

# Litmus

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## Research to inform the FASD Action Plan

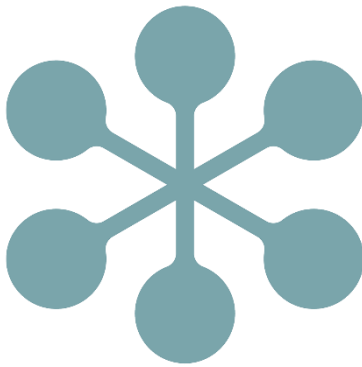
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Phase 2: Research on the whole-of-system response to young people aged 11-18 years with diagnosed and suspected Fetal Alcohol Spectrum Disorder (FASD) in Aotearoa New Zealand

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11 March 2024





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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
<b>Aotearoa</b>	Te reo Māori name for New Zealand.
<b>Behaviour Support</b>	The Behaviour Support service is for students in Years 1–10 who have extreme and ongoing behavioural challenges.
<b>Child and Adolescent Mental Health Services (CAMHS)</b>	Mental health services for children and youth aged up to 18 years with moderate to severe mental health issues.  Also known as Infant, Child and Adolescent Mental Health Service (ICAMHS) or ICAFS (Infant, Child, Adolescent and Family Service).
<b>Child Development Services (CDS)</b>	Child Development Services (CDS) is a team of allied health professionals. CDS provides community-based support and will work with families to support their achievement of development goals.
<b>Disability Support Services (DSS)</b>	Disability Support Services (DSS) are for people who have one or more physical, intellectual or sensory disability, which 1) are likely to continue for at least six months, 2) are likely to result in a reduction of independent function to the extent that ongoing support is required.
<b>Families</b>	Refers generically to families and caregivers interviewed for the research or were referred to by stakeholders interviewed.
<b>Family Group Conferences (FGCs)</b>	A restorative justice process held when young people are alleged to have offended or once the charges have been proven.
<b>FASD</b>	Fetal Alcohol Spectrum Disorder.
<b><u>Fetal Alcohol Spectrum Disorder Care Action Network (FASD-CAN)</u></b>	A registered charity in Aotearoa, New Zealand, that aims to unite caregivers, support families and individuals, strengthen communities, and educate about FASD across Aotearoa, New Zealand.
<b>Gateway assessment</b>	An inter-agency process that identifies ways to address the health and education needs of children entering or at risk of entering care.
<b>GPs</b>	General Practitioners.
<b>High and Complex Needs (HCN)</b>	An inter-agency approach that works with children and young people who have high and complex needs to help families find positive solutions.
<b>Intensive Wraparound Service (IWS)</b>	A support programme for young people aged 5–14 years who: 1) have behaviour, social or learning needs that are highly complex and

<b>Term</b>	<b>Explanation</b>
	challenging, and 2) require support at school, at home and in the community.
<b>Kaupapa Māori</b>	Māori approach, Māori institution, Māori ideology— a philosophical doctrine incorporating the knowledge, skills, attitudes and values of Māori society.
<b>Learning Support Coordinator (LSC)</b>	Seeks to build the capability of teachers, identify support needs for children with additional needs, and be available to support learners and their families.
<b>Manatū Hauora</b>	Ministry of Health.
<b>Mana motuhake</b>	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.
<b>Mana tamaiti (tamariki)</b>	The value and inherent dignity derived from a child's or young person's whakapapa (genealogy) and their belonging to a whānau, hapū, iwi, or family group, in accordance with tikanga Māori
<b>Mātauranga Māori</b>	Māori knowledge.
<b>Needs Assessment Service Coordination (NASCs)</b>	Needs Assessment Service Coordination agencies (NASCs) assess people to identify services and supports they are eligible for and which are funded.
<b>Ola Manuia</b>	Pacific Health and Wellbeing Action Plan 2020–2025
<b>Oranga Tamariki</b>	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.
<b>Ongoing Resourcing Scheme (ORS)</b>	ORS provides support for students with the highest ongoing levels of need for specialist support.
<b>Pae Ora (Healthy Futures) Act 2022</b>	The Act 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.
<b>Pakeke</b>	Māori adult
<b>Pēpi</b>	Māori babies
<b>Primary health care</b>	Primary health care relates to the professional health care provided in the community, usually by a general practitioner (GP), practice

<b>Term</b>	<b>Explanation</b>
	nurse, nurse practitioner, pharmacist or other health professional working within a general practice.
<b>Rangatahi</b>	Māori young people.
<b>Resource Teachers: Learning and Behaviour (RTLBs)</b>	Specialist teachers who work with and upskill teachers and schools to make interventions for students with learning and/or behavioural difficulties.
<b>Services</b>	Refers to service delivery across sectors.
<b>Special Educational Needs Coordinator (SENCO) or Head of Learning Support</b>	SENCOs are members of teaching staff who coordinate support for students with special educational needs and disabilities within a school.
<b>Tamariki</b>	Māori children.
<b><u>Te Aka Whai Ora – Māori Health Authority</u></b>	An independent statutory authority to drive improvement in hauora Māori. Established in July 2022.
<b>Te Ao Māori</b>	The Māori worldview.
<b><u>Te Ao Mārama</u></b>	Enhancing Justice for All. The vision of Te Ao Mārama is to ensure all people who come to the District Court can seek justice and be seen, heard, understood, and meaningfully participate.
<b>Te Tiriti o Waitangi (Te Tiriti, The Treaty of Waitangi)</b>	The founding document of Aotearoa New Zealand represents an agreement between Māori chiefs and the British Crown. Te Tiriti is accepted as a constitutional document that guides the relationship between Māori and the Crown (embodied by the Government).
<b><u>Te Whatu Ora - Health New Zealand</u></b>	The national organisation leads and coordinates delivery of health services across the country. Established in July 2022.
<b>Tino rangatiratanga</b>	Māori self-determination and mana motuhake. Māori are key decision-makers in the design, delivery, and monitoring of health and disability services.
<b><u>Whaikaha – Ministry of Disabled People</u></b>	A Ministry that provides a wider lens on disability across the Government and drives the transformation of the disability support system. Established in July 2022.
<b>Whakamaaua</b>	Māori Health Action Plan 2020–2025.
<b>Whakapapa</b>	Genealogy.

<b>Term</b>	<b>Explanation</b>
<b>Whānau-centred approach</b>	A culturally grounded, holistic approach focused on improving the wellbeing of whānau and addressing individual needs within a whānau context (Te Puni Kokiri, 2015).
<b>Whānau Māori</b>	Māori families interviewed for the research or referred to by stakeholders interviewed.
<b>Whānau ora</b>	A whānau-centred approach to support whānau wellbeing and development.
<b>Whole-of-system response or system response</b>	Refers to the policies and services available to people living with FASD at national, regional, and local levels and across all relevant sectors.
<b>Young people</b>	Refers generically to young people aged 11 to 18 years.

# Executive summary

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## 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 informs 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. We have completed phase 1 of the research, which focused on babies, pēpi and children, tamariki aged 0 to 10 years (primary school age) (Litmus, 2023). This report presents phase 2 research focusing on young people aged 11 to 18 (intermediate and secondary school). 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, delivery of services and support 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. Similar to phase 1, 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. We also interviewed stakeholders, young people and families from other locations. The [Health and Disability Ethics Committees](#) approved the phase 2 research.

Data collection included:

- desktop review of policies and practice documents
- interviews with 27 stakeholders across the health, disability, education, care and protection, and youth justice sectors, NGOs, and Māori providers
- interviews with nine families caring for a young person or young people living with diagnosed or suspected FASD aged between 11 and 18 years
- perspectives of nine young people living with diagnosed FASD aged between 11 and 18 years.



# Research findings

## Families want a joined-up, accessible, nationally consistent whole-of-system response

Different government agencies fund health, disability, education, and other services to support families and young people living with FASD. Figure 1 summarises the services available.

**Figure 1.** Government-funded services that may be available for young people with suspected and diagnosed FASD between 11 and 18 years old (\*eligibility criteria apply)

11–12 years	13–14 years	15–16 years	17–18 years
<b>Health</b>			
Primary health care			
*Child and Adolescent Mental Health Services (CAMHS)			
*Youth One Stop Shop (YOSS)			
*Private psychological services			
<b>Disability</b>			
Child Development Services (CDS)			
*Disability Support Services, including Needs Assessment Service Coordination (NASC)			
<b>Education</b>			
*Teacher support (e.g., teacher aides, Resource Teachers: Learning and Behaviour, Learning Support Coordinators, Special Educational Needs Coordinators)			
*Behaviour support			
*Ongoing Resourcing Scheme (ORS)			
*Alternative schooling, e.g., day specialist schools, residential schools, alternative education, activity centres, Te Kura, home education, regional health schools			
<b>Care and protection</b>			
*Gateway Assessment			
Supports in youth justice, (e.g., Family Group Conferences (FGCs), communication support, health and education assessments, youth forensic mental health services)			
<b>Financial support</b>			
*Child Disability Allowance			
*Supported Living Payment			
*Disability allowance			
<b>Cross-agency</b>			

11–12 years	13–14 years	15–16 years	17–18 years
*High and Complex Needs (HCN)			
*Intensive Wraparound Service (IWS), Te Kahu Tōi			

## **A joined-up, accessible, whole-of-system response for young people living with FASD and their families does not exist**

While these services exist, families and stakeholders interviewed highlighted their severe difficulties in accessing FASD-informed support and services across government agencies for young people living with FASD. Families interviewed shared their frustration at the time, the energy they spent advocating and negotiating access barriers, and, for many, not receiving needed services. Many shared their despair and trauma due to the lack of or inappropriate services for their young people seeking to live their best lives. They also reflected on the broader adverse impacts the lack of support has on their and their families' wellbeing.

Sector reforms in health, education, and Oranga Tamariki present opportunities to create a more joined-up and nationally consistent whole-of-system response for young people and their families 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 FASD-informed services embedded in their whānau, hapū and Iwi. Whānau Māori require strong cultural connectedness and support to ensure good outcomes for rangatahi with an FASD diagnosis or suspected FASD. Feedback from Iwi and Māori providers interviewed in phases 1 and 2 highlights they do not have a defined role in the system response.

Enhancing the FASD system response requires 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 rangatahi 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 young people before they leave primary school. Families and stakeholders want assessment and diagnostic pathways for FASD to be available, consistent and based on best practice guidelines across Aotearoa, New Zealand.

Stakeholders in the youth justice sector indicate the lack of timely assessment and tailored post-diagnostic support contributes to young people with suspected FASD entering the justice system.

## **Families interviewed want early access to FASD-informed interventions to support their young person to live their best possible life**

Transitioning through the teen years presents new challenges for young people with FASD and their families. Young people living with FASD want support to be independent. All families interviewed shared that their young people living with FASD were experiencing secondary impacts of FASD (e.g., school disruption, mental health concerns, poor self-esteem, self-harming and suicidal ideation, high-

risk sexual behaviours and being involved in the justice system). Families living with a young person with FASD also face financial hardships due to care roles, isolation due to stigma and blame, and disruption and trauma for other siblings.

Schools have an essential role in enabling young people with FASD to live their best life. However, families interviewed said many schools do not have the resources, capacity, or FASD-informed capability to support young people living with FASD and their families. Without appropriate tailored support, young people's schooling experience is stressful, traumatic, and dehumanising. As a result, many young people are expelled or withdraw from school with no pathways to other educational or training opportunities.

Families do not know what support and services are available. Available services are inconsistent across the country and tend not to be FASD-informed. Young people living with FASD tend not to meet the eligibility criteria for health and disability and education support services. Families want a joined-up whānau-centred approach that enables their young person living with FASD and offers them and their family support. Young people and families want access to community-based activities or youth mentors, FASD-informed counselling for young people, family group counselling, FASD-informed communication support from speech-language therapists in schools and youth justice, and FASD-informed mental health and addictions services.

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 are fearful for their young people as they move toward adulthood. Families and young people living with FASD are keen to be supported into employment or other voluntary work to participate in society and build a sense of purpose and self-worth. However, little support is available, or the young people living with FASD are seen as 'too hard' to fit into existing employment or training services.

### **Families interviewed want an FASD-informed community and workforce**

Societal awareness of FASD is slowly growing. However, families shared many examples of stigma, shame, and stress when engaging with their families and wider communities. Families also shared many instances where knowledge of FASD was limited across frontline staff (who do not specialise in FASD) in health, education, Oranga Tamariki, justice agencies, NGOs, and Māori providers. In this context, stakeholders and families note that increased awareness of FASD has not translated into understanding or systemic change for young people living with FASD and their families.

Some positive system shifts are evident. The youth court, led by the judges, is working to be more FASD-informed. More training and resources about FASD across health, education, care and protection and justice are available. However, staff struggle to engage with the resources due to a lack of capacity or cannot implement or sustain changes within the constraints of their work environment. Ongoing workforce capability and capacity building across sectors are needed to support young people with FASD and their families.

# A summary of improvement opportunities<sup>1</sup>

Significant work is needed to improve the system response to improve outcomes for young people aged 11–18 living with FASD and their families. The range of future opportunities is listed below. The opportunities identified in phase 2 reflect those noted in the phase 1 research.

## 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 from prevention, identification and assessment of FASD, and wrap-around support for young people living with FASD and their families.
- Support young people living with FASD to participate in their community and to input into policy and other decisions affecting them.
- Ensure strong cross-agency governance (embedded in the wider system reforms) and review the implementation.
- Continue to build the workforce capability and capacity to deliver cross-agency FASD-informed services.
- Continue to provide sustainable support and promote FASD-CAN in providing training to families and professionals.

## 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 rangatahi
- 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

### Awareness and prevention

- Increase the focus on prevention activities and messages to the public on the risks of prenatal alcohol exposure.
- Increase awareness and understanding of FASD in the public and create a dialogue shift from blame and stigma to strengths-based and enabling.

### A young-person and family-centred approach

- Ensure young people and families living with FASD are respected, listened to, have choices and resources, and are actively involved in developing support solutions.
- Access to FASD-informed respite options.

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

- Identify the most effective way to inform and support young people living with FASD and their families in seeking to access help and services.

#### Disability sector: Early identification and assessment

- 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).
- Enable early assessment and diagnosis by developing and implementing a workforce strategy, drawing on Whakamaui and Ola Manuia, to build multidisciplinary and cultural capability in neurodevelopmental and FASD assessment consistently across Aotearoa, New Zealand.

#### Disability and health sectors: Early intervention and FASD-informed support

- Allow a sole diagnosis of FASD to qualify for Disability Support Services so more children with FASD can access disability support services.
- Establish and enable access to evidence-informed early interventions that address systemic influences (e.g., psychoeducation and support for the family, environmental accommodation, child and young person-focused interventions, and integrated case management) (McLean, 2020).
- Enable access to FASD-informed youth mental health services and counselling for young people living with FASD and family group counselling to support caregivers and siblings.

#### Education sector

- Continue work to create an FASD-informed education system that supports young people with FASD based on their needs to remain engaged and support their learning and connection with peers.
- Increase supports tailored to key transition points when the needs of young people living with FASD change and increase (e.g., to adolescence, to intermediate and college, to independence)

#### Youth justice sector

- Continue work on making the youth justice system FASD-informed, including Police, Oranga Tamariki and Youth Courts.

## Areas for further research

Phases 1 and 2 of the research focused on service experiences between the ages of 0 and 18. This research has identified further research and evaluation opportunities, specifically:

- Research into the whole-of-system response to preventing FASD
- Research into the system response for people aged over 18 living with FASD
- Assessment of the diversity of diagnostic and assessment approaches across Aotearoa, New Zealand
- Research into alternative diagnostic pathways to increase capacity for screening and diagnosis.
- Assessment of mental health and addiction services in supporting young people living with FASD
- Research on effective FASD-informed interventions for young people in the youth justice system.
- Research the diverse experiences of people living with FASD in other regions and for other population groups (e.g., Pacific people).

# Research context

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

Alcohol use is common before the recognition of pregnancy. The 2020/21 New Zealand Health Survey found 79% of female respondents aged 15 years or over had drunk alcohol in the past 12 months (Ministry of Health, 2022). 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 Aotearoa, 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; Streissguth and Kanter, 1997).

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).

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

In 2016, the FASD Action Plan<sup>2</sup> set 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).

The FASD Action Plan outlines four priorities to achieve its aims: prevention, early identification, support, and evidence. The Action Plan also identified ten action areas with associated activities that

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



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 Ministry of Social Development, 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.

## On 1 July 2022, the [Pae Ora \(Healthy Futures\) Act](#) took effect

Since July 2022, the changes in the health system have refined the structure of health agencies working on the FASD Action Plan. 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 to the planning, design, and delivery of health services at the local level. The Pae Ora Act established:

- [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.

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

## In 2021, research was commissioned to inform the FASD Action Plan

In 2021, the Ministry of Health<sup>3</sup> 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.

The present research is two-phased. We have completed the phase 1 research, which focused on the whole-of-system response<sup>4</sup> to babies, children, and families living with FASD aged 0 to 10 years (Litmus, 2023). Phase 1 research predominately focused on assessment, diagnosis, and early intervention pathways. Phase 2 focused on the system response to young people living with FASD aged 11 to 18 as they navigate supports and services during adolescence.

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

<sup>4</sup> 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.

# Research method

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## Research purpose

The research purpose is to describe and understand the current whole-of-system response to individuals with FASD or suspected FASD. This report presents phase 2 research focused on the system response to young people living with FASD aged 11 to 18 (intermediate and secondary school).

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.

The [Health and Disability Ethics Committees](#) approved the phase 2 research (Application ID: 2023 FULL 15417).

## Key research 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 support for people living with FASD meet the 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 children and families living with FASD?

## Research method

Below, we summarise 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.

The research was mostly carried out in the Hawke's Bay and Hutt Valley regions. We selected these regions as their respective Child Development Services had a diagnostic pathway for children with suspected FASD within their existing neurodevelopmental diagnosis and assessment pathways. However, due to recruitment challenges, we also included other locations to ensure the inclusion of the voices of young people living with FASD and their families:

We gathered data through the following:

- a desktop review of national strategies, policies, and practice documents provided by sector stakeholders
- qualitative interviews with 27 stakeholders across the health and disability, education, care and protection, and youth justice sectors; NGOs; and Māori providers offering support or working with young people living with FASD and their families
- qualitative interviews with nine families with a young person or young people with suspected or diagnosed FASD



- qualitative interview with and feedback from nine young people living with FASD.

[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

Interviews were audio-recorded and transcribed verbatim, with participants' permission. We systematically coded all interview transcripts based on key themes. We undertook regular debriefs and internal analysis workshops with the research team.

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 analysed families' needs, experiences, and service availability against the framing of Whakamaua to identify key insights and improvement opportunities. We also used the framing of the FASD Action Plan and Whakamaua to identify key insights and opportunities for research questions 1 and 3, drawing from families' and key stakeholder feedback.

The Research Advisory Group, Ministry of Health, Te Whatu Ora, Whaikaha (Ministry of Disabled People), and Department of Corrections reviewed the draft report. Before finalising the report, we considered and incorporated their feedback as appropriate to the evidence.

## Research limitations

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

- We experienced significant challenges recruiting stakeholders involved in the system response for young people (11-18) living with FASD and their families. We received many declines due to a lack of knowledge of FASD, not being perceived as part of a system response to FASD, and a lack of capacity to participate. Recruitment challenges reflect the limited FASD-informed services available for young people living with FASD and workforce capacity issues across sectors.
- The findings are mainly based on the system response in two areas with an established FASD diagnostic pathway. We acknowledge that FASD services are likely to vary across Aotearoa, New Zealand. Young people living with FASD and their families living in other regions with no specific FASD diagnostic pathway are likely to have very different service experiences. Due to recruitment challenges, we included stakeholders, families and young people from other regions.
- We used an opt-in process for young people living with FASD and their families. We only talked to young people and families willing to be interviewed about their journey living with FASD. Young people and families interviewed had similar service experiences, and their feedback reflected regional stakeholders' feedback on services. Given the varied presentation and experiences of FASD, the research does not represent the full diversity of young people's and families' experiences of living with FASD.
- We included a few interviews with families of young people living with FASD older than 18. These interviews focused on the experiences of those aged 11 to 18 years.
- We have limited insight into the experiences of young people and families who live rurally. The service experiences of this group were reflected in some stakeholder interviews.

## Areas for further research

Phases 1 and 2 of the research focused on service experiences between the ages of 0 and 18. This research has identified further research and evaluation opportunities, specifically:

- Research into the whole-of-system response to preventing FASD
- Research into the system response for people aged over 18 living with FASD
- Assessment of the diversity of diagnostic and assessment approaches across Aotearoa, New Zealand
- Research into alternative diagnostic pathways to increase capacity for screening and diagnosis.
- Assessment of mental health and addiction services in supporting young people living with FASD
- Research on effective FASD-informed interventions for young people in the youth justice system.
- Research the diverse experiences of people living with FASD in other regions and for other population groups (e.g., Pacific people).

# Research findings



# Understanding the policies influencing service availability and access

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This section provides key insights and opportunities for national strategies and policies. National-level policies influence the services and support available and the experience of families and young people aged 11 to 18 living with FASD.

## Government agencies fund a range of services to support families and young people living with FASD

Government agencies have different approaches and criteria to support disabled people, reflecting their role within the public service system. Relevant policies and initiatives across government agencies to support eligible young people living with FASD and their families are summarised below (Tables 1-6). Many initiatives are associated with eligibility criteria, an application process, and approval.

While these services exist, young people living with FASD, their families and stakeholders interviewed all emphasised severe difficulties in accessing them. Key access barriers include (discussed further [here](#)):

- challenges in the early identification, assessment and diagnosis of FASD across Aotearoa, New services delaying access to early intervention services (if they exist)
- families not being aware of the services and need to advocate for ongoing support continually
- a lack of and varying service and support provisions across Aotearoa, New Zealand
- restrictive eligibility criteria blocking disability support and education services
- a lack of awareness and understanding of FASD and services available across health, disability, education, care and protection and justice sector workforces, resulting in families being ignored or shunted across services
- gatekeeping of information and resources, given the limited services and support available
- young people ageing out of services, while their needs continue due to development delay and a range of different cognitive abilities.

## The disability and health sector – Whaikaha, Manatū Hauora, Te Aka Whai Ora, and Te Whatu Ora

At the national level, policies in the disability and health sector are mostly developed, funded, and operationalised by Whaikaha (Ministry of Disabled People), Manatū Hauora (Ministry of Health), Te Aka Whai Ora (Māori Health Authority), and Te Whatu Ora (Health New Zealand). Other entities involved in the health and disability sector include the Public Health Agency, ACC (Accident Compensation Corporation), Oranga Tamariki, and the Health Quality & Safety Commission.

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

In July 2022, Whaikaha partnered with the disabled community, Māori, and the Government to transform the disability system in line with the Enabling Good Lives approach.<sup>5</sup> Whaikaha funds disability services for those who meet the eligibility criteria. Since July 2022, Whaikaha has held the funding for Child Development Services<sup>6</sup>.

Whaikaha fund Disability Support Services for disabled people delivered by various organisations around the country. In 2022, a sole diagnosis of FASD<sup>7</sup> does not meet the eligibility criteria for Disability Support Services, despite meeting the Whaikaha's definition of 'disability'.<sup>8</sup> 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. FASD-CAN estimates around 80% of children and young people with FASD are not eligible for DSS.<sup>9</sup> Currently, Whaikaha is reviewing the eligibility criteria for Disability Support Services for all disabilities.

Table 1 provides an overview of the main disability and health services available for young people living with FASD, if they meet the eligibility criteria.

Stakeholders also noted the importance of primary care health needs among young people living with FASD. Depending on health needs, young people with FASD and their families might be supported by GPs (General Practitioners), paediatricians (up to 15 years old), counsellors, dentists, physiotherapists, and others.

**Table 1.** Service descriptions of national disability and health services available for young people aged 11–18 with suspected and diagnosed FASD, if eligible

Health and disability sector	Service description	Eligibility criteria	Referral pathway
<b><u>Child Development Services (CDS)</u></b>  <b>Funded by Whaikaha</b>	CDS comprises multidisciplinary allied health and community-based services with expertise in physiotherapy, speech-language therapy, occupational therapy, and psychology.  The purpose is to promote and facilitate a child's developmental pathway through assessment, intervention, and support services from birth to 16 years.  Few CDS assess and diagnose people with FASD using best practice guidelines. In	Anyone can access CDS if there is an identified disability, developmental delay, Autism Spectrum Disorder, or a possibility of these. Young people with suspected FASD qualify for this service.	Through a general practitioner (GP), health specialist, education professionals, and other service providers.  Due to wait times or late identification, FASD assessments

<sup>5</sup> Enabling Good Lives is an initiative to support disabled people by offering greater choice and control over the support they receive.

<sup>6</sup> While organisation names and funding streams have changed, the services offered by the Child Development Services have not.

<sup>7</sup> 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).

<sup>8</sup> 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."

<sup>9</sup> Personal communication

Health and disability sector	Service description	Eligibility criteria	Referral pathway
	Hawke's Bay, the Developmental Assessment Programme (DAP) is based in CDS in Hawke's Bay, which offers a specific FASD assessment pathway.  Waitlists exist for diagnostic services (Litmus 2023).		might take place at aged 11 or older.
<b>Disability Support Services and NASC</b>  <b>Funded by Whaihaka</b>	NASC services assess people up to 65 years to identify services and supports they are eligible for and which are funded. They then facilitate access to support and services, such as home help, personal care, respite, etc.	Disability Support Services are for people with 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.  Young people with FASD need another eligible condition (e.g., intellectual disability) to qualify for this service.	Anyone can apply for a needs assessment in person or by referral from another person or organisation (e.g., GP).
<b>Child and Adolescent Mental Health Services (CAMHS)</b>  <b>Funded by Te Whatu Ora</b>	CAMHS is for children and youth aged up to 18 years with moderate to severe mental health problems. They might also run acute and crisis services.  CAMHS is a multidisciplinary team that includes family therapists, occupational therapists, psychiatrists, psychologists, mental health nurses, social workers, psychotherapists, and employment and study specialists.	Young people qualify if they have moderate to severe mental health issues, and CAMHS are the best service to help (following referral and an initial appointment).  Young people with suspected FASD or FASD and moderate to severe mental health issues qualify if they meet the criteria.	A referral can be made by a young person, their parents or caregivers, a GP, or their school.
<b>Youth One Stop Shop (YOSS)</b>  <b>Funded through multiple public and private sources</b>	The YOSS model delivers free wraparound health and social care for young people aged 10-24 years and operates in 11 sites across the country (Whangārei, Rotorua, Taupō, Whanganui, Palmerston North, Kāpiti Coast, Hutt Valley, Porirua, Wellington, Christchurch and Invercargill).  The YOSS model aims to increase access to services by providing co-located services. Health services include primary care, sexual and reproductive health, vaccinations, health promotion and education, counselling, psychology, mental health and alcohol and other drug services.  Other services include advocacy, social work, youth transition services, youth development programmes, mentoring, accommodation support, training and education, budgeting and employment.	All young people within the age limit and region qualify for YOSS services.	Young people can self-refer. Referrals can also be made through the public health system and other service providers.
<b>Private psychological services</b>	Private clinical psychologists assess the needs of young people with challenging behaviours, developmental delay, and other issues.	All people qualify for private psychological services if they can pay for them or if they are funded	Referral is by CDS if through the public health system or Oranga Tamariki for

Health and disability sector	Service description	Eligibility criteria	Referral pathway
Might hold contracts with Te Whatu Ora or Oranga Tamariki		by Oranga Tamariki or another source. Young people with suspected FASD qualify, if their families can afford it.	young people in care. People can also self-refer if they pay privately.

## New health strategies to deliver Pae Ora could influence supports and services for young people and families living with FASD in the future

The Pae Ora (Healthy Futures) Act 2022 requires the Minister of Health to prepare and determine six health strategies (the Pae Ora Strategies). The Pae Ora Strategies provide a long-term vision to achieve pae ora (healthy futures) for all New Zealanders. The strategies aim to set the direction for a health system that is equitable, accessible, cohesive, and people-centred. In July 2023, the six Pae Ora Strategies published were:

- The New Zealand Health Strategy
- Pae Tū: Hauora Māori Strategy
- Te Mana Ola: The Pacific Health Strategy
- The Provisional Health of Disabled People Strategy
- The Women's Health Strategy
- The Rural Health Strategy.

The following Pae Ora Strategies may influence the support and services for young people and families living with FASD:

- The Provisional<sup>10</sup> Health of Disabled People Strategy sets the direction and priorities to enable equitable health and wellbeing outcomes for disabled people (Minister of Health, 2023a). The strategic priority areas are:
  1. embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system.
  2. ensure the health system is designed by and accessible for disabled people and their whānau and provides models of care that suit their needs.
  3. ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing.
  4. build health workforce capacity and capability to meet the needs of disabled people and their whānau.
  5. increase the visibility of disabled people in health data, research, and evidence as part of an active learning system.
- Pae Tū: Hauora Māori Strategy (interim strategy) guides health entities to uphold Te Tiriti o Waitangi and achieve Māori health equity (Minister of Health, 2023b). The foundations of Pae Tū: Hauora Māori Strategy come from Whakamaui, which includes:
  1. Māori exercising their authority to improve their health and wellbeing

<sup>10</sup> The Health of Disabled People Strategy was published in a provisional form to enable further targeted engagement with the disability community and shaping of priorities (Minister of Health, 2023a).



2. ensuring the health and disability system is fair and sustainable and delivers more equitable outcomes for Māori
  3. addressing racism and discrimination in all its forms
  4. protecting mātauranga Māori throughout the health and disability system.
- The [Women's Health Strategy](#) will guide health system progress towards equity and healthy futures for women, including equitable health outcomes for wāhine Māori (Minister of Health, 2023c). The strategic priority areas are:
    1. A health system that works for women
    2. Improving care for issues specific to women
    3. Better outcomes for mothers, whānau and future generations
    4. Living well and ageing well.

## The education sector – Ministry of Education

Young people aged 11 to 18 are in intermediate school (10 to 13) and secondary school (13 to 18). School is mandatory until 16 years old.<sup>11</sup>

The Ministry of Education sets policies and funds services in the education sector. The Ministry of Education takes an inclusive approach to support students based on their needs. [Te Tūāpapa o He Pīkorua](#) guides the work of the Ministry of Education. 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.

Priority 4 in the Learning Support Action Plan (2019 - 2025) is focused on providing flexible supports and services for neurodiverse<sup>12</sup> children and young people', which is targeted at children with 'moderate needs' (Ministry of Education, 2019). Key actions under this priority include creating a comprehensive set of tools for teachers and other educators, strengthening specialist supports for children who do not qualify for the highest level of support, and strengthening specialist support for teachers of those with dyslexia or ongoing literacy needs.

The Ministry of Education is implementing inclusive design modules to enable an inclusive curriculum.<sup>13</sup> The modules contain professional learning resources to build educator' capability to be more inclusive in their practice. The three modules are:

1. building inclusive practices and equity
2. design for learner variability
3. inclusive curriculum design and intentional teaching.

The Ministry of Education has published guides on its Inclusive Education website to help teachers and educational leaders plan for the diverse learning needs of young people living with FASD. The guides include:

- understanding FASD

<sup>11</sup> More information on the education system in New Zealand can be found [here](#).

<sup>12</sup> In the Learning Support Action Plan neurodiversity "includes (but is not limited to) dyslexia, dyspraxia, dyscalculia, dysgraphia, autism spectrum disorder, foetal alcohol spectrum disorder, attention deficit/hyperactivity disorder, trauma related disorders, and auditory or visual processing disorders." (Ministry of Education, 2019, p32).

<sup>13</sup> [Inclusive design modules - Planning for diversity | Inclusive Education \(tki.org.nz\)](#)



- strategies for action, including:
  - identify needs and how to provide support
  - support self-regulation and positive behaviour
  - helpful classroom strategies years 1-8
  - helpful classroom strategies years 9-13.<sup>14</sup>

Students with learning support needs, such as those with FASD and other neurodisabilities, might be able to access a range of other education supports. Supports include Learning Support practitioners, teacher aides, and specialist teachers (e.g., Resource Teachers, Learning and Behaviour/RTLBs, Learning Support Coordinators). As discussed here, young people living with FASD and their families struggled to access educational support.

In addition to the mainstream schooling system, alternatives exist, such as regional health schools, day and residential specialist schools, alternative education, home education, and Te Kura (Te Aho o Te Kura Pounamu; a state-funded distance education provider).

Table 2 describes the specialist teachers, initiatives and programmes, and alternative education centres that may be available for young people living with FASD, if they reach the eligibility criteria.

**Table 2.** Service descriptions of education services available for young people aged 11–18 with suspected and diagnosed FASD, if eligible

Education sector <sup>15,16</sup>	Service description	Eligibility criteria	Referral pathway
<b>Teacher support</b>			
<b>Special Educational Needs Coordinator (SENCO) or Head of Learning Support</b>  <b>Funded by the Ministry of Education</b>	SENCOs are members of teaching staff who coordinate support for students with special educational needs and disabilities within a school.  The SENCOs' role and responsibilities varies across schools. Some schools have a dedicated full-time equivalent for this position; the SENCO forms part of an existing role in other schools.	SENCOs generally identify and support all students in a school with learning support needs. SENCOs might support young people with suspected FASD.	N/A
<b>Teacher aides</b>  <b>Funded by the Ministry of Education</b>	Teacher aides assist teachers in helping with students' learning, including managing their behaviour and working with others. Support is offered from Year 1 onwards.	Students qualify if they receive funding from Ongoing Resourcing Scheme (ORS- see below), the School High Health Needs Fund, In-Class Support, Behaviour Services, or Communication Services. Young people with suspected FASD may fit these criteria.	Students are allocated teacher aide funding after qualifying for eligible funding categories (based on support needs).

<sup>14</sup> [Fetal alcohol spectrum disorder and learning | Inclusive Education \(tki.org.nz\)](#)

<sup>15</sup> 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.

<sup>16</sup> The Ministry of Education has an Inclusive Education policy that means all young people living with diagnosed or suspected FASD can access services. There is also an online resource available for schools and families (see [here](#)).

Education sector <sup>15,16</sup>	Service description	Eligibility criteria	Referral pathway
<b><u>Learning Support Coordinators (LSCs)</u></b>  <b>Funded by the Ministry of Education</b>	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 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 <sup>17</sup> , and number of students). <sup>18</sup>	LSCs work with schools, and clusters decide what the LSC role entails. The guiding allocation is a ratio of one LSC to 500 students within a cluster.
<b><u>Resource Teachers: Learning and Behaviour (RTLBs)</u></b>  <b>Funded by the Ministry of Education</b>	RTLBs are specialist teachers who work with and upskill teachers and schools to make interventions for students with learning and behavioural difficulties. RTLBs work across multiple schools, from Year 1 to 10.	Students with learning and behavioural difficulties qualify for support. Young people with suspected FASD may fit these criteria.	Schools can request RTLB support for students who are having difficulties. Families can talk to the teacher to request additional support. RTLB clusters (regional groups) have their processes for managing requests.
<b>Initiatives or programmes</b>			
<b><u>Behaviour support</u></b>  <b>Funded by the Ministry of Education</b>	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, 3) gets in the way of positive relationships with other people.  A Ministry of Education representative will work with the school, young person, family, and specialists to assess needs and co-design tailored support for them.	Students with significant behavioural difficulties qualify for an assessment for support. Young people with suspected FASD may fit these criteria.	Support can be requested by contacting the local Ministry of Education office.
<b><u>Ongoing Resourcing Scheme (ORS)</u></b>  <b>Funded by the Ministry of Education</b>	ORS supports students with the highest ongoing levels of need for specialist support. ORS funds specialists, specialist teachers, teacher aides, and consumables. Once someone 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.  Young people 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 young person.
<b>Alternative schooling</b>			

<sup>17</sup> Māori medium schools refer to schools where all or some students are taught in the Māori language for at least 51% of the time.

<sup>18</sup> Allocation rationale and other information about LSCs can be found [here](#).

Education sector <sup>15,16</sup>	Service description	Eligibility criteria	Referral pathway
<u><b>Day specialist schools</b></u>  <b>Funded by the Ministry of Education</b>	Day specialist schools offer specialist teaching to students in Years 1 to 13 with a high level of need. In addition to having a base school, many day schools have satellite classes with specialist teaching.	Eligible students can be considered if they have high needs (e.g., need to adapt the curriculum, support from specialist staff, additional teaching time and teacher's aide support). <u>Other eligibility criteria apply.</u>	Students and families can request enrolment from the local Ministry of Education office.
<u><b>Residential specialist schools</b></u>  <b>Funded by the Ministry of Education</b>	Residential specialist schools are for students with educational needs relating to vision, hearing, socialisation, behaviour, and learning.	Eligible students can be considered if they are deaf, hard of hearing, blind, have low vision, have severe behaviour needs, or have educational, social and emotional needs together with a slow rate of learning. <u>Other eligibility criteria apply.</u>	Students and families can request enrolment from the local Ministry of Education office.
<u><b>Alternative education</b></u>  <b>Funded by the Ministry of Education</b>	Alternative Education offers a pathway where young people receive additional learning support. Alternative Education aims to enable students' attendance and engagement, academic achievement, personal and relational skills, and re-engagement back into secondary school or other (e.g. training).	Alternative Education is for students between Years 9-11 who are at risk of or have already disengaged from school.	A request for support to Alternative Education providers can be made by the student or their family, <u>Te Mahau</u> , schools, providers, or other agencies (e.g. Oranga Tamariki, or community organisations). Referrals are made with the agreement of the student and family).
<u><b>Activity centres</b></u>  <b>Funded by the Ministry of Education</b>	Activity centres provide educational and pastoral support (including a specialised Learning Programme) to students in Years 9-13.	Centres are for those who are at risk of disengaging from schooling and at risk of low educational, social or vocational outcomes. Other entry criteria include being enrolled in a state school, their behaviour impedes their learning and others, and a specialised programme is the most effective way of meeting their needs. Young people with suspected FASD qualify if they meet criteria.	Eligible students are referred to activity centres by schools, primarily for behavioural concerns.
<u><b>Te Kura</b></u>  <b>Funded by the Ministry of Education</b>	Te Kura is a state-funded distance education provider offering personalised learning programmes and courses, mainly delivered online, from early childhood to NCEA Level 3. Te Kura enables equity of access to education for students whose location, itinerancy, educational or personal circumstances prevent attendance at a reasonably convenient school.	Parents or students aged 5 to 19 can enrol through 'access' or by 'referral'. Students can enrol by access due to exceptional arts or sport performance, geographic location, itinerancy, young parents, or overseas. If referred, criteria include being in Oranga Tamariki care, Corrections custody, being non-enrolled, excluded or expelled, or on psychological or psycho-social grounds. <u>Additional criteria</u> also exist. Young people with suspected FASD qualify if they meet criteria.	If supported by referral documents, eligible parents or students can apply for 'access' pathways directly and apply for 'referral' pathways.

Education sector <sup>15,16</sup>	Service description	Eligibility criteria	Referral pathway
<b><u>Home education or homeschooling</u></b>  <b>Self-funded and may qualify for the home education supervision allowance</b>	Home education is where parents or legal guardians take responsibility for their children's education instead of enrolling them in school.	Anyone can be homeschooled if the Ministry is satisfied that the young person will be taught at least as regularly and as well as they would be in a registered school and any special education needs are met. Young people with suspected FASD qualify if their parent or legal guardian meet criteria.	Any parent or legal guardian of a child aged between 5 and 16 can apply at the Ministry of Education to home educate.
<b><u>Regional health schools (not an alternative pathway for mainstream schooling)</u></b>  <b>Funded by the Ministry of Education</b>	Regional health schools are for students with significant health needs (e.g., in hospital, chronically ill, live in a health-funded institution, have been absent due to medical intervention) who cannot attend their local school. New Zealand has three regional health schools ( <u>Northern</u> , <u>Central</u> , <u>Southern</u> ).	Eligibility is considered when a student is in: 1) an active treatment programme for their health condition, or 2) engaged in a health-funded mental health programme with an active therapeutic programme AND 1) in hospital, or recovering for 10 school days or more, 2) have more than 6 admissions to hospital in one year, or 3) have repeated school absences due to illness, totalling more than 40 days in one year. Young people with suspected FASD qualify if they meet the criteria.	Families can apply directly at each of the regional health schools.

## Work to improve support for students with high needs is in progress, following the Highest Needs Review

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. The work to implement the Highest Needs Change Programme arising from the review is underway.

Support for students with suspected or diagnosed FASD would be influenced by the Highest Needs Change Programme, which is currently being developed. The work programme will outline changes for the next two, five and ten years. In the short-term, the Ministry of Education is strengthening the current model to make it quicker and simpler for learners and their families to get the support they need. The Ministry of Education also supports teaching staff in developing their skills and confidence to work with students with high support needs. However, this training has no specified funding stream.

The Ministry of Education aims to implement the following 'building blocks' for an inclusive and accessible system:

1. A new service delivery system.
2. Customised tailored supports.
3. An integrated and inclusive schooling network co-developed with sector partners.
4. Learning supports for Māori students that are developed by Māori.
5. Learning supports for Pacific students and their families developed by Pacific people.
6. A confident, capable workforce with the capacity to respond.
7. A new funding model to support a tailored and flexible approach.
8. Stronger integration with other agencies.

## Reviews of teacher aides resourcing and residential special schools are underway

A review of how schools are resourced for teacher aides is underway.<sup>19</sup> Reviewing teacher aide allocation aligns with families' and stakeholders' feedback on improving teacher aide support for young people living with FASD.

A review of residential special schools is also currently underway. These residential special schools are an important option for some families when their young person living with FASD starts college and would not be able to navigate a large, unaccommodating mainstream school.

## Oranga Tamariki – care and protection and youth justice

The Oranga Tamariki vision is to ensure all tamariki or children in Aotearoa, New Zealand are in a loving family and communities where oranga tamariki can be upheld. The organisation's work involves supporting families, working with children, supporting children in care, supporting caregivers, working with children and young people through the youth justice process, and working with people during the adoption process.

Oranga Tamariki works with young people with suspected or diagnosed FASD in care or the youth justice setting. An estimated 50% of children and young people in Oranga Tamariki care could be affected by FASD (FASD Working Group, 2016). Internationally, young people with FASD are overrepresented in youth justice settings (Bower et al., 2018). A prevalence study of FASD among the Youth Justice population in Aotearoa New Zealand is currently in progress.

Many stakeholders comment young people living with FASD and their families tend to receive more support in care or youth justice. Since these young people and families are in crisis, many referred to this response as the 'ambulance at the bottom of the cliff'.

### Young people living with FASD are eligible for support in Oranga Tamariki care

Young people in Oranga Tamariki care can be in care until age 18, after which they can leave. Young people can stay in care until age 21 with a caregiver agreement.

The National Care Standards were implemented for all children and young people in the care of Oranga Tamariki. The standards include:

- assessments and plans for children
- needs of children (cultural, recreational, education, health, etc.)
- plans and support for caregivers
- supporting children to express their views
- supporting children during care transitions
- monitoring and reporting on compliance.

Young people in the care of Oranga Tamariki are also eligible for a comprehensive Gateway assessment (described in Table 1). Gateway referral and assessment process varies across the

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<sup>19</sup> [Review of how schools are resourced for teacher aides – Education in New Zealand](#)

country. The Gateway process is currently under review by Oranga Tamariki, Manatū Hauora, Te Whatu Ora, Te Aka Whai Ora, the Ministry of Education and Whaikaha.

Some young people in care may receive a Tuituia assessment instead of a Gateway assessment. The assessment generates a Tuituia report, which may be used when completing a child and family assessment or investigation, for a family group conference (FGC) or court, or referrals to services (e.g., Gateway assessment, residential placements, review of plan or case closure).

Table 3. Service descriptions of services available through Oranga Tamariki for young people in their care aged 11–18 with suspected and diagnosed FASD

Care and protection	Service description	Eligibility criteria	Referral pathway
<b>Gateway assessment</b>  <b>Funded by Oranga Tamariki</b>	A Gateway assessment is an inter-agency process to identify unmet health and education needs of children and young people entering or at risk of entering care. The comprehensive assessment is completed by a paediatrician or nurse-practitioner (with the opportunity to refer to a paediatrician). An inter-agency plan is then developed to follow up on identified needs.	Gateway assessments are for children and young people entering care, already in care, or at risk of going into care.	Social workers make a Gateway assessment referral: 1) when a referral for a care and protection FGC is made, or following it if appropriate, 2) within 10 working days of entering care, or 3) when the child or young person is already in care if it would be beneficial.

### Young people living with FASD may receive support in the youth justice system to ensure their participation and fair treatment

Oranga Tamariki supports young people in the youth justice system in Aotearoa, New Zealand. The youth justice system manages offending by children (aged 10 to 13 years) and young people (aged 14 to 16 years). ‘Alternative action’ is taken where possible, where police respond to offending and aim to keep the young person out of the formal youth justice system. Severe cases that cannot be diverted go through the youth court.

Oranga Tamariki has legislative requirements under the Oranga Tamariki Act 1989 (or Children’s and Young People’s Well-being Act 1989). Key legislation that affect young people with suspected or diagnosed FASD in the youth justice system include:

- **Section 14(1)e** – a child or young person between age 10 and 14 receives care and protection if they have committed an offence or offences of “*sufficient number, nature, or magnitude to cause serious concern for the well-being of the child*”.
- **Section 4A** - practitioners working in Youth Justice should always consider four primary considerations when working with children and young people: their wellbeing and best interests; the public interest (including public safety); the interests of any victim/s; the accountability of young people for their behaviour.
- **Section 7AA** – the duties of the chief executive recognise and provide a practical commitment to the principles of Te Tiriti o Waitangi, including reducing disparities by setting measurable outcomes for Māori tamariki and rangatahi; policies, practices, and services about mana tamaiti (tamariki) and the whakapapa of Māori tamariki and rangatahi and the whanaungatanga responsibilities of their whānau, hapū, and Iwi. Oranga Tamariki seeks to develop strategic partnerships with Iwi and Māori organisations, including Iwi authorities.



- [Section 333](#) - The court may obtain a psychiatric or psychological report to assist the court in determining whether the young person is unfit to stand trial.

The Youth Court deals with criminal offending by children and young people aged 12 to 17 years old that's too serious to be dealt with by the Police in the community.<sup>20</sup> The Youth Court process aims to ensure everyone receives a fair trial and treatment, in line with the UN Convention on the Rights of Persons with Disabilities. If a young person has FASD or other neurodisabilities are suspected, the judge can determine an appropriate intervention to support them. Interventions may include communication assistance to enable young people with FASD to understand what is happening.

District Courts are changing through [Te Ao Mārama](#) – Enhancing Justice for All. The vision of Te Ao Mārama is to ensure all people who come to the District Court can seek justice and be seen, heard, understood, and meaningfully participate.

Table 4 lists the services available for young people in youth justice. Oranga Tamariki funds some initiatives, and the Ministry of Health funds others.

Table 4. Service descriptions of services that may be available for young people in the youth justice system aged 11–18 with suspected and diagnosed FASD

Youth Justice	Service description	Eligibility criteria/referral process
<b><a href="#">Family Group Conference (FGC)</a></b> <b>Funded by Oranga Tamariki</b>	Youth justice FGCs are a restorative justice process held when young people are alleged to have offended or once the charges have been proven. FGCs are convened and facilitated by youth justice coordinators.	FGCs are held for young people in the youth justice system.
<b>Communication support</b>  <b>Funded by Oranga Tamariki</b>	Communication assistance can be provided in youth justice settings (including FGCs and the youth court process) to support young people with FASD so they understand, communicate effectively and participate. They work to remove barriers to the youth justice process through plain language, checking to understand, and using pictures to describe events and outcomes from FGCs and supervision plans.	A social worker might identify a young person who has specific communication needs and would discuss the use of professional support with the youth justice coordinator.
<b>Youth Justice Health Assessments</b>  <b>Funded by Te Whatu Ora</b>	Youth Justice Health Assessments are used to understand the health needs of those between ages 10 and 18 who offended and are referred for a Youth Justice FGC. Health assessments might indicate the need for an FASD assessment.	A judge or others may refer young people who are at high risk of re-offending and have identified health issues, and who consent to the assessment process.
<b><a href="#">Youth forensic mental health service</a></b>  <b>Funded by Te Whatu Ora</b>	Specialist mental health and alcohol and other drug (AOD) services for young people with mental health disorders, AOD problems and intellectual disabilities who have offended or are alleged to have offended and are involved in Aotearoa, New Zealand's justice system. The	Access is based on need and ability to benefit. The mental health needs of young people are intended to be systematically identified at all critical stages of youth justice processing.

<sup>20</sup> [Youth-Court-Factsheet-2019.pdf \(youthcourt.govt.nz\)](#)

Youth Justice	Service description	Eligibility criteria/referral process
	youth forensics service provides consultation, liaison, assessment, and treatment.	
<b>Youth Justice Education Assessments</b>  <b>Funded by the Ministry of Education</b>	Youth justice education assessments support FGCs by identifying the underlying reasons influencing engagement in education, improving their engagement in education or vocational education, identifying and facilitating interventions to improve engagement, and engaging families in the process.	The criteria to determine who might benefit from an education assessment include an FGC that has been convened, consent given from the young person and family, the young person having high educational needs, being at high risk, or having a high risk of re-offending.

## Financial support – the Ministry of Social Development

The Ministry of Social Development uses a social model of disability. This model identifies systemic and social barriers that make navigating the world difficult for individuals with impairments. Policies focus on providing financial support based on need. Young people with a FASD diagnosis and their families are eligible for financial support if they have a diagnosis noted on a medical certificate and meet other criteria (e.g., income level).

Young people living with FASD might be eligible for other financial assistance based on their circumstances. Many supports are accessible to 16 years old (e.g. accommodation supplement, jobseekers support), if they meet the criteria.

Table 5. Funding available for young people aged 11–18 with suspected and diagnosed FASD through the Ministry of Social Development

The Ministry of Social Development	Service description	Eligibility criteria	Application process
<b>Disability Allowance</b>	Weekly payment for people with regular, ongoing costs because of a disability (e.g., visits to the doctor, medicines, extra clothing or travel).	Young people (from 16 years) are eligible if they have a disability that is likely to last at least six months; have regular, ongoing costs due to the disability that another agency does not fully cover; are a New Zealand citizen or permanent resident; normally live in New Zealand and intend to stay here. Young people with FASD qualify if they meet the criteria.	Young people can apply through Work and Income.
<b><u>Supported Living Payment</u></b>	A weekly payment to help if people care 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. Access criteria applies ( <a href="#">here</a> ).	Parents/caregivers can apply through Work and Income.
<b><u>Child Disability Allowance</u></b>	A fortnightly payment made to the main carer of a young person (up to age 18) with a serious disability.	Parents/caregivers are eligible if: 1) they are the main carer of the young person, 2) a New Zealand citizen or permanent resident, 3) the young person has been assessed as needing constant care and attention for at	Parents/caregivers can apply through Work and Income.



The Ministry of Social Development	Service description	Eligibility criteria	Application process
		least 12 months because of a serious disability, and 4) young person is under 18. Parents/caregivers of young people with FASD qualify if they meet criteria.	

## Cross-agency support services

Some cross-agency services provide wraparound support to young people with high and complex needs. Examples include:

- **High and Complex Needs (HCN)** is jointly funded by Oranga Tamariki and the Ministry of Education. In the financial year 2022/2023, 15% of the cohort had a diagnosis of FASD, and 80% had a neurodevelopmental disorder (High and Complex Needs, 2023). In the same year, 65% of plans started between 10 and 14 years and 12% between 15 and 19 years.
- **Intensive Wraparound Service (IWS)** is 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 young people not receiving early intervention.

Table 6. Inter-agency funding available for young people aged 11–18 with suspected and diagnosed FASD, if eligible

Inter-agency	Service description	Eligibility criteria	Referral pathway
<b><u>High and Complex Needs (HCN)</u></b> <b>Funded by the Ministry of Education and Oranga Tamariki</b>	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.	Young people are eligible if they have high and complex needs across at least two sectors (education, health, and care and protection). Young people with suspected FASD qualify if they meet criteria.	Two required agencies have to put in a joint referral.
<b><u>Intensive Wraparound Service (IWS). Te Kahu Tōi</u></b> <b>Funded by the Ministry of Education</b>	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, 2) require support at school, at home and in the community. IWS takes a bespoke, comprehensive, holistic, youth- and family-driven approach.	IWS has two key criteria: 1) a need exists in the school, home, and community, 2) every other intervention has been used or attempted and was unable to meet needs. A panel reviews all referrals and decides if the young person is accepted. Young people 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.

## A joined-up, accessible whole-of-system response for young people living with FASD and their families does not exist

As demonstrated, government agencies fund a range of services and support that may be available to families and young people children aged 11-18 years with FASD or suspected FASD. While these services exist, families and stakeholders interviewed highlighted severe difficulties in accessing FASD-informed support and services across government agencies for young people. Few young people living with FASD and their families had accessed the services they needed across the health, disability, education, care and protection and youth justice sectors.

Everything I know I've had to find myself. I'd love this little magic unicorn to turn up and go 'hey, you're child's been diagnosed with FASD. Did you know you can access? Here's some handy hints'. (Family living with FASD)

Young people and families interviewed shared their frustration at the amount of time and energy they spend advocating and negotiating access barriers and for many then not to receive needed services. Many shared their despair and the trauma due to the lack of or inappropriate services has on their young people seeking to live their best lives. They also reflected on the broader adverse impact the lack of support has on their and their families' wellbeing (discussed [here](#)).

It's [support] more through luck rather than a system-wide approach. (Regional health)

The access barriers identified by families and stakeholders to existing services to support young people living with FASD are detailed below.

### Families and stakeholders do not know what support and services are available

Many families and stakeholders interviewed highlighted they do not know and cannot easily find out what support is available for young people living with FASD. They noted when they approached agencies, they either lacked an understanding of FASD or did not know what support was available. Families are left to spend significant time finding and then forcibly and persistently advocating for services to support their young person. Some families do not have the capability or capacity to do this level of advocacy. As a result, these families and young people living with FASD receive no support until a crisis is reached (e.g., engagement with the young justice, self-harm or suicide attempt). Even at a crisis point, a few families were unable to access FASD-informed support.

The post-permanent care thing has only come about in the last few years. They [OT] have paid for those assessments because I'm pretty good at advocating and saying this is what needs to happen. I hate to imagine what happens to people who can't speak up or, don't speak up, or don't know how to. (Family living with FASD)

### Available services are inconsistent across the country, resulting in a 'postcode lottery'

Stakeholder and family feedback highlighted the variation in the support and services around the country. For example, while Child Development Services is a nationally-funded service across the country, different Child Development Services have different levels of expertise to assess and diagnose FASD (Litmus, 2023). Child Development Services following best practice FASD guidelines (Cook et al., 2016), like Hawke's Bay and Hutt Valley, were established by passionate health professionals rather than system change initiatives.

Young people with suspected FASD and their families need to engage with services and teams that assess and support children and young people with a range of neurodiversities, including FASD. The latter reflects that young people are referred due to general behaviour concerns and are not

suspected of having FASD. All regions need multidisciplinary, culturally-safe services capable of assessing the full range of neurodiversities, including FASD, and offer post-diagnosis FASD-informed support across the sectors.

Too much variation [across the country]. Some places where there have been strong advocates have got improved services. And other places that have had to prioritise other health needs may have significantly less service in their specialist capacity. (Regional health)

Young people also receive varied support depending on their local school. Ministry of Education funding is difficult to access. Therefore, the school's discretionary budget must fund support and services. Support available depends on how schools prioritise and allocate their limited funding. As a result, some schools may employ a full-time SENCO who coordinates support for those with additional learning needs. Others have a part-time SENCO. Some schools do not have this role.

I've always said, "Any service is only as good as the person you strike on the day". You may be lucky enough to get a really clued-up, tuned-in teacher, or you may not be. It goes across every sector, including justice, education and health, and MSD. It's only as good as the person you strike on the day until they get some policy. (Family living with FASD)

Young people and families living with FASD in rural or isolated regions also have less access to specialist services. Travel and other logistics to get to services add a burden to families who are already stretched.

Some of our whānau struggle financially with driving out of town to see specialists. We can't get them into town; it's just about impossible. And the ones that do come up are just so time-pressed that the waiting lists are getting longer and longer. (Regional education)

Inconsistent access to FASD support and services across regions and schools contributes to inequitable outcomes for young people and their families.

### **Young people living with FASD tend not to meet the eligibility criteria for disability or education support services**

Families and stakeholders perceive a primary barrier to effectively supporting young people is a sole FASD diagnosis is not eligible for disability support services. As a result, they do not receive funding that could be used to put appropriate support in place for the young person with FASD. For example, one family explained that when they received ORS funding after an ASD diagnosis, they hired a young person to offer social support and reduce their young person's social isolation. However, stakeholders and families note accessing ORS funding is extremely difficult.

If it's a brain injury, why is it not under the NASC or anything? We need help. We've been screaming out for help, but it's not classed as anything. We've also got [another child] who's got an intellectual disability. He's got all the NASC help and funding, but he's no problem. Not at all. But an FASD child, wow. We're entitled to nothing. (Family living with FASD)

The ORS is only for a very small percentage of the population; I think it's 0.1%. It's a huge application to do and there are a huge group of kids with an intellectual disability or with FASD who don't meet any of their criteria. (Regional education)

Families interviewed comment the system treats FASD differently than other disabilities. Their experience, at times, the needs associated with living FASD are more complex than disabilities eligible for support. Families feel the lack of support is associated with the stigma and blame culture relating to FASD where they and their young people are made to feel unworthy. One example was a school accommodating the needs of one disabled student but not accommodating the student with

FASD, despite having the same need. One birth mother talked about wanting teachers to know about the FASD diagnosis but the school wanting to keep it private which presumes FASD is shameful.

The school spent the whole time going, "We won't tell too many teachers", and I'm like, "No, tell all the teachers. Everyone needs to know what's up with him, so that they know what to do." "Oh, well, we're just thinking about you", and it's like, yes, I did this to him. I'm his birth mum, but this is not about me. This is about him, and what he needs. (Family living with FASD)

Families shared their engagements with gatekeepers who labelled their young person's needs as 'bad behaviour or attitude' and 'bad parenting'. Some families were told supporting their young person living with FASD diagnosis was too much for the service.

I don't know if FASD is regularly diagnosed but once it is and you know what it is, it's almost like you're just swept under the rug, "Oh, well, it's alcohol whatever. You're not important", sort of thing. (Family living with FASD)

The lack of post-diagnosis support impacts other parts of the system downstream. Education and youth justice sector stakeholders can refer young people for an FASD assessment. However, without post-diagnosis support, some question whether a time-consuming and intensive assessment process is necessary. In contrast, families want an FASD assessment to understand their young people's strengths and needs to ensure their parenting is FASD-informed. They also hope that when they get the diagnosis, tailored support will follow.

I guess there's a general lethargy within Oranga Tamariki [because] if they are diagnosed, there is no support that they can get access to anyway, so why bother? Just being frank. (Anon)

### **Families spoke of being shunted across services without obtaining needed support**

Families experience a disjointed process as they navigate the system for support. They are constantly referred between services, and declined due to not meeting eligibility criteria. With every application, families and young people retell their stories and try to prove they are worthy of assistance, which is traumatising.

We got bounced around. We went to an RTLB, and the RTLB said he is what he is, we can't do anything with him. We went to a private Ed Psych with some good recommendations, but the school just wanted to move him on. They recommended Alternative Education, but I said you're not listening. He doesn't like changes. (Family living with FASD)

Families spend significant time and energy seeking support from professionals. They feel hopeful when they eventually make contact. However, some are disappointed as meetings or required support do not eventuate. The lack of reliability causes families to lose trust in the system.

We went to a Strengthening Families meeting. We sat around and chatted for the first meeting, and then there was a follow-up meeting, but none of the people attended the follow-up meeting. The social worker and paediatrician didn't come; they all just didn't come. We were just left on our own. (Family living with FASD)

The constant referrals is further exacerbated by ongoing workforce capacity issues across the health and disability, education, and social support sectors. Lack of capacity means services triage and prioritise families and young people deemed to have the highest needs or risk threshold. Workforce capacity issues are discussed [here](#).

We've said, "He's got FASD". "Right. Well, we'll refer you to this organisation." They referred us there. They don't seem to help. We'd get referred somewhere else. They don't want to help. They're too full. And we're going around in circles, and no one wants to help. We got the offer of a NASC assessment, but because his IQ is two points over, we're not entitled to NASC help. So there's no help for us; we have to deal with it ourselves and walk on eggshells. (Family living with FASD)

Families navigate the system without guaranteed support to prove they qualify for assistance. They talk about attending numerous meetings and going through many application processes across many sectors. Constant declines, referrals, and waitlists contribute to weariness and burnout. Families need resilience and knowledge for this process. Access and outcomes inequities exist as not all families know how to navigate the system.

A lot of whānau do not go any further because they do not know how to go further. (Education)

Struggling through this process, some families and young people grow disillusioned and eventually disengage. Without external support, they have to rely on themselves for support, where their energy and capacity allow. Over time, needs can become more urgent, and when in crisis, some families and young people can access support (e.g., care and protection or the youth justice system), as discussed [here](#).

We spent much of our time being directed somewhere else for them to all go, "Nope, you don't qualify". In the end, I just threw my hands in the air and went, "Fine, I'll do it my way". I had to be his mental health, his therapist, anything that was needed. I just had to either research it or wing it, which makes you very tired at the end of the day. (Family living with FASD)

### **Support received by young people living with FASD is primarily driven and implemented by passionate and FASD-informed staff**

Stakeholders and families interviewed noted a few locally-led initiatives making positive changes for families and young people with FASD. Examples include education transition services to familiarise young people and their families moving into intermediate and college; school hubs to support young people who might otherwise be suspended or stood down.

Families also noted the importance of FASD-informed staff who understand and can accommodate changes to enable the young person. They understand why certain behaviours happen and can use appropriate strategies to work with young people with FASD. Examples have included teaching staff and police officers. However, these examples were one-off instances. Some families noted wider system pressures (i.e., lack of staff) can constrain people working more holistically to support young people with FASD.

We were lucky. We had a really good guy who had been teaching in Canada who knew about FASD. He attempted to put in a lot of wraparound supports for [young person 1 and 2] within the school. It wasn't supported because the teachers do not know about FASD. They do not know how to deal with it in the classroom because there's no PD for them. And quite frankly, if you're one teacher with 30-35 kids, it's very hard to do that. (Family living with FASD)

### **Young people with FASD age out of services they need**

Many services are age limited (e.g., 16 years for Child Development Services, Year 10 for RTLBS services, Year 11 for Alternative Education).



It's a sore point for schools because they say, "well why can't you [RTLB] work with Year 11s?" It's a Ministry thing. When they created their RTLB Service, they set it up to Year 10, but I do know that there is quite a lot of work by a lot of clusters where they are shifting kids into Year 11 to support them. (Education, RTLB)

Families and stakeholders also note that age limits appear to be arbitrary. Age-limited support does not recognise that young people living with FASD can have developmental delays, and their cognitive abilities will develop at different rates. For example, an 18-year-old may have the reading ability of a 16-year-old, the living skills of an 11-year-old, and the social skills of a 7-year-old. Further, FASD is a life-long neurodevelopmental impairment therefore, support remains necessary across the life course. Currently, the system response does adopt a whānau-centred life-approach to supporting young people with FASD.

[Young people] are still trying to seek support in the schooling system, but suddenly, they have aged out of the system and are now classed as adults and have to go through a different system. (Education)

Young people with FASD can be distrustful of services due to their previous experiences. Due to age restrictions, services where young people have a positive working relationship are stopped, which is very disruptive.

### **Young people and families have to reapply for services when they relocate**

Some young people and families are mobile and relocate often. Young people in Oranga Tamariki care can be transient, depending on where their placements are located. Due to housing pressures and the cost of living, stakeholders note families living with FASD are relocating more frequently to affordable areas.

The other thing that can be problematic is, "Will they then move?" So, I've got one young person who lived in [region] and then went to [region] for a while, and then six months later, he's now in [region]. So, that's three different regions in six months. And this is a complex young person with police involvement, Oranga Tamariki, Ministry of Education involvement, and health involvement. So, it's quite problematic when they move. (Regional health)

Many barriers exist when young people and families try to re-establish support in new regions. Stakeholders noted information (including existing diagnoses) does not follow families and young people when they move. Young people and families must restart setting up support in a new location. Navigating services again in a new area is a labour-intensive and traumatic process. Additionally, support might differ or not exist in the new region. Services also do not begin immediately. Some services operate waitlists of months to years, and the young person might not stay in that location for this length of time.

What we find is a young person might get a diagnosis at age 10, and then they might pop up at 14, 16, in Youth Court. Reports on a child often don't travel with that child. They get a diagnosis of FASD at 10, but then at 14, 16, other professionals are not aware that this young person has already got a diagnosis. (Regional health)

# For some, but not all, more support becomes available when in crisis

## Agencies may come together to support people with high needs or in crisis

Some programmes take a cross-sector approach. Cross-agency stakeholders and agencies come together to understand how to support young people living with FASD and their families. Examples include the High and Complex Needs programme and the Intensive Wraparound Service. However, these initiatives tend to cater to families and young people in crisis rather than early intervention to prevent them from being in these circumstances.

We connect with cross-agency groups around lots of different pieces of work, so the Alternative Education area of work definitely connects to Oranga Tamariki, youth justice, and the Regional Health Schools. There's ongoing relationships. (Ministry of Education employee)

Feedback from some families interviewed highlighted that even when facing extreme crises (e.g., suicidal ideation, sexual abuse, violence, persistent bullying), they cannot access FASD-informed help and support.

Some young people living with FASD in care and protection and youth justice settings can access Family Group Conferences, Gateway assessments, and other services to identify and support their needs. These services and assessments usually involve multiple sectors and agencies. They are also more timely, with the assessment and report needing to be completed within strict court timeframes.

Stakeholders comment that being in care or youth justice is due to a culmination of unmet needs over time and a lack of early intervention. Young people with FASD or suspected FASD may only receive support if they end up in youth justice. These circumstances point to the need for early intervention to prevent these situations.

To get access to that resource [access to psychological supports], you have to go to one of the highest tariffs, which is the Youth Court process because you can't get it any other way. (Oranga Tamariki employee)

Stakeholders from youth justice note they work to limit the time young people spend in the youth justice system. Limiting the time can minimise the trauma and harm from the process. However, despite resources and support, interventions are constrained in enabling sustainable change for young people and their families. They would return to the usual system after they leave, which still lacks ongoing support.

We're only supposed to be there for a period of time and it's short and sharp, but how do you undo over a decade's worth of learned behaviour, trauma, diagnosis like ADHD or FASD? How do you manage all of that in a short space of time and turn their life around? That is difficult, near impossible. When we look at interventions, we look at what we can put in place that's long-term and sustainable so that once their time in youth justice comes to an end, that can continue without us needing to be involved. (Oranga Tamariki employee)

## Siloes persist when supporting people in care and youth justice

Some processes in the youth court process require input from other agencies (e.g., health and education assessments). Challenges exist with information sharing. Stakeholders noted that education assessments sit in the Ministry of Education and are sometimes difficult to get to inform the youth court process. Information that may enable appropriate support and intervention is siloed.

Tensions also exist with timeframes. Ideally, young people are in the court system for the shortest time possible. However, the length of time is impacted due to the time needed to do a comprehensive FASD assessment and health professionals' lack of capacity.

In 2019, changes to the Oranga Tamariki 1989 Act allow for greater information-sharing across agencies to ensure the wellbeing and safety of children and young people. However, not all professionals are aware of these provisions (Masari, et al. 2021).

## Stakeholders note future policy settings need to be relevant to the current context

National-level work is ongoing to create a more effective system response to support young people living with FASD. Some initiatives in the FASD Action Plan are completed. Others are in progress. However, the plan expired in 2019. A lack of policy direction currently exists on future directions.

Stakeholders note the need to focus on FASD due to an ongoing lack of awareness and stigma rather than generally focusing on neurodisability. Targeted work is needed to destigmatise FASD, upskill professionals, and develop FASD-informed services.

This is something which often comes up when we talk about FASD. Does FASD need special attention, or can it be part of wider neurodiversity? And my take is it is too early for FASD just to be thrown in there with neurodiversity. FASD is at an early stage, it needs some direct special attention, as it did with autism. For at least five to ten years, FASD needs ring-fenced assessment and support services so that these children and young people do not miss out. (Te Whatu Ora employee)

As in the phase 1 research, stakeholders interviewed noted the reform opportunities for creating a cohesive, nationally consistent, and equitable response for families and young people 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 young people living with FASD and other neurodevelopment disorders and their families may be overlooked in this wider system reform. Their concern arises from the implementation of the FASD Action Plan. While some 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 strong leadership, governance, and accountability are needed 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 young people living with FASD and their families. The strategy needs strong governance, including Māori leadership (linked to wider reforms), and the resources and structures to deliver and review the strategy.

The system is failing kids with FASD and disability in New Zealand. And its across the systems MoE, MoH, OT...Doesn't feel like the system is improving – just feels like I'm managing one chaotic thing to the next. (Family living with FASD)



## Whole-of-system opportunities

The following whole-of-system opportunities were identified to improve outcomes for young people aged 11 to 18 years with FASD and their families. The opportunities reinforce those identified in the phase 1 research. Opportunities include:

- Develop a whole-of-system strategy for neurodiversity generally and FASD specifically to foster a nationally consistent and joined-up response from prevention, identification and assessment of FASD, and wrap-around support for young people living with FASD and their families.
- Support young people living with FASD to participate in their community and to input into policy and other decisions affecting them.
- Ensure strong cross-agency governance (embedded in the wider system reforms) and review the implementation.

# Creating a system response that meets Te Tiriti obligations

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This section provides key insights and opportunities to ensure diagnostic and support pathways for whānau Māori and their rangatahi aged 11-18 living with FASD or suspected FASD meets Te Tiriti obligations as defined by Whakamaua: Māori Health Action Plan (Ministry of Health, 2020b). The findings presented reflect those presented in the phase 1 research report.

## 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). 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 has contributed to the impacts of FASD on whānau Māori.

Te Tiriti o Waitangi (Te Tiriti) is the founding document of Aotearoa, New Zealand. 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). The five guiding principles are:

- 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 eliminate disparities (i.e., equitable access and funding and encompasses freedom from conscious and unconscious discrimination).
- 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 rangatahi aged 11 to 18 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 rangatahi aged 11 to 18 years living with FASD. The four priority areas are<sup>21</sup>:

- 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 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, focusing on seeking an assessment and diagnosis. Whānau Māori and rangatahi had to wait to receive a diagnosis at 10 or 12 years and older due to needing to be developmentally mature and the lack of assessment capacity. Some whānau Māori noted the need for an FASD assessment did not arise until their rangatahi went to intermediate school or college. Before this time, whānau Māori received little, if any, support (Litmus, 2023). Stakeholders also noted for some rangatahi the need for support due to suspected FASD not being recognised until they are in the youth justice system. In the pre-assessment, assessment and post-diagnosis phases, cultural safety and standardised clinical rigour are needed across Aotearoa, New Zealand.

Access to education support and services is intended to place rangatahi 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 rangatahi with suspected FASD are labelled as misbehaving due to 'bad' parenting. Whānau Māori noted schools' response tends to be punitive towards rangatahi, resulting in them being stood down, expelled or leaving school. This labelling and lack of FASD-informed support isolate whānau Māori caring for a young person with FASD and contribute to inequitable outcomes for rangatahi 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.

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<sup>21</sup> For each priority area, Whakamau details the evidence supporting the action area under the section 'Why is this important?'

I believe the health system are trying really hard with that. Do I believe that it's culturally responsive as it stands now? No - I 100% don't. It is an incredibly challenging system for whānau to navigate. I believe there is a lot of cultural bias. I (Ministry of Education staff)

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 rangatahi with FASD or 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 rangatahi with FASD.

Whānau Māori require strong cultural connectedness and support to ensure improved outcomes for rangatahi 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 rangatahi, 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**

Influencing change for improved and equitable outcomes for Māori requires leadership that reflects whānau Māori and rangatahi living with FASD and seeking access to services. Strong, visible Māori participation in decision-making roles within the FASD policy-setting environment is imperative at the national level to contribute to reducing inequities of access and outcomes for whānau Māori and rangatahi with FASD. The FASD Māori Coalition is offering this leadership. The Coalition is a national network of whānau Māori with tamariki and rangatahi living with FASD. The FASD Māori Coalition advocate for and promotes strategies to help whānau Māori who have tamariki, rangatahi, and pakeke (adult) who have been impacted by alcohol pre-birth.

Health, education, care and protection, and youth justice sectors are going through transformative change to better meet the obligations of Te Tiriti. Enhancing the FASD system-wide response needs to be linked to these changes. Māori leaders and whānau Māori with experience of living with FASD need to contribute to this change. Māori leaders also need to be engaged in cross-sector regional solutions to strengthen the response to whānau Māori and rangatahi 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, disability, education, welfare and youth justice 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. Where sector processes intersect can create challenges for whānau Māori seeking joined-up support to enable their rangatahi living with FASD to thrive and grow.

Joined-up thinking, responses, and accountabilities are critical to reducing 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 rangatahi 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 rangatahi with FASD**

Strategies to support whānau Māori and rangatahi with suspected FASD or FASD require the inclusion of FASD-informed Māori providers and Māori workforce. Many Māori providers offer whānau-centred<sup>22</sup> services grounded in culturally informed and culturally responsive kaupapa Māori practice. Many train their staff in the Whānau Ora approach<sup>23</sup>, which guides their work.

In research phases 1 and 2, feedback from Iwi and Māori providers interviewed highlights they do not have a defined role in the system response. Māori providers also tend not to be included in discussions on how best to support whānau Māori and rangatahi 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 a lack of appreciation of the strengths of Māori providers.

Māori providers' capacity and understanding of FASD and other neurodiversities to support whānau can be limited like other services. Māori providers noted a lack of time and access to FASD and neurodiversity training incorporating mātauranga Māori.

Whānau Māori interviewed 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 rangatahi 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.

More investment is needed in Māori providers to build their workforce's understanding of FASD and other neurodiversities 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 rangatahi 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, reflective of phase 1 findings, were identified from the feedback from whānau Māori and Māori stakeholders to improve outcomes for rangatahi aged 11–18 living with FASD and their whānau. The opportunities are:

- Ensure appropriate national and regional 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 rangatahi
- 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.

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<sup>22</sup> 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.

<sup>23</sup> 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 assessment and support pathways

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This section provides key insights and opportunities about the assessment, diagnostic and support pathways to support and improve outcomes for families and young people aged 11 to 18 years living with FASD or suspected FASD.

## Transitioning through the teen years presents new challenges for young people with FASD and their family

### **Young people living with FASD, like their peers, want independence and freedom**

As young people with FASD get older, they seek the same independence and freedom as their peers. They want to have friends feel connected and heard by their peers. They want to have social interaction, explore their sexuality, and engage in sexual behaviour (FASD-CAN, 2022a). They want to contribute at school and work and feel valued in their communities.

Young people with FASD shared they are grateful for their families support (FASD-CAN conference, 2023). They value people who are respectful, open-minded, empathetic, and advocate on their behalf. Young people living with FASD want support to be independent but don't want to be smothered (FASD-CAN conference, 2023).

Being a teenager living with FASD is not easy when schools have increased expectations on achieving academic and social milestones and taking more responsibility for self-management. Young people living with FASD can have difficulty with abstract concepts, and they can fall behind their peers both academically and socially. Young people living with FASD can find school overwhelming and not supportive. Making friends is hard when others do not understand FASD. They highlighted the potential addiction of social media, giving a sense of connection while enabling for some unrelenting online bullying (FASD-CAN conference, 2023).

Young people living with FASD highlighted the benefits of engaging with other young people living with FASD. They shared that FASD-CAN initiatives enabled them to interact with other young people living with FASD. These initiatives created a sense of shared experiences and made them feel accepted, understood, and less alone (FASD-CAN conference, 2023).

### **Families need to balance safety and respecting their young people's wishes**

During the teenage years, families are learning how best to support their young person living with FASD's decision-making within their strengths and challenges (FASD-CAN, 2022a). They seek strategies and support to keep their young person connected to school and friends who enable them to be their best selves.

All families interviewed shared their young people living with FASD had or were experiencing secondary impacts of FASD due to the poor fit between their young person's needs, their level of functioning and their environment (FASD-CAN, 2022a). Streissguth and Kanter (1997) defined secondary impacts for young people living with FASD as school disruption, mental health concerns, poor self-esteem, self-harming, high-risk sexual behaviours and being involved in the justice system.



By 11 or 12, developmental issues take a back seat, like learning and self-care activities. In the front seat, you have more issues related to self-regulation and getting into the mental health side of things: anxiety, depression, psychotic behaviour, anti-social behaviour and all that, and that is where the mental health department kicks in. (Te Whatu Ora employee)

Families interviewed noted that young people with FASD might not be able to thoroughly consider the impacts of their life decisions (e.g., driving without a licence, moving out of home, managing their finances). Families are trying to maintain positive relationships with their young people as they navigate through the changes and stressors of being teenagers in an environment that does not understand them.

Stakeholders and families noted that as young people living with FASD become adolescents, they have increasing difficulties with emotional regulation. Families describe working to support their young people to avoid overreactions, triggers to explosive reactions or angry and aggressive responses.

At the same time, other challenges with FASD remain related to learning, cognition, communication, and attention. Difficulties accumulate over time, which becomes more challenging for young people living with FASD and their families to manage. Many families spoke of their young person becoming increasingly isolated, depressed, even suicidal or having other mental health issues.

I've talked to the boys about puberty and all the body changes that happen. But we would only ever talk about it in terms of physical development and yes, we would talk about, 'you know, your emotions are all over the place'. But, for us the anger that comes with that whole hormonal changes is still very present for us. We've tried to get help, but the help around here is just not there. (Family living with FASD)

Like most teens, friends and other young people also influence young people living with FASD. At college, young people living with FASD interact with various other young people with differing maturity levels. Young people with FASD may not have the social skills to read different social interactions, and adults who can guide decision-making may not be around. Social influences and peer pressure can lead to alcohol and drug use and risky situations where young people with FASD might be taken advantage off. Some young people turn to drugs and alcohol as coping strategies.

He didn't have peer relationships that would be normal for his age group. The only peers that he did mix with were ones that were really anti-social, into drinking and drugs and smoking. And so, he headed off down that track as well. (Family living with FASD)

Some families also highlighted the bullying their young people living with FASD experience in person at college and on social media. The level of bullying described is extreme and is adversely affecting some young people's mental health.

Families interviewed were fearful young people with FASD would disengage from their support or leave home, resulting in adverse life outcomes. Further, at 16, young people can decide whether to continue their services and withdraw their consent.

When she turns 16, she can legally choose where she wants to live. And if she gets into her head that she wants to go live with her mother or father. We cannot legally stop her. We know that they do not have the same understanding or the support. She's also going to be her own person and you can't hold her hand the whole way through. She's going to wind up wherever she's going to end up, and you can't stop it. (Family living with FASD)



## **Living with FASD has wider impacts on the family, social relationships, and finances, which adds stress**

Families living with a young person or people with FASD could include biological parents, other family members (e.g. grandparents, aunt/uncle, siblings, cousins), adoptive parents, and foster parents. Families deeply love and want the best for their young person/people living with FASD. However, they recognised that supporting a young person living with FASD affects the whole family. Further, families interviewed are also coping with wider life stressors, including rising living costs, housing and financial instabilities; some are supporting other disabled children and young people or sick family members.

Families noted the impacts on siblings who also need support. Siblings might be at the receiving end of some behaviours associated with FASD, such as outbursts and aggression. As a result, siblings might also benefit from respite. While caring for a young person with FASD, families note giving adequate attention and energy to their other children's needs and wellbeing can be difficult.

We're struggling; we have no choice but to keep going. You've got three different children with three different challenges that you're trying to balance. And, of course, [young person living with FASD] is very jealous. She doesn't like it when [Name C] and [Name B] have got our attention, so she jumps in and tries to take over. (Family living with FASD)

Families spoke of financial hardship due to leaving the workforce to support their young person living with FASD. Their decision to become full-time carers reflects the lack of FASD-informed services to support young people living with FASD who are not in school. Access to disability support funding for the few eligible enables families to tailor services to meet their young person's needs and can offer them some respite (e.g., the family who hired a student to work with their young person with FASD and ASD to decrease their social isolation).

He was on very limited hours at school because they refused to provide extra supervision during break times. They said they couldn't manage that, so he only did three hours a day. So, what does that mean for a family? It means that one of us couldn't work. Financially, you start to feel the pinch because someone's always got to be at home. (Family living with FASD)

Families also spoke of losing relationships with friends and family who do not understand FASD or are not supportive. Time spent caring for young people also means they cannot spend energy on their friendships and hobbies. Losing social support networks creates isolation and can affect their wellbeing.

You lose friends along the way, and it's not necessarily because you fall out, it's just because you can't go to the same event. And you can't take your kids there because it's not going to be a suitable environment. So you're just not as available for friendships. (Family living with FASD)

## **Without professional or funded support, families rely on family and peer support where they are available**

Some families interviewed relied on family members, usually parents, to help support the young person with FASD. This support might involve caring for the young person and siblings and taking them on trips. Families can, therefore, receive some respite during this time. However, not all families have people they can rely on, or they do not understand or want to understand FASD. Other families noted support networks withdrew as they found they did not have the skills to support the young person.

It's just been my family, really. I'm lucky that I have family that live close by that understood what was going on. A lot of people aren't that lucky. A lot of people, it can destroy their whole extended family. (Family living with FASD)

Some families receive peer support from other families also living with FASD. They can share experiences and strategies to support those with FASD. FASD-CAN was mentioned as a valuable way to connect with other parents.

I did get a hold of FASD-CAN and [the person I connected with] was lovely. She has a son who has it and he's [older] now. She said it does get better. It has gotten better now. [But] we have to wait how many years for it to get better. We've got to take every day as it comes. (Family living with FASD)

### **A whānau-centred approach is needed for support**

As FASD-CAN (2022a) notes, secondary impacts of FASD concern families/caregivers, but they can be reduced through FASD-informed support and services. Families want easy-to-access holistic whānau-centred support that considers the young person's and family's needs and understands they hold expertise in supporting their young person. Families want recognition that FASD affects the wider family system. Families and stakeholders talked about the importance of respite for the family to manage exhaustion and enable wellbeing.

I think the Whānau Ora approach across everything in FASD would work because it's not just the individual, it's about all the people that are around them and how you can support us to support them. We are best placed to help our son, but who's helping us? Because there's nobody. (Family living with FASD)

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

Families interviewed want an early and non-judgemental assessment process to diagnose the strengths and challenges of their young people with suspected FASD. Families want assessment and diagnostic pathways for FASD to be consistent across Aotearoa, New Zealand. Many families interviewed had not received an FASD assessment and diagnosis before their young person turned 11. The delay in receiving an FASD assessment and diagnosis reflects issues identified in the phase 1 research report (Litmus, 2023).

### **A FASD diagnosis and assessment pathway does not exist in all Te Whatu Ora regions**

Families' experiences highlight the ongoing variations in FASD assessment and diagnostic pathways across Aotearoa, New Zealand. Unlike Hutt Valley and Hawke's Bay Child Development Services, other Child Development Services do not have a FASD diagnosis and assessment pathway based on international best practice (Cook et al., 2016) nested in their neurodevelopmental assessment process. FASD-CAN has developed a map showing the FASD diagnostic services in Aotearoa, New Zealand.<sup>24</sup>

A few families interviewed who did not live in Hutt Valley and Hawke's Bay shared their young people received staggered diagnoses. For example, one young person was diagnosed as having ADHD when in primary school, FASD when at intermediate school, and ASD in late teens. Only when the

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<sup>24</sup> [Getting an FASD diagnosis - FASD-CAN](#)

young person received the ASD diagnosis were they entitled to Disability Support Services. Families stressed the importance of understanding coexisting conditions as they impact their young people's lived experience, presentation of FASD, the supports they qualify for, and their effectiveness.

Not all kids with [FASD] are the same. Because [young person] has also got attachment disorder, global delays, and ADHD, and that adds to the mix as well. [Professionals] sometimes say, "Oh, well if you do this, this will work". And it's like, well for her, no it doesn't. And I don't know whether that's because of the other conditions that are involved with her as well, or if that's just because they don't know enough. (Family living with FASD)

### Families faced long wait times of two to three years for an assessment

Most families interviewed spoke of the two to three-year wait time to receive an FASD assessment due to the lack of capacity in Child Development Services. Some families noted the move to intermediate school and college highlighted the need for an assessment. Families spoke of struggling to know where to go to get an assessment and schools not being able to provide direction. A few families paid for an FASD assessment to avoid the waitlist and to be able to identify appropriate support for their young person. The costs for an assessment can be up to \$8,000. Both families and stakeholders reinforce the importance of an early assessment to get effective early intervention support.

We'd still be on the waitlist now if we hadn't gone privately. That would have been two years, nearly. Just thinking if [names] had been picked up with FASD at eight, the support the school might have got, like PD for teachers, coping mechanisms for teachers and other students. (Family living with FASD)

Some health stakeholders noted they expedite applications for waitlisted young people when they reach key transition points (e.g., moving to intermediate school and college).

Once [young people are] in that 11-plus age group, I often expedite them because they will be reaching intermediate age, and we know that's when the wheels fall off in the education system as the expectations increase. And we see school failure, at risk of school exclusion. Often, we see offending and just getting into general trouble. (Regional health)

### Young people may be less open to FASD assessment and diagnosis

Stakeholders highlighted that assessing and diagnosing young people with suspected FASD is challenging. Some young people do not want to undergo an intensive assessment over a long period of time. Other young people who are already struggling to fit in with their peers do not want the stigma of the FASD diagnosis. Stakeholders also highlighted some young people with suspected FASD are prone to confabulation<sup>25</sup>, which makes consent and assessment challenging. Further, an FASD diagnosis may create family rifts.

That's the dilemma because whilst they've got a label now, I don't know if they want the label. I don't know if they're okay with the label. I don't know if an impressionable 15-year-old whose sole purpose in life is to fit in now wants a diagnosis that makes him feel different. (Regional health)

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<sup>25</sup> Confabulation is not lying. Damage to the function of the frontal lobes of the brain means that a child or young person with FASD may make things up that are not true. When they are confused or have forgotten what happened, they may say something that suits the situation or what they think is expected of them. They can have difficulty basing what they say on reality and checking it against evidence. [Understanding FASD | Inclusive Education \(tki.org.nz\)](#)

## Families and stakeholders need support following a diagnosis

As in the phase 1 research, families interviewed are left to navigate the new diagnosis on their own and figure out how to support the young person best. Families spend extensive time navigating available supports for their young person with FASD. Following a diagnosis, families interviewed were not given much information. They had to proactively educate themselves on FASD and how to work with their young person. Learning about FASD while still coming to grips with the diagnosis can be emotional for the family.

We just got some brochures and that was it. I googled it myself. I found it's a brain injury. I didn't know that. Holy heck. That's terrible. I again went to the police to go to OT [Oranga Tamariki] and to the other organisation around the corner from us, and he printed out a lot of information and gave it to us. We should've got that from the hospital on diagnosis day. (Family living with FASD)

Regions, like Hawke's Bay and Hutt Valley Ora, have implemented initiatives to bring agencies together to create a joined-up response. One example is the Child Health Integrated Referral Pathway (CHIRP) facilitated by Hutt Valley Te Whatu Ora to reduce system barriers to access support and achieve the best outcomes for young people with complex needs and their families. Education staff (e.g. RTLBs, SENCos), counsellors, social workers, public health nurses, Te Whatu Ora staff, Oranga Tamariki representatives, and others attend the meetings.

We have a meeting that includes all of the external agencies who work with the students to ensure we offer a holistic approach and support. Some families have multiple agencies working with them, and everyone's trying to pull in different directions, so we try to make sure that we've got a collaborative approach (Regional education)

## Families and stakeholders emphasise the need for navigators to access support

Both families and stakeholders stress the importance of having a reliable and consistent support worker or navigator following diagnosis. The navigator would provide them with information, let them know what support is available, and assist them with applications. This role could help navigate referrals and appointments, provide advice and information, and alleviate family burden. Tailoring support to the young person's needs and family's circumstances is vital, given the diversity of experiences and presentations of FASD.

We've got a diagnostic model where you see people once to tell them what they've got. But we don't have an intensive post-diagnosis support package or anything. [An intensive support system might look like] some form of peer support worker they meet beforehand helps them through the process, is available during all the appointments, and is around post-diagnosis. It would be quite helpful. (Regional health)

In 2021, a pilot part-time FASD-CAN navigator role was created to advocate and support families living with FASD (or suspected FASD).<sup>26</sup> The FASD-CAN navigator found limited FASD-informed support existed. They have found that providing FASD training is more effective for people living with FASD, educators, youth workers, and others working with families and young people living with FASD. Consideration is needed, therefore, on the feasibility and value of navigators and other possible ways to support young people and families (e.g., training organisations already providing navigation or support roles to be FASD-informed).

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<sup>26</sup> [Our Navigators - FASD-CAN](#)

## Schools have an important role in enabling young people to live their best life

Children in Aotearoa New Zealand aged 6 to 16 must be enrolled in school by law. However, in some circumstances, students aged 15 can leave school for training or a job. Young people around 10 to 13 years old are in full primary or intermediate schools, and between 13 and 18 years old are in college (secondary school).

### Stakeholders note the importance of being engaged in school through adolescence

School lends young people structure and routine to their lives. In addition to academic skills, school enables young people to learn social skills and how to participate in their community. Being at school also offers respite for the family. Staying engaged with school supports young people in building on their strengths and can provide a pathway to further education, employment, and other options.

If you think about protective factors for a child, keeping them in school, particularly if home life isn't great, is a really, really positive thing. Not even the academic side of it, just the social side of it, being part of a community, all those prosocial things that happen in a school setting. And it provides respite for whānau. If the kids are going to school regularly, whānau can work. (Regional health)

### The transition to intermediate and college is difficult for young people living with FASD

The school setting significantly changes as young people transition from primary school to intermediate and again from intermediate to college. This transition is significant as usual routines are disrupted. Young people living with FASD have to become familiar with a completely different structure and environment. The two-year span at intermediate schools also does not offer continuity of support across time.

We are often floundering a bit to try and meet the needs of the kid as best as we possibly can and trying to seek that help. And often we start the process of getting help, but because it's only two years, by the time they leave us. (Education)

Young people living with FASD described their college experience as 'overwhelming' and 'full on' (FASD-CAN conference, 2023). Students go from one main teacher to several subject-specific teachers with different working styles and understanding of their needs. Students are also expected to follow a curriculum with a different daily schedule and move classrooms with each class. Students are expected to meet academic standards and be able to undertake assessments and examinations within specified timeframes. Young people in a college setting are also exposed to more students of various ages and maturity. Open-plan education settings are also difficult to navigate for young people living with FASD.

[Students in intermediate and secondary school] have a different teacher; they are rotating around, there seems to be lots of different activities that they are going off to. It's quite different from a primary school. So, often, that first term is challenging just to learn all the new things. (Education)

Young people living with FASD and their families discussed the importance of choosing the right school that understands FASD and can adapt to meet their young person's needs (FASD-CAN conference, 2023). However, families may not have a choice in schools, particularly in rural areas. Families' experiences of support in transitioning between schools varied.



Most families and young people were not supported with transitioning to intermediate schools or college. A few families had a positive experience working with SENCO, the principal, and other staff. For about a quarter or half a year beforehand, the SENCO or other staff members involved in learning support would usually begin to familiarise the students and their families with their next school. The initiative might include having conversations with families to alleviate concerns, visiting several schools to determine the best fit, meeting their potential teachers and beginning to build these relationships, and understanding the layout of the new school. Some schools are less receptive to having these visits due to a lack of capacity, which requires staff members to advocate and push for this support.

They have asked for all the documentation. We talked with the SENCO and the principal when I went down there. They know the system. They have talked about teacher-aide support, but she doesn't meet ORS funding. They have all that other funding and are changing how they're doing the pastoral care, so they might be able to do something from that angle. (Family living with FASD)

### **Some schools have set up their initiatives to enable students with neurodisabilities and other needs**

Some schools have set up their own initiatives to support students with additional learning support needs. These initiatives are funded using the school's discretionary budget. Examples shared by stakeholders and families are transition services (discussed above) and a learning hub. One school established a hub for students who need their space and time away from the classroom. The approach considers the students' needs instead of being punitive. Staff reflected that since establishing the hub, stand-down rates have reduced.

The college here, we have a learning hub which is basically a time out space so if the kids are not coping in class or they are feeling whakama they can go, take their work, sit in the hub and have that quiet space. That has been really successful and has kept many kids from getting into trouble they can't control. Since we've had the hub, our stand down exclusion rate's right down. (Regional education)

Stakeholders and families noted additional one-on-one support is needed to enable young people living with FASD in intermediate and college. Families and stakeholders perceive the benefit of having a consistent person working alongside a young person in mainstream schooling. At present, few young people are eligible for teacher aide support. These hours are limited and divided between many students who require this support.

### **If unsupported, negative experiences from school can contribute to trauma and disengagement**

Most families shared experiences of the challenges their young people face in college. They struggled with the changing environment and had difficulties connecting with peers and teachers. Families noted when issues arose, young people were labelled as being deliberately disruptive and were stood down or expelled. Without accommodations and support, young people fall behind their peers. Schools might not have the capacity to manage young people's cognitive challenges and other learning and social needs.

They hit high school, and the wheels went flying off in all directions really fast because they were in a high school of 1,300 students. They were changing teachers every hour and 15 minutes as their blocks. They couldn't last a whole block with their attention. They started experiencing horrific bullying through social media and face-to-face with the kids. And they couldn't connect with the teachers. (Family living with FASD)

Families reported many teachers did not understand FASD and did not listen to families on how best to support their young person with FASD. Some services and supports exist, but as discussed earlier, supports might be inaccessible, inadequate, or not FASD-informed. Some families acknowledged that the college environment did not support teachers in adapting their practice to be FASD-informed.

Thing that was frustrating was trying to explain to teachers how to deal with him, and they would just do the eye roll and just dismiss what I was saying. (Family living with FASD)

Many families became increasingly frustrated with their young person's school. They saw schools' response to their young people as punitive and not FASD-informed. When families informed the school about FASD, they perceived the school felt it was too hard to support the young person, and nothing changed. Families spoke of not being able to access support at college to address the bullying or the use of resolution strategies that are not FASD-informed (e.g., Positive Behaviour for Learning (PB4L)<sup>27</sup>). As one parent explained:

PB4L is a restorative process. It only works if the two people in the restorative process are equal. They understand the process; they are on the same level of speech development and being able to process the information and how it's all occurring, and things like that. So [young people] often walked out because they felt like they weren't being heard, that they were being blamed and that it was all their fault. That they had caused it. (Family living with FASD)

Some young people living with FASD are stood down or expelled by the Boards of Trustees who know little about FASD. Other families spoke of their young people disengaging from education through wagging school or refusing to attend.

The school was 'very punishment focused. Even though they said they were PB4L they weren't; they were quite punitive. (Family living with FASD)

Some families decided to withdraw their young person from school as they saw the school was not keeping their young person safe and doing significant harm to their mental health and wellbeing.

He's got such social anxiety he's been self-excluded from school. He gets into so much strife, mainly with his mouth, that he can't attend. (Family living with FASD)

### **Appropriate alternative schooling pathways are limited and not FASD-informed**

With limited alternative pathways, getting stood down or expelled can signify the end of schooling. Stakeholders observed many young people in the youth court process have been disengaged from school for several years. Families shared stories of their young people staying home and becoming increasingly isolated. Homeschooling is an option. However, homeschooling requires a family member to have the capacity and capability to take on this role.

School was just a waste of time, an absolute waste of time. Not only that but it destroyed any self-esteem he had. It just compounded his mental health issues. A whole raft of issues are rooted in FASD, but they were added due to inadequate service through the education sector. Not only inadequate, it was damaging. (Family living with FASD)

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<sup>27</sup> Positive Behaviour for Learning (PB4L) initiatives help parents, whānau, teachers, early childhood centres, schools and kura address behaviour, improve children's well-being, and increase educational achievement. [Welcome - Positive Behaviour for Learning \(tki.org.nz\)](https://www.tki.org.nz/Welcome-Positive-Behaviour-for-Learning)



Stakeholders noted alternative education centres can lack funding, capacity, and providers to support young people with FASD.

There's a couple of alternative education-type pathways. That's another big gap in the system though. Some students are leaving school much younger than 16 with no alternative pathway. Not enough funding for it. Not enough locations for it. (Regional education)

A few families successfully gained access to alternative schools that better supported their young person's needs. Enrolling in these schools tended to happen after the young person was in the youth justice system. However, families also feared mixing with other young people with challenging behaviours may exacerbate or not enable their young person.

That school has a lot of troublemakers, so both children refused to go there because they were scared they'd get beaten up, which would more than likely happen. (Family living with FASD)

## Young people living with FASD and their families identified other FASD-informed supports needed to live well

Families and young people interviewed want FASD-informed support in schools to navigate the challenges of college. Families also identified other wider services to support their young person living with FASD and their families, including:

- Community-based activities or youth mentors for young people to connect them with peers (e.g., Riding for the Disabled, hobby groups)
- FASD-informed counselling for young people living with FASD and family group counselling to support caregivers and siblings
- FASD-informed respite care for families
- FASD-informed communication support from speech-language therapists in schools and youth justice
- FASD-informed mental health and addictions services for young people living with FASD. The incidence of mental health issues and suicidal ideation is higher for people living with FASD than for the general population.<sup>28</sup> Stakeholders noted limited access to adolescent mental services due to limited workforce capacity and high demands. Further, some noted that not all therapies are effective for young people living with FASD (e.g., cognitive-based therapies designed for mental health issues). More research is needed to ensure adolescent mental health services are accessible and appropriate for young people living with FASD.

There needs to be communication support in the courts. There needs to be communication support in school. So much goes wrong because of their communication skills. They talk way more than they can understand. And they're really clever at hiding it if they don't understand something. It takes a special eye to see that. (Family living with FASD)

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<sup>28</sup> 90% of people with FASD have co-occurring mental health diagnoses compared to 20% in the general population (Lebel et al., 2021). 30% have suicidal ideation and suicide attempts compared to 3-12% in the general population (Flannigan, et al., 2022).

A lot of the work we do is cognitively based when it's individual with younger people. We had the situation many times where the interventions that we provide aren't conducive to the [FASD] client group because the cognitive challenges associated with their condition precludes their effective engagement in a therapeutic process. (Regional health)

Families and stakeholders emphasised the importance of meeting families and young people with FASD where they are, rather than the other way around. Some services have policies to discharge people if they miss appointments or do not tolerate lateness. These processes disadvantage families and young people who might have reasons or cognitive challenges that make it harder for them to attend appointments.

## Young people need FASD-informed support in the youth justice system

### Police need to be FASD-informed in their approaches and interactions with young people living with FASD and their families

Families and stakeholders emphasised the important role of the Police, given they are the first line of engagement with the youth justice system. The reasons families and young people living with FASD interacted with Police varied:

- A few families had proactively reached out to the Police when their young person's impulsivity was getting them into trouble. They reached out to explain their young person's strengths and challenges and to seek an FASD-informed response.
- A few families shared that their young person with FASD had contacted the Police to make complaints about them.
- Other families contacted the Police seeking advice and interventions related to extreme social media bullying to find little could be done.
- A few families interacted with the Police as their young person entered the youth justice process.

We found the Police quite helpful through adolescence. Once we got diagnosed, I put an alert on our son's name so if the Police ever picked him up, they would know that he had a neurological condition. That has served us quite well over the years because the Police did understand a little bit. They didn't appear to be judgemental. They could see that we were just normal parents, doing the best we could. (Family living with FASD)

Families had mixed interactions with the Police. Some noted the Police may not have understood FASD, but they listened, de-escalated and sought to find solutions. One family note the Police paid the transport costs for their young person to attend a particular school when the Ministry of Education and Oranga Tamariki would not. The Police recognised the importance of the young person engaging in a school they enjoyed to minimise the behaviour bringing them into the justice system.

Other families had less positive interactions with frontline Police who did not listen to the family's advice on how best to support their young person. In some cases, families thought Police actions escalated a tense situation.

The Police have got a lot to learn about how to deal with our two teenagers with FASD. They need to have a look at how they approach the young people. The Police antagonize situations a lot and won't listen when a parent is trying to guide you on how best to approach this situation. (Family living with FASD)

Police have an essential role in keeping families and young people with FASD safe. More work is needed to ensure Police processes and frontline interactions are FASD-informed.

## **Many young people in the youth justice system may have FASD; but prevalence is unknown**

Stakeholders interviewed suspected many young people in the youth court have FASD or other neurodisabilities<sup>29</sup>. However, few young people with suspected FASD have received neurodevelopment assessments.

Stakeholders reflect that young people with suspected FASD are in the youth justice system due to the impacts of their specific FASD challenges (e.g., impulsivity, poor or no self-regulation). Further, many young people with suspected FASD have been exposed to broader trauma and have been disengaged from education for long periods. These young people are described as having high needs, with limited support and repetitive behaviour that results in them being in the youth justice system.

Most of the kids we see have been disengaged from school for years. We've got 13-year-olds that haven't been to school since they were eight. We've got layers of trauma, sexual abuse, physical abuse, neglect, parental substance abuse. We've got kids that are so disenfranchised, so marginalised, isolated from their culture. (Youth justice sector)

Youth justice stakeholders are frustrated that to get to this point, young people have experienced many failures from the system, including no assessments and a lack of or inappropriate intervention. They note that the short-term support they provide will likely have limited impact. Stakeholders emphasised the need for FASD prevention of the effects of prenatal alcohol consumption and early neurodevelopment assessments and interventions.

By time they get to 14, all the damage has been done in terms of education. They are well entrenched in offending behaviours, have had a lifetime of challenging experiences. There's alcohol and drugs. They are passed from pillar to post, have been in care. None of the kids we see have had early assessment of FASD. To end up with charges, it's serious offending or a lot of offending. It's really hard to do anything at that point. (Youth justice sector)

Further education and probably that prevention space. The earlier that things can be put into place and walk alongside a family, the better outcomes for a young person. Ultimately, if things aren't done at that early stage, they'll more than likely end up in our space. (Youth justice sector)

## **The youth court is working to be more FASD-informed**

Over the last ten years, awareness of FASD and other neurodevelopment disorders and a focus on solution-focused judging has increased. Judges, lawyers and others in the youth court have received training on FASD and other neurodevelopment disabilities. This knowledge has enabled more reflection on why specific and repetitive behaviour is occurring (e.g., bail breaches) and determine more appropriate solutions. Further, action can be taken in the court to provide appropriate support and services to ensure young people can understand the process and decisions (e.g., support from speech-language therapist through plain language, checking understanding, and using pictures to describe events and outcomes from Family Group Conferences and supervision plans).

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<sup>29</sup> Currently, a research study is being conducted on the prevalence of FASD in youth justice residential facilities.

However, this shift is not consistent, and more workforce capability building is needed on FASD and other neurodevelopment disabilities. Some stakeholders commented youth court structures and processes do not accommodate the cognitive abilities of young people with FASD. For example, many young people with FASD have difficulties communicating, understanding and remembering what is said to them. The unfamiliarity and structure of court processes (e.g. time allocations) can add to confusion.

Our busier courts with up to 12 kids. They have a 15-minute slot and then it's the next kid. This doesn't work with FASD. They're bamboozled by the environment, language, and could not tell you what they're just told. They don't know bail conditions, curfew, or basic stuff. As a system, we do a poor job supporting kids through that stuff. (Oranga Tamariki employee)

One family involved in the youth justice system had positive interactions with the judge and felt they understood and took into consideration their young person's challenges relating to FASD. However, some families noted that community sentencing was more of a sentence for them. As one family explained:

He had to do community service, which was just a sentence on us, really. There was no point in giving someone with FASD community service because he just didn't do it. Then it just causes friction for the family. It's not a whānau-focused type of mechanism. It's just punitive and not really connected to the crime, and they should have taken a Whānau Ora approach to youth justice. (Family living with FASD)

Families were also less positive about the Family Group Conferences, saying they are poorly facilitated and do not listen to the young person with FASD.

I've been to two family group conferences. They've both been dreadful events and run poorly by people not qualified to run them. There's a skill in facilitating a session like that; just because you're a social worker doesn't mean you have that skill. So, FGCs really need an overhaul. At the first - he'd assaulted a boy - They just let this boy's father shout and abuse us and nobody intervened. He was 14 at the time, I remember walking out of that meeting and saying to him, "I'm so sorry you had to hear all of that". He said, "Oh don't worry, Mum, people say worse to me every day". (Family living with FASD)

### **Being in the youth justice system offers opportunities to get FASD assessment**

A key challenge for the youth court is gaining information about FASD or neurodevelopment assessments in education or health. The youth court needs this information to ensure procedural and substantive fairness by providing appropriate support and interventions for young people with suspected FASD.

Stakeholders acknowledged the youth court can require neurodevelopment assessments in health and education to be completed. However, despite paying privately, wait lists exist for up to eight to nine months. The wait times are in tension, with the preference for young people to be in the court system for the shortest time. Stakeholders also note the regional variability in access and quality of FASD and neurodevelopment assessments across Aotearoa, New Zealand.

Research shows that the longer a young person remains in the youth justice pathway, the more likely they are to continue to escalate through the system. So, in and out, but we can't do that with foetal alcohol because we can't meet the need. (Youth justice sector)

## Post-diagnosis, few long-term FASD-informed supports are available

Stakeholders noted that while an FASD diagnosis can inform court decisions, it does not create access to long-term support to minimise the risk of the young person's return to the youth justice system. FASD-informed support and services in the community do not exist or are very limited. Further, young people who are required by the court to complete the assessment may not want to engage with support or services.

Given the young person's age, some stakeholders did not believe receiving FASD-informed support would change their behaviour and potential future engagement with the justice system. Their despondency reinforces the need for an ongoing focus on prevention, early diagnosis, and interventions. Further, more research and insights is needed on effective FASD-informed interventions for young people in the youth justice system.

If you're looking at assessments for foetal alcohol at the age of 15, we have missed the boat. All we know is the "Why", but we will never unpack the learnt behaviour that that 15-year-old has already absorbed as a coping mechanism to survive their environment. We will be unable to combat their thinking and dysregulation in the timeframe we have them. (Youth justice sector)

## Young people with FASD need support to gain employment or do other meaningful activity

Families and stakeholders noted the importance of supporting young people living with FASD into employment or other voluntary work to participate in society and build a sense of purpose and self-worth. To achieve this goal, workplaces must be FASD-informed, flexible, and adaptive. A few families have supported their young people into employment through opportunities in their networks. For example, a young person offered voluntary work at their local marae, leading to a part-time job.

It's really important to get a sense of self-worth from employment. I don't know what that looks like, but we do need to start thinking about how we make these people a useful part of society. It's about tapping into what they can do. They can do some stuff really well. But with employment comes a whole lot of expectation about being on time and being there every day. And so, some flexibility in the workforce would be ideal. (Family living with FASD)

Young people living with FASD may struggle to meet the expectations in traditional employment and training structures. One family found employment services are not FASD-informed; they were told their young person living with FASD was 'too hard' to place. Consideration is needed on supporting flexible training and employment arrangements for young people with FASD.

[The course] helps you get into a job. And we're working at an orchard and getting paid. But we always have to do these assessments, and I'm always sitting there lost. So I just gave up on the course. (Young person living with FASD)

Some families acknowledged the severity of the young person's FASD characteristics may mean employment is not an option. In these circumstances, young people aged 16 or 18 can apply for financial assistance from the Ministry of Social Development. However, young people living with FASD struggled to engage with the application process effectively. MSD should consider simplifying and clarifying their processes, sending multiple reminders, and keeping families involved.

## Families and young people with FASD want support in adulthood

Many families are worried about their young person living with FASD's transition from adolescence to adulthood. They are concerned about whether they can get a job with an understanding employer and, if not, what other options are available. They are concerned about their young people being manipulated, making choices that have severe consequences and not finding appropriate housing options. Families are also concerned that existing support (although limited) will be removed, resulting in no support to ensure the safety and wellbeing of young adults living with FASD.

My concern is they're going to be manipulated. It's the realisation that we are going to have to be supporting [names] for the rest of our lives. Oranga Tamariki and all the other supports walk away once they turn 18. It's going to be on us. That's something I'd like to see changed, that young people who were in OT care that OT or a government agency have responsibility for them and making sure they're OK. (Family living with FASD)

Research on the system response and how to strengthen it for adults living with FASD is needed.

## Opportunities to enhance the assessment and support pathway

The following opportunities were identified from the feedback from families and stakeholders to improve the assessment and support pathway for young people aged 11 to 18 years with FASD and their families. The opportunities reinforce those identified in the phase 1 research. Opportunities include:

### A young-person and family-centred approach

- Ensure young people and families living with FASD are respected, listened to, have choices and resources, and are actively involved in developing support solutions.
- Identify the most effective way to inform and support young people living with FASD and their families in seeking to access help and services.
- Access to FASD-informed respite options.

### Disability sector: Early identification and assessment

- 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).
- Enable early assessment and diagnosis by developing and implementing a workforce strategy, drawing on Whakamaua and Ola Manuia (Ministry of Health, 2020 a & b), to build multidisciplinary and cultural capability in neurodevelopmental and FASD assessment consistently across Aotearoa, New Zealand.

### Disability and health sectors: Early intervention and FASD-informed support

- Allow a sole diagnosis of FASD to qualify for Disability Support Services so more children with FASD can access disability support services.
- Establish and enable access to evidence-informed early interventions that address systemic influences (e.g., psychoeducation and support for the family, environmental accommodation, child and young person-focused interventions, and integrated case management) (McLean, 2020).



- Enable access to FASD-informed youth mental health services and counselling for young people living with FASD and family group counselling to support caregivers and siblings.

#### Education sector

- Continue work to create an FASD-informed education system that supports young people with FASD based on their needs to remain engaged and support their learning and connection with peers.
- Increase supports tailored to key transition points when the needs of young people living with FASD change and increase (e.g., to adolescence, to intermediate and college, to independence)

#### Youth justice sector

- Continue work on making the youth justice system FASD-informed, including Police, Oranga Tamariki and Youth Courts.

# Developing an FASD-informed workforce

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This section provides key insights and opportunities to inform decisions about workforce capability and capacity to support and improve outcomes for families and young people aged 11 to 18 years, living with FASD or suspected FASD. The phase 1 report presents the findings on workforce capacity and capability relating to the assessment and diagnosis of FASD (Litmus, 2023).

## Societal awareness is growing but not systemic change

Stakeholders and families perceived increased societal awareness of FASD. Increased awareness is seen to be driven by media reports on living with FASD. Stakeholders noted the need for public awareness and understanding to accommodate the challenges of living with FASD. For young people with FASD and their families, not being understood across interactions makes navigating life and confidently participating in society difficult.

It's not just the teachers who need the education, it's the whole community. Because it is that interaction with a shopkeeper, or an interaction with the police, or interaction with someone in the community that's going to make or break that student. (Regional education)

Professionals are becoming increasingly aware of FASD across health, education, care and protection, and youth justice sectors. Increased awareness is partly driven by engaging with more young people presenting with FASD and gaining experience in how to work best with them. Neurodisability and FASD are discussed more frequently among colleagues, and more training is available. Although awareness of FASD is growing, young people and families continue to engage with professionals across the sector with little knowledge about FASD. Further, they reflected no systemic change has occurred to support young people and families living with FASD.

I feel encouraged, but at the same time, I don't feel like there's any change in education. There's been no change in diagnostic services. The groundswell has come from the parents, but there doesn't appear to be any systemic change. The knowledge is growing, but the action isn't. That's really disheartening. (Family living with FASD)

## Ongoing professional development is needed across sectors

### Families and young people appreciate people who are understanding and willing to accommodate their needs

Young people living with FASD want to work with non-discriminatory people who understand how FASD can influence their thinking and behaviour (FASD-CAN, 2023). Families want staff to be trauma-informed, understanding, and willing to accommodate their needs. They appreciated staff willing to learn how to best work with the young person and their family, recognising that FASD can be present in diverse ways and every family is unique.

[The support worker] would meet him at the beach, he would come to his home, they would go for a bike ride together. He met him where he was physically and figuratively. So, it worked. It was a different philosophy about risk mitigation rather than complete abstinence, so it was just a different model, but it helped. (Family living with FASD)

## Families perceive some professionals are not interested or willing to understand FASD

Following a diagnosis, families interviewed proactively educate themselves on FASD and how to support their young person best. Families know what works and does not work for their young person. However, tensions occur when professionals do not listen to family advice.

The message I keep all through these years is you've got to listen to the parents. We know our kids. We know what they can or can't do. I don't like the air of, "I'm the professional. I'm the teacher. I'm the psychologist. I'm the doctor. I'm this and this, so I know." And it's like, "Well, do you?" (Family living with FASD)

Families feel discouraged when interacting with professionals unwilling to learn more about FASD.

The school didn't know anything and didn't want to know anything. That was the thing that got me most upset. I would send them articles that had been written about FASD in education. In fact, their SENCO told me to stop sending information because I was using too much of her folder space. (Family living with FASD)

## Training exists on FASD and neurodisability in Aotearoa New Zealand

Educational resources on how to work with people with FASD exist online. Government agencies, such as Oranga Tamariki (through their practice centre<sup>30</sup>) and the Ministry of Education (through Te Kete Ipurangi, TKI<sup>31</sup>), have released information on strategies and approaches to engaging with people with FASD.

Other educational resources exist. NGOs, such as FASD-CAN and Caring Families, provide guidance and run educational workshops for families and professionals. Some local teams (e.g., Te Whatu Ora Hawke's Bay) have led training sessions on FASD for their staff and staff in other sectors. FASD-CAN has provided training to over 400 educators without government funding - an unsustainable position.

Some education stakeholders, such as RTLBs and SENCOs, are using these resources to upskill. However, other stakeholders note learning about FASD is self-motivated and needs to fit into their heavy workloads. Some stakeholders do not have the capacity for this self-learning.

## Ongoing capability building is needed to support young people with FASD

Stakeholders and families noted the need to continue building an FASD-informed workforce across the sectors. Key roles that interact with young people with FASD, such as teachers and social workers, were not directly trained in FASD, or neurodisability in general until recently. Families feel that some social workers and other support roles do not understand FASD in depth.

I don't think people know enough about FASD. You get a report and recommendations of how to help someone, but how and who will train the people who will support that young person? Who will teach them that things are changing all the time. (NGO)

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<sup>30</sup> The [Practice Centre](#) is an online resource for "Oranga Tamariki practitioners for must-dos, how-tos and guidance in their work with tamariki and their whānau or family."

<sup>31</sup> [Te Kete Ipurangi](#) is New Zealand's education portal which "provides New Zealand schools and students with a wealth of information, resources, and curriculum materials."

# All sectors face workforce capacity challenges, which is exacerbated by workforce recruitment and retention issues

## Stakeholders note they are seeing more complexity among young people

Education stakeholders perceived more students are presenting with complex needs, particularly over the past five years. They see more young people with neurodisability diagnoses, learning support needs, and complex living situations. Stakeholders are unclear as to why these changes have occurred. They hypothesised that changes are due to social media, increased day-to-day pressures on families, and a greater understanding of neurodisabilities.

We are seeing more and more of those neurodiverse students than ever. I have done more referrals in my three years in this job than my 30 years as a principal and all those come back with a diagnosis, so, it's not like we are referring randomly. (Regional education)

Stakeholder feedback suggests the current size and skills of the education workforce do not meet the demand and needs of students living with FASD and other neurodisabilities. More students with neurodiversity needs means additional learning support is needed in the education system. However, stakeholders note class sizes, resourcing, and funding for education have not changed.

The gaps with the funding are of being able to get additional adults to work with these students. The gaps are the number of people you can hire to come into the school to work with the students. (Regional education)

## Limited workforce capacity across sectors makes delivering an FASD-informed service challenging and contributes to staff burnout and turnover

Stakeholders interviewed emphasised the impact of limited workforce capacity<sup>32</sup> on delivering FASD-informed services to families and young people with FASD, specifically:

- Having limited capacity to collaborate across sectors and respond to requests for information in a timely way to provide a holistic service to families.

I find the health system quite challenging to have a relationship with because they are currently overloaded and overworked... and do not have enough time. (Education)

- Needing to triage and prioritise applications to services based on risk criteria resulting in families and young people with FASD experiencing long wait times.

When I think of mental health services, they are already overworked so what's going to take priority? They tend to prioritise risk rather than someone coming in for an FASD assessment. It's dependent on what's their mental health risk first. I think that is probably an issue for a lot of providers. We never used to triage and now we're doing triage. That wasn't something we used to do in the past. (NGO)

- Using one-size-fits-all responses due to lack of time to deliver a response to the unique needs of families and young people living with FASD. For example, some stakeholders note RTLBs provide

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<sup>32</sup> Workforce capacity refers to having the number of staff to sufficiently carry out work.

approaches that could be applied to a range of learning needs in the classroom. Teachers noted a lack of capacity to meet their students' complex and diverse needs.

Our RTLB service tries really hard, but they tend to come down and bring programmes, and while programmes are good, they are targeted generically. Sometimes they're helpful, but sometimes it's just another thing that we've got to get our head around, and teachers struggle with that. (Regional education)

- Training passionate people in the community for teaching and support roles to manage the shortfall of FASD-trained teachers.

If we do have teacher aides, they're just willing people from the community. They don't have a background in any of this. We are so desperate. We look for really keen people who relate well with children, and then we train them on the job. (Regional education)

- Retaining experienced FASD-trained staff is challenging due to the high demand and complexity of working with families and young people living with FASD in a system with limited services and support. High staff turnover means families and young people living with FASD have to retell their stories and build new relationships, which the young people find challenging.

She [young person] worked with a school counsellor, and then they left. They've had many people leave in their life. They don't trust professionals because as soon as the professional arrives, they start working, they resign and move on. I don't know how any service can fix that up, as everyone can get a promotion or change their job. (Family living with FASD)

In growing clinical and non-clinical workforces that support preassessment, assessment, and post-diagnosis support across sectors, care is needed to create integrated services and void fragmentation.

## Opportunities to develop an FASD-informed workforce

The following opportunities were identified to inform decisions about workforce capability and capacity to improve outcomes for young people aged 11 to 18 years living with FASD and their families. The opportunities reinforce those identified in the phase 1 research.

### Awareness and prevention

- Increase the focus on prevention activities and messages to the public on the risks of prenatal alcohol exposure.
- Increase awareness and understanding of FASD in the public and create a dialogue shift from blame and stigma to strengths-based and enabling.

### Workforce development

- Continue to build the workforce capability and capacity to deliver cross-agency FASD-informed services.
- Continue to provide sustainable support to and promote FASD-CAN in providing training to families and professionals.

# Conclusion and opportunities

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The research purpose is to understand the current whole-of-system response to individuals with FASD or suspected FASD. This report focused on young people aged 11 to 18 years (intermediate school and college) living with FASD and their families.

Government agencies fund various health, disability, and education services to support families and young people living 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-system response to families and children living with FASD. However, much more work is needed to create a nationally cohesive and joined-up cross-agency response that meets Te Tiriti obligations and enables young people living with FASD to live their best lives.

Opportunities to strengthen the whole-of-system response are listed below. The opportunities identified in phase 2 reflect those noted in the phase 1 research.

## 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 from prevention, identification and assessment of FASD, and wrap-around support for young people living with FASD and their families.
- Support young people living with FASD to participate in their community and to input into policy and other decisions affecting them.
- Ensure strong cross-agency governance (embedded in the wider system reforms) and review the implementation.
- Continue to build the workforce capability and capacity to deliver cross-agency FASD-informed services.
- Continue to provide sustainable support and promote FASD-CAN in providing training to families and professionals.

## 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 rangatahi
- 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

### Awareness and prevention

- Increase the focus on prevention activities and messages to the public on the risks of prenatal alcohol exposure.
- Increase awareness and understanding of FASD in the public and create a dialogue shift from blame and stigma to strengths-based and enabling.



### A young-person and family-centred approach

- Ensure young people and families living with FASD are respected, listened to, have choices and resources, and are actively involved in developing support solutions.
- Access to FASD-informed respite options.
- Identify the most effective way to inform and support young people living with FASD and their families in seeking to access help and services.

### Disability sector: Early identification and assessment

- 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).
- Enable early assessment and diagnosis by developing and implementing a workforce strategy, drawing on Whakamaui and Ola Manuia, to build multidisciplinary and cultural capability in neurodevelopmental and FASD assessment consistently across Aotearoa, New Zealand.

### Disability and health sectors: Early intervention and FASD-informed support

- Allow a sole diagnosis of FASD to qualify for Disability Support Services so more children with FASD can access disability support services.
- Establish and enable access to evidence-informed early interventions that address systemic influences (e.g., psychoeducation and support for the family, environmental accommodation, child and young person-focused interventions, and integrated case management) (McLean, 2020).
- Enable access to FASD-informed youth mental health services and counselling for young people living with FASD and family group counselling to support caregivers and siblings.

### Education sector

- Continue work to create an FASD-informed education system that supports young people with FASD based on their needs to remain engaged and support their learning and connection with peers.
- Increase supports tailored to key transition points when the needs of young people living with FASD change and increase (e.g., to adolescence, to intermediate and college, to independence)

### Youth justice sector

- Continue work on making the youth justice system FASD-informed, including Police, Oranga Tamariki and Youth Courts.

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[https://www.fasdcn.org.nz/the\\_handbook\\_caregiver\\_toolkit](https://www.fasdcn.org.nz/the_handbook_caregiver_toolkit)
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## Website resources

### Ministry of Health

- [About the Health of Disabled People Strategy | Ministry of Health NZ](#)
- [About Pae Tū: Hauora Māori Strategy | Ministry of Health NZ](#)
- [About the Women's Health Strategy | Ministry of Health NZ](#)

### Ministry of Education

- [Flexible, tailored model of support – He Pikorua \(education.govt.nz\)](#)
- [A new model for delivering learning support – Education in New Zealand](#)
- [Inclusive Education | Inclusive Education \(tki.org.nz\)](#)

- [Fetal alcohol spectrum disorder and learning | Inclusive Education \(tki.org.nz\)](#)
- [Home | Te Aho o Te Kura Pounamu](#)
- [Welcome to our whare | Te Mahau](#)
- [Response to the Highest Needs Review – 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/>

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

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

FASD-CAN [Fetal Alcohol Spectrum Disorder - Care Action Network \(fasd-can.org.nz\)](#)

Health and Disability Ethics Committees [Home | Health and Disability Ethics Committees](#)

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

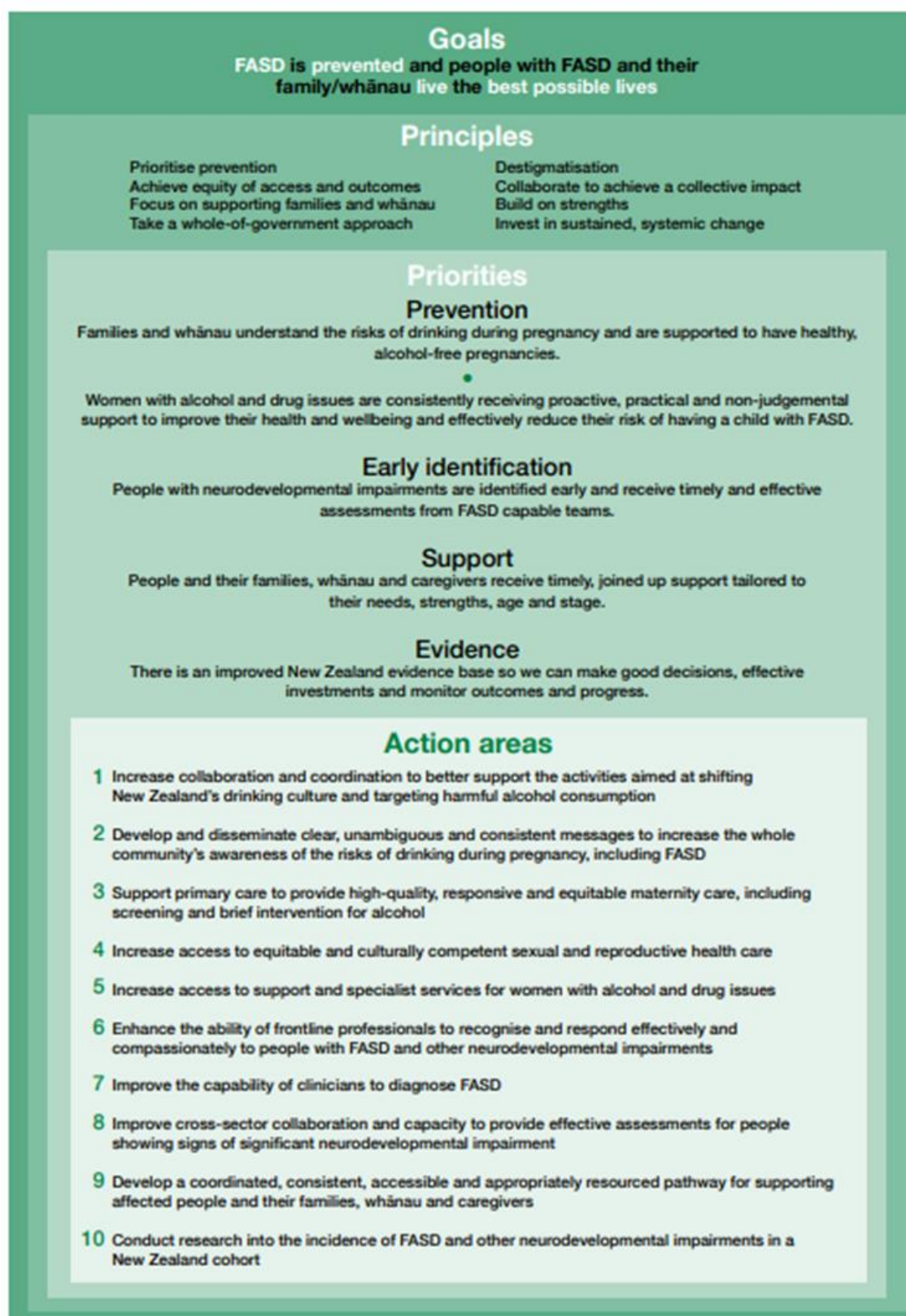
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# Appendices





# 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 the 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, and review of the draft report. Members of the Research Advisory Group include:

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

## Research methods

In 2021, the research was designed based on briefings, a high-level literature review, hui and key informant interviews from sector stakeholders. In 2023, the research plan was updated based on the phase one findings. The research plan was reviewed by Te Whatu Ora, the Research Advisory Group and Health and Disability Ethics Committee.

### Policy and practice review

We reviewed policy and practice documents related to FASD at the national level. The review purpose was to understand the system response for young people living with FASD through:

- national strategies related to neurodiversity or FASD
- documented processes and practices
- existing workstreams and initiatives
- how and where funding is allocated for support and services
- cross-agency integration of policies and practices.

The review informed this report and our understanding of the system.

### Qualitative interviews with 27 key stakeholders

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

We focused the sample on stakeholders whose role is related to working with young people living with FASD and who have some understanding of FASD. We interviewed stakeholders across the health, disability, education, care and protection, youth justice sectors, and NGOs and Māori providers.

We used a snowballing approach to recruitment. We approached interview participants in the following ways:

- At the national level, we recruited Ministry stakeholders involved in the cross-agency FASD coordination group. The contract and project manager at Te Whatu Ora identified stakeholders.
- At the regional level, we received contact information for regional stakeholders through Ministry stakeholders. We also 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 connected us with key contacts in their regions. We recruited stakeholders at the FASD-CAN conference (10 September 2023).

We note difficulties existed in connecting with stakeholders, given the lack of supports and services available for those living with FASD, the perceived lack of involvement in the system response, and the lack of capacity to participate. We followed up participants for interviews at least three times after the initial invite email.

We achieved the following sample across sectors:

	<b>National</b>	<b>Regional</b>	<b>Total</b>
Health	2	9	<b>11</b>
Education	1	5	<b>6</b>
Care and protection and youth justice	2	5	<b>7</b>
Māori perspective	-	1	<b>1</b>
NGO	-	2	<b>2</b>
<b>Total</b>	<b>5</b>	<b>22</b>	<b>27</b>

Across the sectors, we engaged with:

- Five Ministry stakeholders from Te Whatu Ora, Oranga Tamariki, and Ministry of Education
- Nine health professionals from Child Development Services (e.g., paediatrician, social worker) and mental health services
- Five education employees including RTLBs, SENCOs, and Learning Support Coordinators
- Five Oranga Tamariki employees, including Youth Justice managers and supervisors and regional disability advisor
- One member of the FASD-CAN Māori rūpu
- Two NGO employees.

Completed interviews followed an informed consent process and were up to 60 minutes long.

### **Qualitative interviews with ten families (caregivers and parents) caring for a young person or young people living with FASD**

We gathered families' perspectives on navigating services and support for FASD. We explored what worked well and what could be strengthened during this process.

We recruited families through Child Development Services, FASD-CAN, Caring Families Aotearoa and at the 2023 FASD-CAN conference. We followed informed consent during recruitment and interviewing.

The sample included whānau Māori (n=4) and families with young people with a confirmed diagnosis of FASD (n=10). Families cared for young people between the ages of 11 and 19. Young people had co-existing conditions. The sample included family, whānau, and caregiver arrangements, including biological parents, extended family members, grandparents, and foster parents.

### **Qualitative feedback from nine young people living with FASD**

We worked to gather young people's perspectives on navigating services and support for FASD. We explored what worked well and what could be strengthened during this process. We recruited one young person living with FASD through Child Development Services.

We followed a comprehensive informed consent during recruitment and interviewing. We used a modified Older Adults' Capacity to Consent to Research scale to determine the capacity to consent to the research (Lee, 2010). After giving an overview of the research, we asked potential participants:

1. What is the purpose of the interview?
2. Tell me some things you may be asked about?
3. What are the things that might worry you about taking part in an interview?
4. If you don't want to, do you have to take part in the interview?

We used the following decision hierarchy to determine consent:

- Informed consent is reached if a potential participant answered all four questions
- Supported decision-making was used if potential participants could answer 1 and 4. In supported decision-making, we worked with the family/caregiver and young person to determine whether they wanted to take part or not.
- Exclusion occurred if a potential participant could not answer questions 1 and 4.

We also heard feedback from eight young people living with FASD who attended the 2023 FASD-CAN conference in September 2023. The young people shared their reflections on what they want professionals to know about FASD, college transitions, coping with peers, social media, and other topics. We gained their permission to include their reflections in this research.

## Research tools

### Young people research tools

#### Information sheet



FASD system  
research\_info sheet\_y

#### Consent form



FASD system  
research\_consent form

#### Discussion guide



FINAL%20discussion  
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research\_younger ass

### Families research tools

#### Information sheet



FASD system  
research\_info sheet\_c

#### Consent form



FASD system  
research\_consent\_car

#### Discussion guide



Discussion%20guide  
\_caregivers\_14April23

### Stakeholder research tools

#### Consent



FASD%20system%20  
response\_stakeholder

#### Information sheet

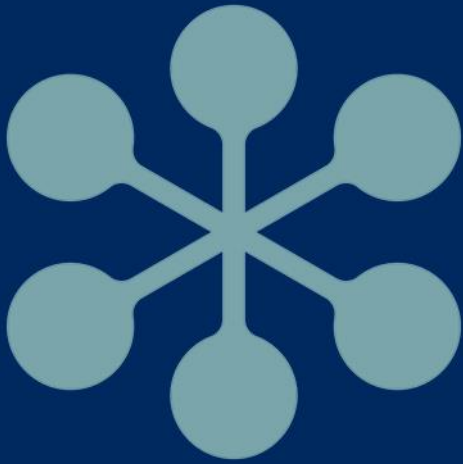


FASD%20system%20  
response\_stakeholder

#### Discussion guide



FASD%20regional%20  
Ostakeholder%20disci



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