New Zealand citizen or permanent resident, 3) the child has been assessed as needing constant care and attention for at least 12 months because of a serious disability, and 4) the child or young person is under 18. Parents/caregivers of children with FASD qualify if they meet criteria. | Parents/caregivers can apply through Work and Income. |
| <u>Extraordinary Care Fund</u> Funded by the Ministry of Social Development | The Extraordinary Care Fund supports extra costs (up to \$2,000/year) if someone is caring for a child who shows promise in an ability, skill, or talent and is experiencing difficulties that impact their development. | Parents/caregivers are eligible if their child: 1) shows promise in an ability (e.g., participating in a competition, programme, event, coaching and mentoring, lessons) and 2) has learning or behavioural difficulties. MSD can support with costs associated with technology (e.g., laptops), musical instruments, lessons, clothing, programmes, therapy, etc. Parents/caregivers of children with FASD qualify if they meet criteria. | Parents/caregivers can apply through Work and Income. |

Cross-agency support services exist but have high eligibility criteria

Some cross-agency services exist which provide wraparound support to a child with high and complex needs. Examples include High and Complex Needs (jointly funded by Oranga Tamariki and the Ministries of Health and Education) and the Intensive Wraparound Service (led by the Ministry of Education). Stakeholders perceive these services to be highly effective, given the cross-agency approach. The services require extensive resourcing and staff to provide intensive support. However, some stakeholders described these services as the ‘ambulance at the bottom of the cliff’ due to the child not receiving early intervention.

Eligibility criteria are as follows:

- High and Complex Needs requires the child to be identified to have high and complex needs by two agencies – one of which is usually the Ministry of Education, followed by the Ministry of Health and Oranga Tamariki. The 2021 High and Complex Needs’ annual report¹⁷ shows that 78% of people in the service have a neurodevelopmental disorder and 16% have a diagnosis of FASD, an increase of 4% compared to the previous year.

¹⁷ The High and Complex Needs’ annual report can be found [here](#).

- The Intensive Wraparound Service accepts children with highly complex and challenging needs who require support at school, home, and community. Stakeholders note people tend to be accepted in the service after other educational services have not worked.

The family's consent is sought to be involved in these programmes. However, stakeholders interviewed said participating can be difficult for families as the programmes can be intrusive and demanding on families.

Table 5. Inter-Agency Funding Available for Children aged 0–10 with Suspected and Diagnosed FASD

| Inter-agency | Service description | Eligibility criteria | Referral pathway |
|-------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|
| High and Complex Needs (HCN) Funded by the Ministries of Health and Education and Oranga Tamariki | HCN works with children and young people who have high and complex needs. They work with multiple government and non-government agencies to help families find positive solutions. The service is intensive and lasts between six to 24 months. | Children are eligible if they have high and complex needs across at least two sectors (education, health, and care and protection). Children with suspected FASD qualify if they meet criteria. | Two required agencies have to put in a joint referral. |

A regionally joined-up whole-of-system response to support families and children aged 0–10 with FASD does not exist

A postcode lottery of FASD assessment and support exists across Aotearoa New Zealand

As demonstrated, government agencies fund a range of services and support that may be available to families and children aged 0–10 years with FASD or suspected FASD. While these services exist, families' and stakeholders' feedback highlight they are not consistently available across regions. A few families interviewed moved areas to try to access health and education services and support in other regions.

The system is like **hitting brick walls** all the time...**Underfunded**, under-recognised, **unsupported**, and unknown. (Family living with FASD)

Families interviewed experience barriers to understanding, navigating, and accessing siloed services. In addition, families are frustrated services are not joined up and working together. As a result, they experience being referred to several services and retelling their stories multiple times. Families interviewed spoke of needing resilience, capacity, knowledge, and time to navigate the system and actively advocate for support. A few families interviewed did not have these resources or had other pressing priorities (e.g., housing and food insecurity). They did not, therefore, receive the support they need for their child, leading to poor and inequitable outcomes. In addition, these families had become disengaged and were not seeking support despite struggling.

The fact that the **services don't operate together** is incredibly frustrating. Yeah, we talk about inter-agency. **They're really not joined up** as they should be. (Family living with FASD)

Without an FASD assessment pathway, families and their children with suspected FASD struggle to get a diagnosis and access support services

Currently, no national standards or guidelines exist on the expected diagnosis, assessment, and intervention pathways for children with FASD or suspected FASD aged under 10 years or across their life course. However, national diagnostic guidelines for Aotearoa New Zealand are under development.

Health stakeholders interviewed noted the internationally accepted standards for diagnosing FASD (Cook et al., 2015) are only applied in a few regions. As a result, children with suspected FASD, particularly those with moderate needs, tend not to meet the eligibility criteria set within the different assessment and diagnostic services in the health system.

Families interviewed spoke of being shunted across health services (e.g., Child Development Services, paediatric services, and Child and Adolescent Mental Health Services) and hoping for the 'right' presentation of symptoms to fit into a service. Health stakeholders in the two regions also highlighted that children with suspected FASD did not easily 'fit' into their existing diagnostic pathways before introducing FASD diagnostic pathways and multidisciplinary team meetings. For example, the Child Health Integrated Referral Pathway (CHIRP) was set up in the Hutt Valley to strengthen its response to children with high needs. The multidisciplinary group meets weekly and comprises managers and frontline staff across sectors. At CHIRP meetings, the group discusses referred children's needs and which organisation is best placed to offer support.

Not necessarily at our [local] level but at a higher systems level, **there's a 'No, that's your job. No, that's your job' kind of an attitude** because services are overloaded. (Health)

The limited capacity within health services means they prioritise who is seen and when. Services tend to triage families who have the highest needs. If families do not qualify they can be left without support, or attempts are made to get another service to support them.

If your child **doesn't have behavioural problems, they're not going to be taken**. And it's not just behavioural problems, it is moderate to severe behavioural problems. So [service] has a **chronic staffing shortage**. I understand they **have to put those limitations in place because they can't do everything**. (Health)

Passionate health staff, not a system response, are creating best-practice FASD pathways in the two regions

In Hutt Valley and Hawke's Bay, FASD diagnosis and assessment pathways have been established within existing neurodevelopmental diagnosis and assessment pathways. Their FASD diagnosis process aligns with the international best practice (Cook et al., 2015). An FASD diagnosis requires evidence of alcohol exposure before birth and severe impairment in at least three out of 10 domains of central nervous system structure or function (e.g., motor skills, neuroanatomy, language, attention, executive function).

To carry out an accurate FASD assessment, a multidisciplinary team (e.g., a paediatrician, psychologist, speech-language therapist, occupational therapist, and social worker) work together, with input from education providers and the child's family/caregiver, to complete a comprehensive physical and neurodevelopmental assessment.

These FASD diagnostic and assessment pathways were established by passionate health professionals, including paediatricians and psychologists, who saw the need for a more effective response to families living with FASD in their regions. The drive to develop the FASD diagnosis and assessment pathway was not due to national-level direction.

We had a **passionate paediatrician around FASD** – so they provide **FASD services without additional funding**. [Other DHB] don't have funding and we know that occurs across the country. Where there's no funding, it is **reliant on potentially passionate people who feel ethically** the need to make a service happen. (Oranga Tamariki employee)

In these regions, multidisciplinary FASD diagnosis and assessment pathways were developed using limited discretionary DHB funding. As a result, services face challenges with the capacity and capability to meet the level of demand from their communities for FASD assessment and diagnosis (discussed [here](#)). In addition, stakeholders questioned the sustainability of these responses as they are not funded, are relationally based, and the demand for assessment is growing.

Both regions are working to create a joined-up and collaborative inter-agency response to support families and children living with FASD, which is an area of ongoing work

In Hawke's Bay and Hutt Valley, establishing multidisciplinary networks has increased members' awareness of other services and their role in supporting families and children living with FASD. However, professionals from health, education, Māori providers, and NGOs interviewed and not involved in these networks said they had a limited understanding of FASD services and the regional assessment and diagnosis pathways. They are keen for opportunities to build their knowledge of FASD and the services available, recognising the need of families in their service.

[Education sector] has more of an influence than [health sector]. Because [education sector] teaches our kids. **[Education sector] and [health sector] can make or break a positive pathway for a FASD child**. They have a significant influence on caregivers and the community for our tamariki to minimise judgement in the system and raise awareness. (Family living with FASD)

In Hawke's Bay, health professionals are working to enhance education connections, understanding, and collaboration to support families. Hawke's Bay introduced a Developmental Coordinator role to strengthen the inter-agency links and provide post-diagnosis support. In Hutt Valley, health professionals trained in FASD-informed response are offering training sessions to other professionals working with families to strengthen their knowledge of FASD. These responses are relationship-based; if people leave, the connections gained may disestablish. This connecting and training work is occurring on top of large clinical workloads.

In the two regions, Iwi and Māori providers' feedback highlighted they were not contracted or involved in supporting whānau Māori living with FASD. In Hawke's Bay, some work is occurring to connect whānau Māori with Māori providers.

The challenges of sharing data across agencies can also create delays and a disjointed cross-agency experience for families. Families must provide consent for services to access their information. Services can experience difficulties accessing historical records and information (e.g., medical notes) from previous doctors, DHBs, or schools. Waiting and requests for information can create a disjointed experience for families.

Sector reforms present opportunities to enhance the whole-of-system FASD response

Many sectors are undergoing changes in their strategic directions and priorities. These reforms present opportunities to strengthen and create a joined-up whole-of-system response to people living with neurodiversity generally and FASD specifically.

The health and disability reforms create an opportunity to strengthen the system response for families living with FASD

The Pae Ora Act lays the foundation for transforming the health system to support all New Zealanders to live longer and have the best possible quality of life. Stakeholders interviewed felt the health and disability reforms present opportunities to strengthen the focus on FASD and the health system response to support families living with FASD, particularly Māori whānau and those with moderate needs.

The education sector reform includes more flexible support for neurodiverse children and young people with moderate needs

The Ministry of Education's Learning Support Delivery Model is supported by the Learning Support Action Plan (2019 - 2025), which is currently being implemented (Ministry of Education, 2019). The Action Plan seeks to contribute to:

- Outcome 1 of the New Zealand Disability Strategy ('we get an excellent education and achieve our potential throughout our lives')
- obligations under the United Nations Convention on the Rights of Persons with Disabilities, and
- Te Tiriti o Waitangi through ensuring the education system values mātauranga Māori.

One of the Action Plan's six key priorities is 'flexible supports and services for neurodiverse children and young people', which is targeted at children with 'moderate needs.' Changes in this space could improve support for children with FASD who do not qualify for higher-need services. Consideration is needed on how this action plan's implementation will support and interlink with a whole-of-system response to FASD.

In 2022, the Ministry of Education completed the Highest Needs Review, to inform options for a new fit-for-purpose support system for learners with the highest needs.¹⁸ The Highest Needs Change Programme is now underway.

Oranga Tamariki is shifting to be Te Ao Māori-grounded, rights-based, and oranga-framed, which may benefit whānau Māori living with FASD

In 2021, the Oranga Tamariki Ministerial Advisory Board report was released.¹⁹ The report recommends Oranga Tamariki progresses its relationships with families, whānau, hapū, Iwi, Māori, professional social work practices, and Oranga Tamariki organisational culture.

Over the next two to five years, Oranga Tamariki will implement its Future Direction Action Plan.²⁰ Oranga Tamariki is shifting its practice to become Te Ao Māori-grounded, rights-based, and oranga-framed. This shift influences how the organisation will work with tamariki with FASD and their whānau and develop solutions through partnership with hapū, Iwi, and Māori organisations.

The Oranga Tamariki Action Plan is also one of the mechanisms to support the implementation of the Oranga Tamariki Future Direction Plan. The Oranga Tamariki Action Plan²¹ promotes a collective approach to wellbeing for children, young people and families with the greatest needs, by enabling

¹⁸ More information on the Highest Needs Change Programme can be found [here](#).

¹⁹ The Oranga Tamariki Ministerial Advisory Board report can be found [here](#).

²⁰ The Oranga Tamariki Future Direction Action Plan can be found [here](#).

²¹ Under the Children's Act 2014, [the Oranga Tamariki Action Plan](#) must set out how children's agencies will work together to achieve the outcomes set out in the Child and Youth Wellbeing Strategy for the core populations of interest to Oranga Tamariki and may include any other steps considered important to improving the wellbeing of those populations.

government agencies to work more effectively together and support whānau and communities to realise oranga tamariki²².

Additionally, Oranga Tamariki is developing a Disability Strategy for neurodiverse conditions (including FASD) in its care and protection and youth justice populations.

Strategy and processes are needed to ensure focus on a whole-of-system approach for FASD within these wider system reforms

Stakeholders interviewed noted the reform opportunities for creating a cohesive, nationally consistent, and equitable response for families living with FASD. However, they also warned care is needed that the reforms do not perpetuate existing access barriers and siloed approaches to supporting families living with FASD.

Stakeholders worried families and children living with FASD and other neurodevelopment disorders may be overlooked in this wider system reform. Their concern arises from the implementation of the FASD Action Plan. While actions specific to each government agency have been achieved, enabling a nationally consistent and joined-up whole-of-system response for FASD has not emerged. Feedback indicated the need for strong leadership, governance, and accountability to facilitate different agencies' priorities and reforms.

Within this wider reform, stakeholders advocated for a whole-of-government strategy for neurodiversity generally and FASD specifically to foster a sustained and localised system-based response with FASD-informed services and support for families and children living with FASD. The strategy needs strong governance, including Māori leadership (linked into the wider reforms), and the resources and structures to deliver and review the strategy.

Whole-of-system opportunities

The following whole-of-system opportunities were identified from the feedback from families and stakeholders to improve outcomes for families and children aged 0–10 living with FASD:

- Develop a whole-of-system strategy for neurodiversity generally and FASD specifically to foster a nationally consistent, and joined-up response for families living with FASD, linked to wider system reforms
- Ensure strong cross-agency governance (embedded in wider system reforms) and review the implementation.

²² Oranga Tamariki definition: "'Oranga' is the wellbeing Oranga Tamariki want to help the children they work with to have. 'Tamariki' reminds them that children are descended from greatness. They are born with an inherent mana that can be damaged by abuse and neglect."

Creating a system response that meets Te Tiriti obligations

This section provides key insights and opportunities to ensure diagnostic and support pathways for whānau Māori and their tamariki under 10 living with FASD or suspected FASD meets Te Tiriti obligations as defined by Whakamaua: Māori Health Action Plan (Ministry of Health, 2020b).

Government agencies' enhancements to the FASD system response need to meet Te Tiriti o Waitangi obligations

Colonisation and the resulting loss of land and culture have devastatingly affected whānau Māori health and wellbeing (Durie, 2017; Cram, 2019; King et al., 2018; Pihama et al., 2019; Moewaka Barnes & McCreanor, 2019). Key losses for Māori include the separation of whānau from their whenua, destabilising whānau, hapū and iwi identities; losses of language, economic and political independence, and whānau as a protective collective; and the undermining of agency and autonomy. Māori experience significant health inequities compared to non-Māori and have the poorest health status of any ethnic group in Aotearoa New Zealand (Curtis et al., 2019). The inter-generational trauma of colonisation related to alcohol will have contributed to the impacts of FASD on whānau Māori.

Te Tiriti o Waitangi (Te Tiriti) is the founding document of Aotearoa New Zealand. Manatū Hauora, Te Whatu Ora and other government agencies are responsible for contributing to the Crown meeting its obligations under Te Tiriti. The research has been guided by Manatū Hauora's expression of Te Tiriti as outlined in Whakamaua (*Māori Health Action Plan 2020–2025*) (Ministry of Health, 2020b).

Five principles guide Manatū Hauora:

- Tino rangatiratanga, which provides for Māori self-determination and mana motuhake. Māori are key decision-makers in service design, delivery, and monitoring.
- Equity requires the Crown to commit to achieving equitable health outcomes for Māori and to eliminate disparities (i.e., equitable access and funding and encompasses freedom from discrimination, both conscious and unconscious).
- Active protection requires the Crown to act to the fullest extent practicable to protect Māori health and achieve equitable outcomes for Māori.
- Options require the Crown to provide for and properly resource kaupapa Māori services. This principle requires the availability and viability of kaupapa Māori solutions alongside mainstream services and the assurance Māori are not disadvantaged by their service choices.
- Partnership requires the Crown to work in partnership with Māori in the governance, design, delivery, and monitoring of services.

Whakamaua also enables the health and disability system to implement actions that can contribute to the Crown upholding the UN Convention on the Rights of Persons with Disabilities (Ministry of Health, 2020b).

Whakamaua offers key priorities for Manatū Hauora to develop policies and strategies to enhance the system response to whānau Māori and tamariki aged 0–10 years. While Whakamaua does not directly reference FASD, we used the four priority areas to consider how the FASD system response

can be strengthened to improve outcomes for whānau Māori and tamariki living with FASD. The four priority areas are²³:

- Māori governance and leadership as a significant enabler for achieving equity and wellbeing
- Intersectoral collaboration as a whole-of-government approach is needed to create healthy environments (wai ora) to support hauora Māori across social, cultural, emotional and spiritual domains
- Māori sector development to enable a connected network of providers to deliver whānau-centred and kaupapa Māori services to provide holistic, locally-led, integrated service and support.
- Māori workforce development as Māori are under-represented in health and other professional workforces. Having Māori staff contributes to addressing racism in the services by providing culturally safe and responsive services and support.

A way forward is culturally led and clinically and educationally partnered

Enhancing the FASD response needs to lead with strengthening tino rangatiratanga for whānau Māori

A key response to Te Tiriti o Waitangi is to reclaim and strengthen tino rangatiratanga for whānau Māori, hapū, and Iwi. Strengthening tino rangatiratanga enables whānau to make well-informed decisions, identify strategies for change, and include cultural imperatives, whether whānau, language, place, or face.

Whānau Māori interviewed highlighted the FASD response is primarily clinically led with a focus on seeking to get an assessment and diagnosis. Whānau Māori and tamariki had to wait to receive a diagnosis at 10 or 12 years due to tamariki needing to be developmentally mature and the lack of assessment capacity. During this time, whānau Māori received little, if any, support (discussed [here](#)).

Access to education support and services places tamariki at the centre and does not require a confirmed FASD diagnosis. However, as whānau Māori interviewed demonstrate, the people they engage with in the education system do not fully understand FASD. They noted their tamariki with suspected FASD are labelled as 'naughty' due to 'bad' parenting. This labelling and lack of support isolate whānau Māori caring for a child with FASD and continue to contribute to inequitable outcomes for tamariki Māori and their whānau. Some whānau Māori interviewed also highlighted a reluctance to engage with services, even when under significant pressure, for fear of punitive repercussions linked to the ongoing impact of colonisation.

The isolation of whānau Māori is driven by a lack of understanding of the presentation of FASD, the pathway to receive help, and the strategies to support tamariki with suspected FASD. Opportunities exist to actively engage whānau Māori in the development of a population health strategy to increase whānau Māori understanding of:

- the impact of alcohol during pregnancy
- FASD symptoms
- the pathways to diagnosis and FASD-informed services
- how to support whānau Māori living and caring for tamariki with FASD.

²³ For each priority area, Whakamau details the evidence supporting the action area under the section 'Why is this important?'

Whānau Māori require strong cultural connectedness and support to ensure improved outcomes for the tamariki with an FASD diagnosis. Whānau Māori interviewed want culturally led, culturally responsive, and FASD-informed services so they can make well-informed decisions, take control of circumstances affecting them and their tamariki, and create healthy, positive environments.

Māori leadership and governance are needed to inform decision-making about how to enhance the FASD system response nationally and regionally

As demonstrated through whānau Māori interviews, Māori have the solutions to create more culturally safe and responsive services and FASD-informed whānau, hapū, and Iwi. For example, one whānau Māori interviewed described how they built their understanding of FASD and worked as a whānau to apply strategies that reflected the strengths and challenges of tamariki. They worked to develop their solutions after engaging with education and other services who would not listen and negatively labelled their tamariki and them. Based on their research about FASD, they changed their parenting style and home and school environment to a more enabling environment for their tamariki. They have a life plan for their tamariki strongly linked to their culture and whānau and hapū.

Influencing change for improved and equitable outcomes for Māori requires leadership that reflects whānau Māori and tamariki living with FASD and seeking access to services. Strong, visible Māori participation in decision-making roles within the FASD policy-setting environments are imperative, at the national level, to contribute to reducing inequities of access and outcomes for whānau Māori and tamariki with FASD. Health, education, and care and protection sectors are going through transformative change to better meet Te Tiriti obligations. Enhancing the FASD system-wide response needs to be linked to these changes, and Māori leaders and whānau Māori with knowledge or experience of living with FASD need to contribute to this change.

As indicated in feedback from Hawke's Bay, Māori leaders also need to be actively engaged in cross-sector regional solutions to strengthen the response to whānau Māori and tamariki living with FASD. Māori providers interviewed highlight a lack of Māori leadership in developing a whole-of-system response to support whānau Māori living with FASD.

Cross-sector integration across health, disability, education, and social welfare is needed at national and regional levels to support whānau Māori-centred services

In line with Te Tiriti obligations, government agencies need to work together to reduce inequities across the social, health, education, and welfare domains. Currently, the policy settings supporting an FASD system response sit with a cross-agency Coordination Group and a Governance Group at a national level. These groups are vital to ensuring the alignment of FASD priorities and policies across agencies and their high-level strategies. As indicated, where sector processes intersect can create challenges for whānau Māori seeking joined-up support to enable their tamariki to thrive and grow.

Joined-up thinking, responses, and accountabilities are critical to support the reduction of inequities. Without it, whānau Māori will continue to suffer, and inequities will grow. The cross-sector FASD approach needs strengthening to enhance outcomes for whānau Māori and tamariki living with FASD. This cross-sector FASD approach needs to be embedded into the wider sector transformation work to ensure gains to date and ongoing work are not lost in the change process.

Māori sector and workforce development needs to be supported through equitable commissioning to support holistic services for whānau Māori and tamariki with FASD

Strategies to support whānau Māori and tamariki with FASD (or suspected FASD) require the inclusion of FASD-informed Māori providers and Māori workforce who can support whānau Māori

and tamariki with FASD (or suspected FASD). Many Māori providers offer holistic whānau-centred²⁴ services grounded in culturally informed and culturally responsive kaupapa Māori services and practice. Many train their staff in the Whānau Ora approach²⁵ which guides their work.

Feedback from Iwi and Māori providers interviewed highlight they do not have a defined role in the system response. Māori providers also tend not to be included in the cross-agency forums on how best to support whānau Māori and tamariki living with FASD (or suspected FASD). This lack of engagement can reflect a prioritisation of western methodologies over a Te Ao Māori worldview approach, or worse, a lack of appreciation of the strengths of Māori providers.

Like other services, Māori providers' capacity and understanding of FASD can be limited. Māori providers noted a lack of time and access to FASD training which incorporates mātauranga Māori.

Whānau Māori interviewed clearly identified a need for access to culturally safe services. Māori providers bring a cultural and environmental understanding of the local knowledge and values in meeting the needs of whānau Māori and tamariki living with FASD. They can also strengthen whānau Māori connections in their communities and culture. Having FASD-informed Māori providers is a priority to enable whānau Māori living with FASD to experience the benefits of a Te Tiriti responsive system fully. More investment is needed in Māori providers to build their workforce's understanding of FASD and how their strengths can contribute to supporting whānau Māori. Iwi and Māori providers have their tino rangatiratanga and know how they are best placed to walk alongside whānau Māori and tamariki living with FASD. Engagement is also needed with Iwi and Māori providers to determine their role in supporting the FASD system response.

Opportunities to better meet Te Tiriti o Waitangi obligations

The following opportunities were identified from the feedback from families and stakeholders to improve outcomes for families and children aged 0–10 living with FASD.

- Ensure appropriate national and regional level cross-agency governance includes Māori leadership and whānau Māori living with FASD.
- Ensure whānau Māori living with FASD are respected, listened to, have choices and resources, and are actively involved in the solution to support their tamariki.
- Invest in Māori providers to build their workforce's understanding of FASD.
- Engage with Iwi and Māori providers so they can determine their role in the FASD system response.

²⁴ We have used Te Puni Kokiri's (2015) definition of a 'whānau-centred approach' as a culturally grounded, holistic approach focused on improving the wellbeing of whānau and addressing individual needs within a whānau context.

²⁵ Whānau Ora recognises the strengths and abilities that exist within whānau and aims to support and develop opportunities that fulfil potential. Whānau Ora enables whānau Māori to identify their priorities and action their solutions.

Enhancing the diagnostic and support pathway

This section provides key insights and opportunities about the diagnostic and support pathways to support and improve outcomes for families and their children aged 0 to 10 years living with FASD or suspected FASD.

Cross-sector collaboration underpins a coordinated and accessible pathway for families and children with FASD

As noted, across government agencies, a range of health, disability and educational services and supports are available for families and children living with FASD. The Hutt Valley and Hawke's Bay regions were selected for the research as their Child Development Services' FASD assessment and diagnostic pathways align with international best practice. While this is a positive regional development, both families and regional stakeholders interviewed highlighted challenges for families with children with suspected FASD to access timely FASD diagnosis and joined-up support services. The challenges of accessing support services are particularly marked for families of children with a sole diagnosis of FASD or more moderate needs.

The feedback from the two regions demonstrates the importance of an FASD diagnostic and assessment pathway based on international practice. However, improving outcomes and reducing inequities for families and children with FASD requires cross-sector collaboration to deliver a coordinated, consistent, accessible, and appropriately resourced service and support pathway. This section highlights the service gaps and challenges for families interviewed, reinforced by stakeholder feedback and indicates improvement opportunities.

Families interviewed want to understand their child's needs

Professionals working with children need to identify potential signs of FASD

Families interviewed expressed feeling 'something was not quite right' with their child as they grew up. They noted their child's behaviour and responses were different from other children. Some suspected FASD due to family history. Others said a teacher at their child's kindergarten, kōhanga reo, or primary school raised concerns about their child and advised seeing their GP to see if any underlying issues existed.

[Name] looks normal because now I know it's a hidden illness. People would judge her, they didn't mean to because she looks normal, because they expect to see something physical wrong with her. They used to go, **'Oh, she's just acting it', but now they know. Now she's getting help.** (Family living with FASD)

Some families went to their GP to discuss their concerns, and some raised the possibility of FASD. Some families were supported by their GP to understand FASD and referred to assessment services. However, other families noted their concerns were dismissed as the child did not have identifiable FASD facial features. Their experience indicates the need to build understanding and awareness of FASD in primary care to ensure smooth referral paths to Child Development Services. A few families not referred to the Child Development Services (or facing a long waitlist) had a private FASD assessment.

I said to the doctor, 'I think she's got FASD. **And he looked at her, and he said, 'No, she's not got the facial features.'** At age eight, we paid to get a private diagnosis and she did have FASD. (Family living with FASD)

Health and education sector and Oranga Tamariki stakeholders noted a crisis point in primary school could trigger the assessment process at school as the child ages. Reaching this crisis point may reflect that mild or moderate issues have been exacerbated due to a lack of early support. Interventions for crises are usually more resource-intensive and require more effort. Interventions include those available in the justice system, care and protection sector, mental health services through Infant, Child, Adolescent, Family Services [ICAFS] or Infant, Child, Adolescent, Family Mental Health Service [ICAMHS], and wraparound services (IWS and HCN).

I often get called in quite late. **I get called in at crisis point**, and often when children are stood down. We really need to work in that prevention space. When a child is in care is too late too. When they come into care, we should be setting up right there and then, and hopefully, slowly, that is shifting a little. (Oranga Tamariki employee)

Families want access to timely and early assessment and diagnosis processes

Families interviewed want a diagnosis to understand their child's strengths and challenges. For some families, receiving an FASD diagnosis is both a relief and proof their child is not naughty and they are not a bad parent or caregiver.

I burst into tears because it was like **for years, we had been trying to get her diagnosed** on this. Because we know that as she moves on, **she's got FASD. This needs a different approach**. Having that acronym means a lot for us because it gives us more ammunition to say that **she's not being a bad kid**. (Family living with FASD)

Having a diagnosis meant families could learn how best to parent and care for their child with a traumatic brain injury. Families talked about their research into FASD and working to educate their families and other health and educational professionals. Knowing their child's strengths and challenges enables families to plan for their child's future, seek support, and help to enable them to live their best lives.

Relief and now we have a plan, we know where we're heading. We're not on this road by ourselves, and she will get that support. The good thing about being diagnosed and she will have this for life, **is she will get that support she's going to need**. We feel comfortable now that she's going to be **okay if we're not around. She's going to be okay**. (Family living with FASD)

Having an FASD diagnosis meant families could receive appropriate health support (e.g., speech-language therapy, as many children with FASD struggle with severe language disorders). With permission, the Child Development Services in Hawke's Bay and Hutt Valley (as in other Child Development Services) could share relevant information with the child's school and Learning Support professionals to help develop appropriate in-school support. Highly personal family information is not shared.

If you don't have the right diagnosis for anything, and this is not just FASD, then you're **not going to get the right intervention**. The intervention follows diagnosis. The benefit of an **FASD diagnosis is to get FASD-specific interventions on board**. (Health)

Oranga Tamariki stakeholders also noted that a diagnosis might support people with FASD who end up in the youth justice system to ensure they receive support and help to create an understanding of their disability.²⁶

Families interviewed face challenges with the assessment and diagnosis process

Once families are referred to the Child Development Service in Hutt Valley and Hawke's Bay, getting assessed and diagnosed can be challenging for many reasons.

Children with suspected FASD cannot get diagnosed until they are around eight years old

Clinically, a definitive diagnosis occurs from around eight years old. At this age, children are more mature developmentally, and cognitive and neurodevelopmental signs of FASD are more pronounced. As a result, families must wait to commence the assessment process.

There were things we did while she was five years old and **then we had to wait a long time, 'til she was seven.** From that point on, I knew what we were dealing with. I needed information on **how the brain functions with this FASD.** Because I was thinking, '[Name A], **you're just playing up.**' I'd treat her like a normal kid, but then I couldn't. It was **getting more frustrating for me, for [child],** for the family. (Family living with FASD)

Children with high needs tend to be seen annually by their paediatrician and may receive some support.

Limited diagnostic capacity means a long waitlist exists for an assessment

Once a child with suspected FASD turns eight years old, they are placed on an active waitlist for an FASD assessment in Hutt Valley and Hawke's Bay Child Development Services. However, diagnostic capacity is limited in these regions, and existing assessment teams are stretched due to increasing demand, resulting in long wait times (discussed [here](#)).

Currently, the waitlist is around four years in Hawke's Bay and one to two years in the Hutt Valley as demand exceeds the capacity to deliver a comprehensive assessment. Once a referral is made, families wait for their assessment. In the interim, families noted they lack access to FASD-informed services and support.

I've been in this process of being diagnosed since she was five. **It's a long process.** It's not fair because the early years are important, especially at school. **They let her fend for herself, which I feel is cruel, and there was nothing we can do about it.** (Family living with FASD)

For some families, the wait is too long. Hope is lost and life moves on. Hawke's Bay provides families on the waitlist with a face-to-face visit by the Clinical Coordinator to address this gap. This role aims to answer questions and link families to other services and supports available (e.g., parent support groups, parent education, applying for the Child Disability Allowance, social support, hearing tests). Families might also continue with follow-up appointments with their paediatrician.

²⁶ Phase 2 of the research will explore the role of youth justice.

The child can sometimes become lost to the health system as families move away for various reasons. They might also move to areas that do not have an FASD assessment pathway in the Child Development Service.

Often, a lot of the parents that our service works with, the **hope is gone. The kids disappear from the systems very quickly and are quite old now.** We need this here to work well so that the **hope is put back into our services** and into the life journeys for these young people. (Health)

Families need to go to multiple appointments with different experts to get an FASD diagnosis

An FASD assessment requires a multidisciplinary team. The family and their child go through a series of appointments with different health professionals. One stakeholder estimated the assessment process probably takes 30 to 40 hours of practitioner time (which includes team discussions and developing the report) and up to 20 hours of the family's time. The assessment can therefore take several months. In addition, families talked of an emotionally and mentally draining time, where they must be patient and advocate for their child.

We could have had help earlier. **It's been emotionally, mentally, physically draining.** It's not the child's fault, but it could have been easier in getting some support through the school, whether it be the Education Department, Health Department, **they all should have helped.** (Family living with FASD)

Having to go to multiple appointments can create an additional burden on families. Families might not have the money for transport (particularly if services are far away) or parking. Some families cannot take time off work.

A few families go privately for an assessment, although some health stakeholders question their quality

Due to the waitlists, families may pay for a private assessment. Children with Oranga Tamariki may also access a private assessment following a Gateway assessment. However, some stakeholders noted the variability of assessment approaches in private practice. For example, some private practitioners do not draw on a multidisciplinary assessment approach.

Private practice is variable, and that concerns me. Best practice is a multidisciplinary assessment involving a paediatrician, a psychologist and plus or minus an occupational therapist. I know that there are **some just clinical psychologists** (diagnosing). **They might be very well-qualified, but best practice points to a multidisciplinary team.** (Oranga Tamariki employee)

A lack of cultural safety exists for Māori and Pacific families and caregivers

Feedback from Māori and Pacific whānau highlighted cultural stigma perpetuating negative stereotypes relating to FASD in their engagement with health. As one whānau explained:

I felt we were judged. 'Oh, look another....' because when we did the forms, we put [Pacific nation], [Pacific nation], and Māori. **Straight away you're judged and I'm like, 'No, you don't even know the history.'** (Whānau)

The assessment and diagnosis process can create stigma and shame

FASD is associated with stigma and blame toward the biological mother. Part of the diagnosis process for FASD requires the biological mother to confess to the relevant health professional(s) (e.g.,

paediatrician) that they drank during pregnancy. This process is disempowering and can be filled with shame. The biological mother's admission cannot be replaced with other evidence of pre-natal alcohol exposure (e.g., someone else saying they saw the mother drink during pregnancy).

Stakeholders noted asking about alcohol use is difficult and must be approached sensitively. At times, difficulties arise with finding and engaging with the biological mother.

Some stakeholders suggested prenatal alcohol exposure could be noted in a child's records by midwives, Well Child Tamariki Ora providers, and Gateway assessors. With maternal consent, accessing this information would help the assessment process.

The assessment process may not build families' understanding of how FASD affects their child

The assessment and diagnosis process, if following health literacy principles, creates an opportunity for families to understand FASD and the strengths and challenges for their child. Families interviewed deeply understood FASD and its effects on their children. They indicated much of their knowledge derived from their own research. Given their depth of knowledge, if listened to, they took on the role of educating other family members, services, and supports they engage with about FASD.

Feedback from health professionals recognised more work was needed to ensure families understood the assessment, the report, and the plan. In Hawke's Bay, they are currently working on making their diagnosis report in plain English and accessible to families and other professionals supporting them.²⁷

A clinical psychologist or a developmental paediatrician might talk in a language that probably some mothers wouldn't necessarily understand. One of the boys I'm working with, the family don't understand the report. (Health)

Hawke's Bay health stakeholders also noted that some parents and caregivers have cognitive challenges. Therefore, where suitable, they take a holistic approach and enable parents to access an assessment and support.

The Gateway assessment can be daunting and uncertain for families and not always welcome

The Gateway process can sometimes speed up access to an FASD assessment, including through private practice. However, stakeholders suggested recommendations may not be actioned due to limited services and funding to support children with FASD.

The Gateway assessment can enable a pathway for a child to get an FASD diagnosis. Feedback from health professionals spoke of benefits for the child having a full health and wellbeing assessment.

One of the things I say to anybody, 'I'd love every child in New Zealand to receive a Gateway.' I don't mean to say it's unfortunate that Oranga Tamariki lead it, it's unfortunate that the perception that **Oranga Tamariki seem to hold in the community is a punitive one.** (Health)

Stakeholders highlighted the process could be challenging, with families not being clear on what they have consented to and fear of punitive repercussions if they do not engage. They also noted families, particularly whānau Māori, who have faced systemic bias and racism, may not want to engage. Some

²⁷ The new Diagnostic Guidelines for FASD in Aotearoa New Zealand is working on protocols for plain English reporting.

families interviewed also noted the stress and uncertainty of this process and their underlying fear of not retaining guardianship.

Hutt Valley and Hawke's Bay work to create a more positive and enabling process and space for families (e.g., working in safe community spaces, working with Manāki whānau, and Whānau Ora staff). However, stakeholders noted more Māori approaches are needed to support better whānau Māori going through a Gateway assessment and potentially an FASD assessment.

Families struggle with the lack of post-diagnosis support

Families and stakeholders interviewed highlighted, following an FASD diagnosis, support and intervention services are extremely limited.

We can assess them and give them a label. That's an **ethical dilemma** that you would put them through that process for a name for which **there are no services** and no support that will follow from it. (Health)

A diagnostic-based plan does not mean access to early intervention to set a child up to live their best possible life

After receiving a diagnosis and plan for their child, families interviewed expect they will be linked to early intervention to support their child and family now and as their child grows. However, many did not receive early intervention support from health or education,²⁸ particularly for children with moderate needs.

We didn't get any extra real assistance when she was diagnosed. It's nice to know what it is but it's not any more support. **She doesn't qualify for any additional assistance** at school so even though she's behind, that's it. (Family living with FASD)

Families interviewed mentioned few health services supporting their child or family after diagnosis. Child Development Services staff who have gotten to know families through the intense diagnosis process are frustrated they cannot offer post-diagnostic intervention support. They noted they have an established trusted relationship with the child and understand their strengths and challenges. They said they are well placed to support the child and family in navigating challenging transitions such as changing schools.

I've done the **assessment and then going, 'Bye!'** It just breaks my heart because **I know that kid now. I could do that follow-up.** I'd be able to say then, 'Right, **now you're at high school; what does this mean?** We know you; we've done your assessment; you know us.' (Health)

Some families struggle to access health and disability support services due to the eligibility criteria

As shown, health and disability services have eligibility criteria. However, families interviewed struggle to access health and disability support services for their child with FASD, particularly for children with moderate needs or a sole FASD diagnosis.

Families interviewed highlighted their frustration that a sole diagnosis of FASD did not meet the eligibility criteria for Disability Support Services (except for access to Child Development Services).

²⁸ Support from the education sector is discussed below.

Families and stakeholders interviewed spoke of their frustration in dealing with NASC and support being tied to accepted disabilities and not the needs of the family and child.

We need disability support, not behavioural support. It is a disability. If FASD is recognised as a diagnosis and funded, the relief would be huge for me. **I am really scared of the future, really scared.** (Family living with FASD)

Families voiced frustration at the inequity of access, given children with Autism Spectrum Disorder (ASD) are eligible for wider disability support services through NASC, while their child with FASD was not.

There is a lot out there if your child is autistic, or even if your child has Aspergers or if your child is ADHD. There's medication, there are support groups. **But when you start talking FASD, it's lonely, lonely!** (Family living with FASD)

One family also highlighted the ongoing stigma when trying to explain to others their child's disability:

There's probably **more support out there for autism** and way **more** understanding. If we say to people as we walk into a situation, **'Sorry, my child is autistic.'** You know they're going to **understand their behaviours.** But if you go, 'Look, our child has FASD.' They're like, 'What? **Fetal alcohol. What does that mean? Did you drink?**' **Then you've got to unpack their story whereas autism, you don't.** (Family living with FASD)

Some children with FASD may receive publicly-funded child mental health services if their needs meet the threshold for severity. However, families interviewed highlighted children with moderate needs miss out or they try to 'fit' their child's needs to the set criteria. Further, stable living arrangements are required to enter child mental health services. As a result, some stakeholders noted these services are less accessible for children living in more transitory environments (e.g., those supported by Oranga Tamariki).

Families interviewed highlighted the difficulties in accessing and maintaining access to funding and resources to support their child's needs

Families interviewed worked to create a safe environment and experiences for their children with FASD. However, many noted their financial struggle to offer these experiences, given the lack of access to government-funded services. A few families interviewed sought financial support from MSD but found the process time-consuming and not FASD-informed. For example, one family highlighted the difficulties of accessing MSD funding when health professionals do not understand FASD and will not sign off a medical certificate.

A doctor is fobbing us off when literally it will **cost her nothing to sign a document that then goes back to WINZ that says we qualify for an allowance of \$50 a week.** I think it's a lack of understanding or a lack of her time right now. (Family living with FASD)

Families interviewed highlighted the current health and disability system takes a 'prove you need support' approach rather than focusing on solutions. Misconceptions also exist that previous assessments become invalid over time. While some families received some health services based on their child's need, they had to prove annually their child continued to need the service. Families interviewed had to be resilient and repeatedly complete paperwork to access ongoing support. For example, families fostering children with FASD noted having to apply annually to Oranga Tamariki to retain funding for services like speech and language therapy.

You've got a disability, but you have to prove you've still got it. We're talking about neurodisabilities that are not going to go away. **Very negative, prove-it type thing.** 'Do you

really need this wheelchair?' How ridiculous but that's the tone, rather than, 'How can we enable you?' **The system is obstructive.** (Health)

Families wanted to access health and disability support services tailored to their growing child's needs

Families interviewed who did not meet the Disability Support Services criteria had access to little, if any, disability support services. These families want support services tailored to their child and family's needs and to evolve to meet their child's changing needs as they grow. Families and health stakeholders interviewed suggest the need for services to support families and children at key transition points, such as starting or changing schools.

The challenge is that [people with FASD] have **something for life**, and it stands alongside them and in situations that may be helpful. I think the **episodic nature** of care can be quite a challenge. (Health)

One family mentioned a holistic service that worked for their children living with FASD. The service came to their home and built a relationship with their children and tailored support to enable their development. Unfortunately, this service is no longer in operation as it was unable to get core funding.

The education system needs to enhance support for families living with FASD

Families and stakeholders noted the education system's important role in supporting children under 10 living with FASD to grow and learn. The education system has an inclusive approach based on the child's needs, not a medical diagnosis. However, most families interviewed were frustrated with the engagement and support from their primary schools. Families mainly reflected on their primary school experience, as this tended to be when their child's neurodevelopmental difficulties became more noted or when they knew their child had FASD and wanted FASD-informed support. No families interviewed mentioned receiving Early Intervention Services.

Families interviewed felt their child's needs with FASD were not recognised or understood in early childcare or primary schools

While a diagnosis is not needed in education to gain support, families highlighted the lack of accommodation to enable their child's engagement and learning. Most families interviewed said the needs of their children with FASD or suspected FASD were not recognised in early childhood centres and primary schools. They noted that early childhood and primary teachers did not understand their child's neurodevelopmental difficulties, associated needs, and the best ways to work with them. They felt staff made assumptions about their child's behavioural challenges seeing them as 'naughty' and 'acting out'. Children were put into time-out in early childcare to manage their behaviour; some were side-lined in class or suspended from school. As a result, some families withdrew their children from early childhood education, and others changed to more FASD-informed primary schools.

The teacher got to the stage where **'Ignore [name] and just focus on the good ones.'** And that's basically how they dealt with [name], and other kids in the class who had the same thing... That's **not fair because everybody else is getting a good education, but where our kids have to wait** and suffer until we get the tick [diagnosis]. And by that time, it's too late. (Family living with FASD)

Families assumed that when their child received an FASD diagnosis, primary school teachers would offer FASD-informed support in the classroom. However, some families spoke of schools not reading or applying the insights from their child's FASD assessment report in the classroom. Some talked of working to educate their child's school about the support needed in the classroom. However, teachers were not listening to them. Others noted primary school teachers offering support that did not reflect their child's strengths and challenges (e.g., their language or cognitive capacity).

You're put all through these oppressive practices, so they can tick boxes to say, 'We've done that for the family, and it didn't work.' **Nothing was working. It's just exhausting doing things that you know won't work.** (Family living with FASD)

For some families interviewed, this level of advocacy in the classroom was not possible due to other pressures (e.g., housing, income and food insecurity, caring for other children, and other disabilities in the family). Some families, particularly whānau Māori, impacted by colonisation, chose not to engage with their schools.

Some stakeholders also noted that this lack of accommodation in the classroom reflects the class size and teachers' workload. In addition, education stakeholders noted teacher training does little to prepare teachers to support children with FASD or other neurodiversity.²⁹ Further, they noted schools do not have the money to send teacher aides and other staff on FASD training.

Families struggled to access additional FASD-informed support in primary schools

Families interviewed highlighted the challenges of accessing additional or tailored education support in primary school classrooms. Some families also noted schools were not sharing information on what and how much support is available (e.g., the amount of teacher-aide time allocated). Some schools did not share issues arising in the school setting and enable families to work with the school on potential solutions. As discussed, families with expertise on their child and FASD were not included in developing solutions to enable their child to learn and connect in school.

At school, **she wasn't getting any extra support.** She'd got a diagnosis of an intellectual disability now, plus ADHD, plus possible [name], speech and language disorder. **She had all these diagnoses and no services.** (Family living with FASD)

One family was home-schooling, and while this supported their children, they received little support from the education system.

How do home-schooling parents access the necessary services and support that may be more accessible through the child attending the school system? **Like a teacher aide or resources?** (Family living with FASD)

Families did not know or could not access wider education support in primary schools

Most families interviewed were unaware of wider educational support services available (e.g., Learning Support Coordinator or RTLB) and did not mention having an Individual Education Plan for their child. A few families interviewed who sought support from RTLB were told they support teachers, not families.

I contacted the RBLT. I said, 'Oh, okay, so what's the deal? What do we need to do?' She goes, 'Oh no, **I don't talk to you, I talk to the teacher.**' They didn't want to give me any info. 'Oh, okay, it works like that,' I said. 'Well how much support does she get from teacher's

²⁹ The Ministry of Education is investing in teacher training, discussed [here](#).

aide – 45 minutes?’ And then the school wouldn’t tell me what was going on. So I went, ‘Okay, stuff it,” so I kind of like gave up with it. (Family living with FASD)

The Learning Support Coordinator is a newly established role in education and not all schools have access to one. However, the families and stakeholders interviewed are unclear about the purpose of the position. Not all schools have Learning Support Coordinators, and those that do, use them differently. Feedback indicated an opportunity for this role to work more closely with Child Development Services and families and children with FASD to access appropriate support in their region.

I think the role (Learning Support Coordinator) is quite mucky. The vision was for another layer of resourcing within schools to support schools with students that might have special learning and/or behaviour needs. But they weren’t rolled out into every school so the system’s inequitable to start with. (Education)

ORS funding is for students with the highest level of need. No families interviewed mentioned receiving ORS funding, which reflects children with moderate needs would not reach the criteria for this specialist support. A survey by FASD-CAN found most members were unsuccessful when they applied for ORS funding (FASD-CAN, 2022b). The Ministry of Education’s Learning Support Action Plan (2019 - 2025) is working to enhance flexible support and services for neurodiverse children and young people with moderate needs.

Families interviewed worried about the transition from primary school

Families worry about the transition of their child with FASD out of primary school. Families with support from their primary school talked about plans to enable a positive transition to intermediate school. However, other families did not have this sense of reassurance.

The FASD response needs to support families living with FASD

The limited response to a child with FASD is focused on the child and not on families

Families play a crucial role in the lives of children with FASD. For families, living with FASD is a stressful experience, particularly if they have limited support. Families interviewed talked about how their parenting styles had to change and adapt to their child’s needs. As a result, many invested their time and resources to educate themselves and others in their families and communities.

You cannot focus on the child when you have a diagnosis like FASD, you need to focus on the caregiver and the family. If they know what’s going on, if they understand how to enhance this child’s strengths, if they understand growth-enhancing skills and strategies, that child will be successful. (Health)

Families noted few FASD-informed parenting courses and programmes exist. Some families had attended courses on attachment disorders and Incredible Years. Families spoke positively about the courses but noted little focus on living with a child with FASD.

Families interviewed want to be connected to other families living with FASD

Living with FASD can be isolating. Families perceived community support groups as helpful as they could connect with other families over similar experiences. FASD-CAN and Caring Families were key sources of information and training for some families. Clinicians doing assessments inform families about FASD-CAN. However, a few families were unaware of their services.

I'm in that group (FASD-CAN) because I can relate to them, they can relate to me. **We share information.** And those are the groups I'm really interested in, that I can relate to. (Family living with FASD)

Some families wanted access to FASD-informed respite care

Life can be challenging and exhausting for families living with a child with FASD. Given the challenges, some families spoke of family members withdrawing support or stopping contact. These families felt isolated and unsupported.

Some families interviewed want FASD-informed respite care. However, their child did not meet the NASC eligibility criteria for this support. While needing rest, a few families fear respite care will not be FASD-informed and may be traumatic for their children. A few families talked of using respite care only to be called early as their child was distressed and the carer was not coping.

Having that **break for you to reset as a family** and for [Name] to have a place where she can go and just do whatever she feels like doing. **It was an amazing help.** It was manageable at that time. **When the respite stopped, it really exacerbated.** (Family living with FASD)

Residential care needs to be FASD-informed

One family highlighted significant issues with their young person's residential centre. The care received was not FASD-informed and focused on punishment. The family raised concerns, but no action was taken, even when the family offered advice on how best to work with their child.

They have no FASD-informed care. FASD-CAN has written a bi-cultural resource that gives all the strategies of how to deal with someone with fetal alcohol. I said, 'Right, **I want this to underpin her care plan.**' Because they're not doing it right. They're **punishing her** all the time. The **manager refused**, said, 'No, I'm not following any of that. **I'm going to do what I want to do. What we do is working.**' (Family living with FASD)

More research is needed into the experiences of families and children living with FASD in residential settings.

Stakeholders suggested solutions to address the siloed system response

A community hub for cross-sector professionals to cultivate collaboration

Some stakeholders proposed a community hub for professionals across agencies and NGOs to come together. A comparison was made to a similar initiative for children with ASD. The hub could have professionals who are knowledgeable about FASD and can advise others. The hub would also provide a welcoming space for families living with FASD to support each other. The hub may reduce the barrier for those who have had a negative experience with the formal system.

Stakeholders and families suggested having an FASD coordinator role

Stakeholders and families see the value in having a support navigator or equivalent role for children with FASD (similar to the ASD coordinator). The FASD coordinator role would be knowledgeable about available services and help families access services and support. While an FASD navigator role would not fix the siloed system response, the role would take pressure off families trying to navigate

the system and work to remove access barriers for families unable to navigate the system for whatever reasons.

What I would love to see is the **establishment of connectors, navigators, whatever you want to call them, kaitiaki, kaiāwhina**. Having highly trained kaiāwhina who could specialise in FASD, SUDI [sudden unexpected death in infancy], and who are the **first point of contact**...They can **advocate for them** across health, social development, anywhere.
(Health)

Stakeholders and families want access to support at key life transition points

FASD is a lifelong disability, and support needs can vary throughout life. Families want access to support that reflects their child's needs now and as they grow. In addition, they want more intensive support at key life transition points for their child under 10 and as they age and develop³⁰ (e.g., entering primary and secondary school, leaving school, moving into further education or employment, living independently).

Assessment, diagnosis and support opportunities

The following assessment, diagnosis and support opportunities were identified from the feedback from families and stakeholders to improve outcomes for families and children aged 0–10 living with FASD.

- Ensure families living with FASD are respected, listened to, have choices and resources, and are actively involved in the solutions to support their children.
- Have an assessment and diagnosis pathway for FASD nested in a wider neurodevelopmental assessment process based on Aotearoa New Zealand's diagnostic guidelines (when released).
- Develop and implement a workforce strategy, drawing on Whakamaua and Ola Manuia, to build multidisciplinary and cultural capability in the neurodevelopmental and FASD assessment.
- Consider the opportunity for a sole diagnosis of FASD to qualify for Disability Support Services so children with more moderate needs can access disability support services.
- Enable access to evidence-informed early interventions that address systemic influences (e.g., psychoeducation and support for the family, environmental accommodation, child-focused interventions, and integrated case management) (McLean, 2020).
- Continue work to create an FASD-informed education system that supports children with FASD based on their needs to support their learning and connection with peers.
- Establish localised FASD or neurodiverse community hubs to enable cross-sector and family collaboration.
- Have FASD coordinators to support families in accessing services and offering advice.
- Have access to FASD-informed respite options.

³⁰ Key transition points and needs of older children and teenagers (aged 10 and over) will be explored further in Phase 2 of the research.

Developing an FASD-informed workforce

This section provides key insights and opportunities to inform decisions related to workforce capability and capacity to support and improve outcomes for families and their children aged 0 to 10 years living with FASD or suspected FASD.

More work is needed to increase understanding of FASD

Awareness of FASD is increasing, but universal understanding is needed

Families and stakeholders noted that FASD awareness is slowly growing over time. Increasing awareness is linked to media coverage and other promotion on the impacts of prenatal alcohol use.

People are **becoming more open** now because there is **more talk in the media about fetal alcohol**. We'll get referrals in when nana says 'mum did this.' (Health)

However, families and stakeholders interviewed note FASD awareness and understanding are not universal. Families shared stories of wider family members disengaging due to not understanding how FASD affected their child's behaviour. Some families were able to rebuild connections by educating their wider families. However, some decided to remain separated due to their ongoing negative and stigmatising attitudes to them and their child.

All families interviewed offered examples where they experienced judgement and a lack of FASD-informed practice when engaging with professionals. These negative experiences can result in families disengaging from services and losing trust or reinforcing existing distrust in the service.

In the **final (health) session** I was in with (child), they were **really struggling** in the environment and were breaking down. I was like, '**Let's have a breather**, let's walk around the office, let's sit back down.' **They wouldn't re-engage and finish the game**. The (health) person turned around and went, '**I'm not going to be your friend anymore because you won't finish this game**.' I went, 'And on that note, we're leaving.' This isn't how it should operate, and **that was the breaking point**. (Family living with FASD)

Some families highlighted they try to educate professionals who are not FASD-informed. However, not all are receptive to increasing their understanding or changing their practice.

We were like, 'Help us out. This is what we've got.' They've got all the paperwork but it was like **the school didn't want to work with us**. (Family living with FASD)

Frontline staff need to know the potential signs of FASD to increase access to support

Families and stakeholders interviewed highlighted that awareness and understanding of FASD and the potential signs of FASD vary across and within sectors (e.g., primary care, Well Child Tamariki Ora providers, early childhood and primary teachers, NGOs, residential care, Māori providers). This lack of understanding is partly due to their formal training not including or only having a limited perspective on FASD (or neurodiversity).

Families and children with suspected FASD need frontline staff they engage with in the early years (i.e., before eight years) to know the potential signs of FASD. Frontline staff need to be confident in having non-judgemental and strength-based conversations with families about FASD. These conversations need to take place in a wider environment that is focused on preventive messages on

prenatal alcohol use that do not heighten stigma and shame for families living with FASD. As appropriate, they must actively remove access barriers to assessment and support pathways.

Positively, some workforce development opportunities on FASD exist

Frontline staff interviewed with limited and more advanced FASD knowledge were keen to learn and build their understanding of FASD and how to apply it in practice. Linked to the FASD Action Plan, Ministries and wider agencies have developed FASD-specific training and resources, which will contribute to building a more FASD-informed workforce over time. FASD training and resources mentioned by national and regional stakeholders and families interviewed are:³¹

- The Ministry of Education has invested in a Postgraduate Diploma in Specialist Teaching at Massey University, where supports for neurodiverse learners is woven into the course content. Currently, over 350 educators have received study awards for this course.
- FASD-CAN³² have training and resources for families and professionals on their website. They delivered training to midwives, teachers, and public defence services. FASD-CAN heavily relies on volunteers and donations and needs ongoing investment to sustain this professional training.
- FASD-trained professionals in Child Development Services in Hutt Valley and Hawke's Bay run FASD training for services that engage with families and children living with FASD (e.g., community talks and presentations, modular training).
- Oranga Tamariki³³ has collated information on its website on supporting children with FASD, the voices of those living with FASD, and links to e-learning modules and overseas resources.
- The Ministry of Education's TKI³⁴ website provides guidance to educators to enable inclusive education and includes strategies for teachers to meet the diverse needs of children with FASD.
- Overseas resources are available like the FASD Hub in Australia.³⁵
- Te Pou o te Whakaaro Nui (2019) has an essential strategies resource to support frontline professionals to make a positive difference in the lives of people with FASD and their families.

³¹ Other FASD training and resources may exist. The list is not exhaustive but more to offer an overview of the actions taken to support workforce capability building.

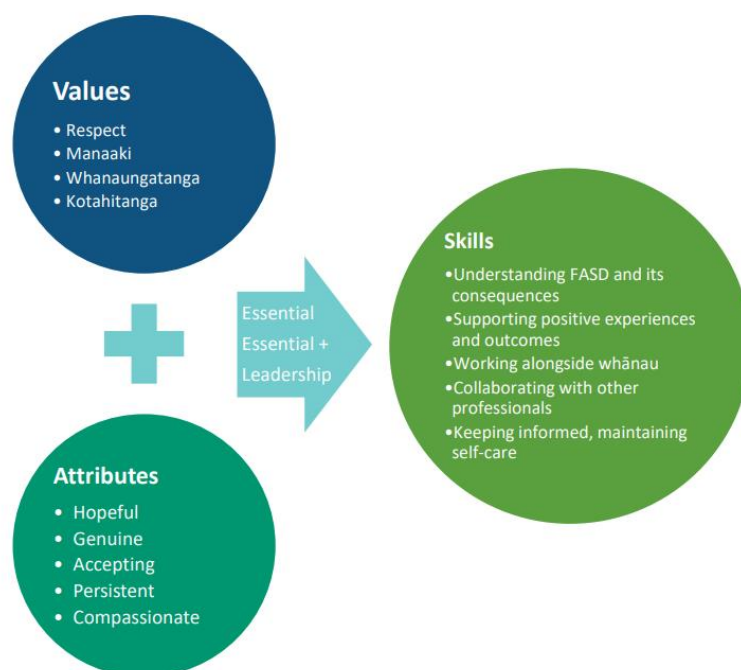
³² The purpose of [FASD-CAN](#) is to unite caregivers, support whānau and individuals, strengthen communities and educate about FASD across Aotearoa.

³³ See information on FASD on Oranga Tamariki website [here](#).

³⁴ See the TKI website [here](#).

³⁵ See [FASD Hub](#) here.

Figure 2. *The Values, Attitudes and Skills Needed to Support People Living with FASD* (Te Pou o te Whakaaro Nui, 2019, p. 5)



Non-FASD specialist staff supporting children need awareness and capacity to engage with FASD-informed training and apply it in their practice

Not all stakeholders interviewed know about the FASD resources available through the Ministries and other sources. Health, education, and other stakeholders noted barriers that impeded their engagement with the resources and training.

Cross-sector stakeholders commented they are seeing more families with complex needs in the last five years. They are seeing children with multiple diagnoses, trauma, and families with wider needs (e.g., housing insecurity, family violence, alcohol and other drug issues). Stakeholders said services are under pressure working within the same capacity. As a result, they prioritise and determine where best to place their effort for maximum return. In this context, prioritising time to focus on capability building on FASD-informed practice can be challenging.

Educators interviewed were aware of the need to know how to apply FASD-informed practice in the classroom and to support key transition or life event points (e.g., moving location, going to or moving schools). However, feedback indicated teachers and other education professionals lack capacity or have not prioritised FASD training and its application due to workload pressures. While having FASD training and resources is a positive step, more work is needed to enable time to focus on FASD learning and how to apply it in the practice environment.

There's a huge amount on there [TKI website] on FASD. **The problem is: who has time to look at that? I know teachers haven't.** It's really a Catch-22 situation. (Education)

Stakeholders suggested having a dedicated regional FASD-informed specialist to provide education and training and to add capability and capacity to the system.

It would be nice to have **someone whose job it is to be a fetal alcohol advisor.** They sit somewhere in education or health. **They're not ring-fenced.** They're not just saying, 'Sorry. I can't come and help you guys because I can only work for health.' (Education)

A national workforce strategy is needed to support an FASD assessment and diagnosis pathway

Families interviewed want an early and timely assessment and diagnosis process for FASD and for assessment processes to be consistent across Aotearoa New Zealand. No national FASD diagnosis guidelines exist, although guidelines are currently being developed.

Child Development Services stakeholders interviewed recommend the FASD assessment pathway is nested in a wider neurodevelopmental assessment process to ensure appropriate diagnosis. They noted that, following international best practices, a multidisciplinary team is needed to complete an accurate FASD assessment. However, stakeholders indicated a lack of capacity and FASD-informed capability in the Child Development Services workforce across Aotearoa New Zealand to meet the international standard.

Feedback indicated Child Development Services' capacity is stretched

In Hutt Valley and Hawke's Bay, Child Development Services stakeholders highlighted they are facing increasing service demand and greater complexity of families and children's needs. As a result, significant waitlists exist, delaying families' access to early assessment and support (if available). These Child Development Services are triaging to manage their limited capacity effectively by weighing up different factors.

They noted other Child Development Services are likely to have similar capacity challenges and work to resolve competing tensions. Examples given of likely tensions being weighed up include whether Child Development Services:

- offer the full FASD assessment and see fewer families or offer a more streamlined (but potentially less valid) assessment and see more families
- prioritise younger children over older children when early intervention may have more benefits for younger children
- prioritise referrals from Oranga Tamariki over referrals from education and other sources
- increase access to FASD assessments by reducing post-diagnostic support for children with FASD
- support capability building and workforce development in other sectors by reducing assessment time.

How Child Development Services resolve these tensions is likely to vary across regions, resulting in differences in FASD assessment pathways.

The health workforce is committed but at risk of burnout and high staff turnover

In Hutt Valley and Hawke's Bay, health staff highlighted they actively seek workforce efficiencies to maximise the support given to families and children with FASD and the wider sector. However, the efficiencies created over time do not result in sufficient capacity to meet the current demand levels. Further, demand continues to grow as health staff in Hutt Valley and Hawke's Bay work to increase understanding of FASD in other sectors. Staff are burning out due to high workloads, stress, and vicarious trauma from working with families with high and complex needs.

We are **always being told to work smarter, harder** and all of that, but we are a bit over that... **We're burning out.** That's pretty tough. (Health)

Feedback indicated a lack of diagnostic capability for FASD exists

Feedback indicated a lack of clinicians trained to do a full FASD assessment across Aotearoa New Zealand. Feedback from the two Child Development Services found recruiting suitably qualified staff difficult. To address this shortfall, they are recruiting from overseas where some FASD training exists and investing in building their staff's FASD capabilities.

Recruiting and retaining senior skilled staff with the skills to tease out the various factors in these complex whānau **is a challenge**. There are very few speech-language therapists, psychologists, occupational therapists, and doctors with this kind of training so **we needed to find intelligent young professionals and train them**. (Health)

In Hutt Valley and Hawke's Bay, clinicians from various disciplines have received training in FASD assessment in Canada and Australia. Some have paid for the training themselves. Health professionals in both regions recommended whole team training, given the multidisciplinary diagnostic process for FASD. Training also needs to consider the Aotearoa New Zealand context.

You need to **train a small group**, so they know what they're doing together **because it's a team assessment**. (Health)

Managers also spoke of the challenges of retaining clinicians due to workload pressures and the difficulties of recruiting FASD-informed staff.

The health workforce interviewed is working to strengthen cultural safety

In Hawke's Bay, clinical staff highlighted they are working to strengthen cultural safety³⁶ and links to Iwi and Māori providers. They also acknowledged the lack of Māori clinicians. Increasing the Māori clinical workforce will help address racism by providing culturally safe support (Ministry of Health, 2020a). As noted in Whakamaui, Māori leadership is a significant enabler for achieving Māori health equity and wellbeing (Ministry of Health, 2020a). Through Māori leadership, Iwi, hapū, whānau, and Māori communities can exercise their authority to improve their health and wellbeing.

Pacific leaders and the clinical workforce are also needed to achieve equitable health outcomes for Pacific families and children (Ministry of Health, 2020b).

A workforce strategy is needed to address the capacity and capability challenges

The feedback from the two Child Development Services who are working to meet international best practice guidelines for FASD assessment indicates the current workforce model is not sustainable long term due to increasing demand and the known global deficit in the health workforce. A workforce strategy is therefore needed to build capacity and capability in the neurodevelopmental and FASD assessment and diagnosis pathway. The workforce strategy needs to contribute to the priority leadership and workforce actions in Whakamaui: Māori Health Action Plan 2020–2025 (Whakamaui) and Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025 (Ola Manuia) (Ministry of Health, 2020 a and b).

³⁶ Curtis et al. (2019, p. 4) define cultural safety as requiring "healthcare professionals and their associated healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect the quality of care provided."

Community and workforce capacity and capability opportunities

The following whole-of-system opportunities were identified from the feedback from families and stakeholders to improve outcomes for families and children aged 0–10 living with FASD.

- Increase the focus on prevention activities and messages to the public.
- Increase awareness and understanding of FASD in the public and create a dialogue shift from blame and stigma to strengths-based and enabling.
- Continue to build FASD training in frontline professionals' training.
- Actively promote existing online resources and create enabling learning and practice environments for professionals to prioritise their use and apply in their practice.
- Continue to support and promote FASD-CAN in providing training to families and professionals.
- Have dedicated FASD-informed specialists located in a community hub to offer capability building and advice to families and professionals working with them.
- Develop and implement a workforce strategy, drawing on Whakamaia and Ola Manuia, to build multidisciplinary and cultural capability in the neurodevelopmental and FASD assessment.

Conclusions and opportunities

The research purpose is to understand the current whole-of-system response to individuals with FASD or suspected FASD. This report focused on families with babies and children/tamariki aged 0 to 10 years (early childhood and primary school age).

Government agencies fund various health, disability, and education services to support families and children with FASD and suspected FASD. Except for some education services, many services have eligibility criteria to access them. Since 2016, actions have been taken to understand and strengthen the whole-of-government response to families and children living with FASD. However, feedback from both families and stakeholders shows more work is needed to create a nationally cohesive and joined-up cross-agency response that meets Te Tiriti obligations and enables children living with FASD to live their best lives.

Feedback from families and stakeholders highlighted ongoing stigma and a lack of knowledge in their community and services about FASD. Māori and Pacific families gave examples of racism and systemic bias when seeking help. As a result, some families disengaged from services for fear of negative repercussions.

In regions where Child Development Services are working within existing funding envelopes to implement international best practice FASD diagnostic and assessment processes, families face long wait times (two to four years) due to limited FASD-informed capacity. Children with suspected FASD are assessed when they are 10 to 12 years old and miss out on tailored early interventions (if they exist) to enable them to live their best lives. Across Aotearoa, not all Child Development Services have international best-practice FASD diagnostic and assessment processes.

Families and stakeholders noted the lack of support for FASD-informed services after receiving an FASD diagnosis (and before). Families whose children are solely diagnosed with FASD do not meet NASC criteria for disability support services and cannot access respite and other services.

Where able, families are actively building their knowledge of FASD and developing family strategies on how best to support their child. However, for some families, wider pressures (e.g., income, food and housing insecurity) can impede this learning process and their ability to advocate in a system with access and stigma barriers.

Many frontline stakeholders highlighted their need for ongoing FASD training and how to apply it in their practice. While FASD training and resources exist, stakeholders lack awareness and time (or priority) within their workload to use.

Families with children under 10 see the education system as vital in helping their children to learn and develop. However, families' experience of primary school tends to be one where children with FASD are labelled as naughty, assessments from health are not read, and strategies used do not recognise the strengths and challenges of the child with FASD. Families are also frustrated their knowledge and advice on how best to work with their child is not heard.

The feedback from families and stakeholders paints a bleak picture. In taking part in this research, both families and stakeholders wanted to enable the development of a system response that best supports children aged 0–10 years and as they grow older. In this context, families and stakeholders

identified system improvements³⁷ to strengthen the system response and improve outcomes for families and children aged 0–10 living with FASD.

Whole-of-system opportunities

- Develop a whole-of-system strategy for neurodiversity generally and FASD specifically to foster a nationally consistent and joined-up response for families living with FASD, linked to wider system reforms.
- Ensure strong cross-agency governance (embedded in wider system reforms) and review the implementation.

Opportunities to better meet Te Tiriti o Waitangi obligations

- Ensure appropriate national and regional level cross-agency governance includes Māori leadership and whānau Māori living with FASD.
- Ensure whānau Māori living with FASD are respected, listened to, have choices and resources, and are actively involved in the solution to support their tamariki.
- Invest in Māori providers to build their workforce's understanding of FASD.
- Engage with Iwi and Māori providers so they can determine their role in the FASD system response.

Assessment, diagnosis, and support opportunities

- Ensure families living with FASD are respected, listened to, have choices and resources, and are actively involved in the solutions to support their children.
- Have an assessment and diagnosis pathway for FASD nested in a wider neurodevelopmental assessment process based on Aotearoa New Zealand's diagnostic guidelines (when released).
- Develop and implement a workforce strategy, drawing on Whakamaua and Ola Manuia, to build multidisciplinary and cultural capability in the neurodevelopmental and FASD assessment.
- Consider the opportunity for a sole diagnosis of FASD to qualify for Disability Support Services so children with more moderate needs can access disability support services.
- Enable access to evidence-informed early interventions that address systemic influences (e.g., psychoeducation and support for the family, environmental accommodation, child-focused interventions, and integrated case management) (McLean, 2020).
- Continue work to create an FASD-informed education system that supports children with FASD based on their needs to support their learning and connection with peers.
- Establish localised FASD or neurodiverse community hubs to enable cross-sector and family collaboration.
- Have FASD coordinators support families in accessing services and offering advice.
- Have access to FASD-informed respite options.

Community and workforce capacity and capability opportunities

- Increase the focus on prevention activities and messages to the public.
- Increase awareness and understanding of FASD in the public and create a dialogue shift from blame and stigma to strengths-based and enabling.
- Continue to build FASD training in frontline professionals' training.
- Actively promote existing online resources and create enabling learning and practice environments for professionals to prioritise their use and apply in their practice.
- Continue to support and promote FASD-CAN in providing training to families and professionals.

³⁷ Some opportunities are being addressed by relevant government agencies (e.g., work on workforce capability and capacity in the health sector through the health reforms).

- Have dedicated FASD-informed specialists located in a community hub to offer capability building and advice to families and professionals working with them.

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Website resources

Ministry of Education

- [Flexible, tailored model of support – He Pikorua \(education.govt.nz\)](https://www.education.govt.nz/he/pikorua/)
- [A new model for delivering learning support – Education in New Zealand](https://www.education.govt.nz/education-in-new-zealand/)

Oranga Tamariki policies, procedures, and guidance:

- <http://practice.orangatamariki.govt.nz/policy/assessment/http://practice.orangatamariki.govt.nz/our-work/assessment-and-planning/assessments/conducting-an-assessment/>
- <http://practice.orangatamariki.govt.nz/our-work/assessment-and-planning/assessments/conducting-an-assessment/assessment-of-needs-relating-to-any-disability/>
- <https://practice.orangatamariki.govt.nz/core-practice/practice-tools/other-practice-and-assessment-tools/gateway-assessments/>
- <https://practice.orangatamariki.govt.nz/previous-practice-centre/knowledge-base-practice-frameworks/fetal-alcohol-spectrum-disorder/>

Centre for Disease Control (US) <https://www.cdc.gov/ncbddd/fasd/articles.html>

No-FASD (Australia) <https://www.nofasd.org.au/parents-carers-and-families/>

Canada FASD Research Network <https://canfasd.ca/topics/top-papers/>

Te Puni Kōkiri [Whānau Ora \(tpk.govt.nz\)](https://www.tpk.govt.nz/whanau-ora/)

Appendices



Appendix 1: Overview of the FASD Action Plan



Source: FASD Working Group (2016).

Appendix 2: Detailed research methods

Key research questions

The research addressed three key questions. The overarching and sub-questions were as follows:

1. How does the FASD system work across government and other agencies at the two life stages? At each life stage:
 - What are the roles, policies, and funding streams of the different government agencies supporting people and families living with FASD?
 - What support and services are available to enable early identification, assessment, and diagnosis of people with suspected FASD? How accessible are these services? How well do they align with best practice FASD diagnosis guidelines?
 - What support, services, and interventions are available for people and families living with FASD? How well do these services meet their needs?
 - How do the different agencies work together to offer integrated support to meet the needs of people and families living with FASD?
 - How are people and families supported at key life stage transition points?
 - What is the current workforce capacity and capability to deliver FASD-informed services to meet the needs of people and families living with FASD?
 - Where services are successful, what were the enablers of success?
 - Where services are limited, what are the barriers to establishing services?
2. How does design and delivery of services and supports for people living with FASD meet obligations of the Crown as a Treaty Partner as defined by Whakamaui: Māori Health Action Plan?
3. What improvements are needed to strengthen the FASD system across agencies to better support people and families living with FASD?

Research Advisory Group

We established a multidisciplinary Research Advisory Group (the Group) to provide advice and guidance to the research team. The Group met at key research milestones and advised on the research design, tools, analysis and reporting approach, and draft report. The Group also provided sensemaking of the preliminary insights. Members of the Research Advisory Group include:

| Name | Organisation | Role |
|-----------------------|--------------------------------------|-------------------------------------------------------|
| Professor Anita Gibbs | University of Otago | Researcher and lived experience perspective |
| Dr Leigh Henderson | FASD-CAN | Chair of FASD-CAN and lived experience perspective |
| Marty Rogers | Independent | Kaupapa Māori, research, and health system expertise |
| Dr Russell Wills | Hawke's Bay DHB | Paediatrician |
| Dr Timothy Jelleyman | Ministry of Health and Waitematā DHB | Chief Advisor to Ministry of Health and paediatrician |

Research methods

The research design was informed by a briefing meeting with the Ministry of Health, a brief literature review on FASD, a cross-agency hui with Ministry representatives, and 11 key informant interviews (including FASD researchers, advocates, and Ministry stakeholders).

Policy and practice review

We reviewed policy and practice documents related to FASD at the national level (and regional level, where available). The purpose of the review was to understand:

- documented processes and practices to support children living with FASD and their families
- existing workstreams and initiatives related to children living with FASD and their families
- how and where funding is allocated for support and services for children living with FASD and their families
- the cross-agency integration of policies and practices to support children with FASD and their families.

We requested documents from the Ministry of Health, the Ministry of Education, Oranga Tamariki, and the Ministry of Social Development. We also requested documents from the Child Development Services (at Te Whatu Ora Te Matau a Māui, Hawke's Bay and Te Whatu Ora Hutt Valley) and were provided with documents by the Research Advisory Group.

We received both formal documents (where available) and written responses. We reviewed all documents. The review informed this report and our understanding of the system. The documents reviewed are listed in the bibliography.

Qualitative interviews and hui with 87 key stakeholders

We gathered stakeholder perspectives on policies and services for FASD through in-depth interviews and cross-sector hui. We sought to understand how policies and services worked at national and regional levels, the enablers and barriers to supporting children living with FASD and their families, and the opportunities for positive system change.

At the national level, we recruited Ministry stakeholders through the FASD Coordination Group. At the regional level, we worked with the Child Development Services teams in Te Whatu Ora Te Matau a Māui, Hawke's Bay and Te Whatu Ora Hutt Valley, who provided a list of key contacts providing support to children living with FASD and their families in their region. We recruited Māori providers through personal and professional networks. We took a snowballing approach, where we interviewed all stakeholders who were recommended to us by existing interviewees.

We focused the sample on stakeholders whose work is directly related to children with FASD or who had a level of knowledge of FASD. We interviewed stakeholders across the health, education, care and protection sectors, and NGOs and Iwi and Māori providers.

We achieved the following sample:

| Location | Stakeholder group | Number of participants | Number of interviews | Number of hui |
|-----------------------------|--------------------------------------------|------------------------|----------------------|---------------|
| National Hawke's Bay | Ministry stakeholders | 13 | 11 | - |
| | Regional stakeholders | 10 | 6 | - |
| | Frontline staff (general) | 18 | - | 1 |
| | Frontline staff (follow-up ³⁸) | 10 | 9 | - |
| | Kaimahi (Māori providers) | 12 | - | 1 |
| Hutt Valley | Regional stakeholders | 11 | 6 | - |
| | Frontline staff (general) | 10 | - | 1 |
| | Frontline staff (follow-up) | 2 | 2 | - |
| | Kaimahi (Māori providers) | 1 | 1 | - |
| Total | | 87 participants | 35 interviews | 3 hui |

Across the two regions (excluding National interviews), we engaged with:

- 38 health professionals from DHBs (including Child Development Services, mental health services, NASC, Gateway, pregnancy and parenting services, and Māori health services) and private practice, including psychologists, paediatricians, social workers, speech-language therapists, public health nurses, and team leaders and managers
- 14 education employees including educational psychologists, RTLBs, Special Educational Needs Coordinator, and IWS staff
- 11 Māori provider employees
- Seven Oranga Tamariki employees including managers, advisors, and staff from Gateway, HCN, and other services
- Four NGO employees.

Recruitment and interviews followed an informed consent process and were up to 60 minutes long. Hui were two hours and involved cross-sector breakout group discussions.

Qualitative interviews with eight families with a child (or children) living with FASD

We gathered families' perspectives on navigating services and support for their child (aged 10 or under) living with FASD. We explored what worked well and what could be strengthened during diagnostic assessment and when navigating and accessing other supports and services.

We recruited families through local community connectors,³⁹ Child Development Services, FASD-CAN, and Caring Families Aotearoa. We followed informed consent during recruitment and interviewing.

³⁸ We offered interviews to frontline staff who were unable to attend the cross-sector hui.

³⁹ Community connectors are people (from the research team's networks) with extensive personal and professional networks in the region.

We achieved the following sample:

| Location | Number of families | Number of interviews |
|-------------|--------------------|----------------------|
| Hawke's Bay | 5 | 5 |
| Hutt Valley | 4 | 3 |
| Total | 9 participants | 8 interviews |

The sample included whānau Māori (n=5) and families with children with a confirmed diagnosis of FASD (n=5). Children ranged between the ages of three and 10, and one in their teens. Children tended to have coexisted disabilities, including intellectual disability. The sample included a range of family, whānau, and caregiver arrangements, including extended family members, grandparents, and foster parents.

Research tools

Families research tools

Information sheet



FASD system
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Consent form



FASD system
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Discussion guide



FASD system
research_discussion g

Stakeholder research tools

Consent



FASD system
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Information sheet



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Hui agenda



FASD system
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FASD system
research - hui consent

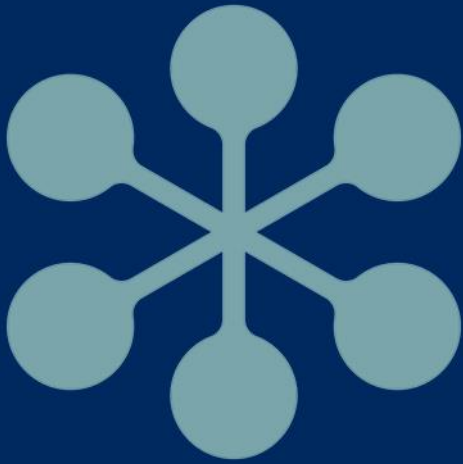


FASD system
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Discussion guide



FASD system
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