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s 9(2)(a)

By email: s 9(2)(a)
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Tēnā koe s 9(2)(a)

Thank you for your request under the Official Information Act 1982 (the Act) to the Ministry of Health (the Ministry) on 7 March 2022. You asked for:

“...the Litmus research report”

Please find the Litmus report *Overview of services available for people with FASD and their families* attached. This has been released to you in full.

I trust this information fulfils your request. Under section 28(3) of the Act, you have the right to ask the Ombudsman to review any decisions made under this request. The Ombudsman may be contacted by email at: info@ombudsman.parliament.nz or by calling 0800 802 602.

Please note that this response, with your personal details removed, may be published on the Ministry of Health website at: www.health.govt.nz/about-ministry/information-releases.

Nāku noa, nā



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LITMUS

Overview of services available for people with FASD and their families

Prepared for:
Ministry of Health
Manatū Hauora

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Summary of findings

This working document presents a stocktake and gap analysis of services for children and young people with neuro-developmental delays. These services may be providing support to children and young people with Fetal Alcohol Spectrum Disorder (FASD) and their families across District Health Boards (DHBs). Twelve health professionals were interviewed across nine DHBs to inform the stocktake.

Understanding of FASD has increased but more work is needed

Stakeholders acknowledge awareness and understanding of FASD has improved over the last ten years. However, awareness and understanding of FASD varies across health and other professionals interacting with children and young people with FASD and their families.

More training on FASD is needed for health and other professionals, particularly in primary care and NGOs. Health and other professionals need to be confident in asking about alcohol consumption in pregnancy. They also need to know how to refer children with suspected FASD, and be able to support families through this process.

Stakeholders' perceptions of services available reflect two philosophies

One stakeholder group is critical of existing referral and diagnosis processes and available interventions for children and young people with FASD and their families. Their critique reflects existing services do not align with the Canadian best practice FASD guidelines (Cook et al 2016).

The other group acknowledges the challenges faced by children and young people with FASD. However, they do not see these challenges as more difficult than for children and young people with other neuro-developmental delays. This group has a preference for one referral pathway for children and young people with neuro-development delays. Having one referral pathway will ensure access to assessments and interventions are tailored to individual needs.

Initial focus has been placed on identifying and diagnosing people with FASD

Stakeholders acknowledge much work is needed to improve prevention, diagnosis and interventions for children and young people with FASD and their families. Stakeholders comment priority is and should be placed on diagnosing children and young people. One stakeholder notes diagnosis has been proven to be preventative. Through the diagnosis process, families and communities become informed about the risks of drinking alcohol in pregnancy.

Stakeholder feedback highlights children and young people can cycle through paediatric and Child, Adolescent Mental Health Service (CAMHS) services. These children and young people tend to receive symptom based diagnoses. Few receive a unifying FASD diagnosis that provides greater understanding of their underlying neuro-disability.

Across New Zealand four FASD diagnostic approaches were identified

The use of the best practice multi-disciplinary diagnostic approach for FASD is limited across New Zealand. Where FASD diagnostic pathways do not exist, stakeholders acknowledged many health and allied professions are actively working to achieve the best outcomes for children and young people with suspected FASD within the health system's existing limitations.

The four identified diagnostic models are:

1. **A demonstration diagnosis model which has strong alignment to best practice FASD principles.** The DHB demonstration model has a multi-disciplinary diagnostic team including paediatricians, psychologists, speech and language therapists and occupational therapists who work with children with developmental difficulties.

The service has a diagnostic assessment programme (DAP) to assess children with complex learning and behavioural needs. DAP is used to diagnose ASD, FASD and other neuro-developmental difficulties. The team is primarily focused on assessment and diagnosis. The service provides some education modules including FASD education modules to the community. Children with neuro-development delays can have a key worker.
2. **A virtual model where FASD assessments are undertaken in a staged approach across different disciplines.** For example, children with potential developmental delays or intellectual disabilities are referred to paediatrics. These children receive a one-hour assessment using information previously gathered from other relevant disciplines and the family. The paediatrician cannot complete the full FASD assessment across the 10 domains within the one hour assessment. The paediatrician will make a FASD diagnosis if the child presents with the facial features of FASD. In most cases, the paediatrician will refer to other clinical specialists (i.e. psychologist, speech language therapist) to assess the other domains to complete the FASD diagnosis.
3. **A restricted FASD multi-disciplinary diagnostic pathway** that only a limited and tightly defined number of children can access. Examples include:
 - i. A private practice undertaking assessments for FASD using the Canadian clinical guidelines. Referrals to the private practice come from CYF, youth justice and self-referral.
 - ii. A collaboration between a paediatrician in a Child Health Service and a psychologist from the Ministry of Education's Severe Behaviour Team. The diagnostic pathway aligns with the best practice guidelines. This diagnostic pathway is only accessible to children who are older than seven and enrolled with the Severe Behaviour Team.
4. **A business-as-usual model** where individual paediatricians and psychologists seek to diagnose children and young people FASD within existing processes. For some stakeholders, this equates to there being no FASD referral and diagnostic approach.

In these regions, children are referred to the most appropriate service based on their symptoms. If a child is suspected of having FASD, they may be referred to the general paediatric or developmental paediatric services depending on the severity of their developmental delays. In the paediatric service, the child and family receive a 45 minute appointment with a paediatrician to assess whether or not they have FASD. The assessment process does not follow the Canadian guidelines of using a multi-disciplinary team to diagnosis FASD.

System structures and eligibility criteria are barriers to establishing FASD diagnostic pathways

Funding priorities are a key barrier to establishing multi-disciplinary diagnostic teams. Some regions do not have a clinical psychologist on their team which restricts the ability to undertake a full FASD assessment.

Determining the service that has responsibility for children and young people who potentially have FASD is challenging. Their disabilities can straddle child development, paediatrics and mental health services. The eligibility criteria for child development and mental health services can prevent access to services for children with FASD. In these situations, the children and young people's needs do not meet the severity criteria for the services.

Existing contracts and job descriptions can stop those who received FASD assessment training from supporting a multi-disciplinary process. Services such as CAMHS are overloaded. Care is therefore taken to ensure referrals received fit their eligibility criteria. Further, FASD is not recognised as a mental health disorder which also creates an access barrier.

Inequities in service access exist, especially for Māori and those on a low income

Those who miss out tend to be:

- people who have difficulty navigating the health and education system,
- children with mild symptoms who do not get referred until they are older,
- Māori, and
- those on a low income.

Opinion on when to undertake FASD assessment varies

Feedback suggests differing opinions on the appropriate age to undertake FASD assessments. Some state the full FASD assessment should occur when the child is older than seven and more cognitively mature. For some DHBs, the delay reflects the lack of resources to do an assessment twice. Others disagree with the need to delay the assessment. They argue delaying the assessment may be preventing the child from assessing individualised interventions.

Specific interventions to support people with FASD and their families are lacking

Neuro-development services are available through paediatrics and child development units. Given the lack of a full FASD assessment, services tend to focus on presenting symptoms (e.g. ADHD). They do not holistically support the child or young person with FASD. Key gaps in these services tend to be a lack of clinical psychologists and speech and language therapists. Wait lists also exist. Private practice can address some of these gaps. However, families may be unable to afford this option or are not organised enough to access the support.

Education has an important role in supporting children with FASD. This support is received via RTLB and the Severe Behaviour Team. Unless children have a significant disability, interventions in the education system tend to focus on one issue and are of short duration. This approach is at odds with best practice principles of FASD

NGOs provide services such as Triple P, Incredible Years and other parenting and relationship based services. The evidence of whether these interventions are appropriate for children and young people with FASD and their families is unknown. Some stakeholders note applying non-modified interventions to children and young people with FASD can be harmful.

Some stakeholders note families are receiving the wrong advice from organisations contracted to offer support. A few diagnosing agencies comment some services do not modify services to fit with the findings of their reports but continue to offer their generic behavioural strategies. As in education, intervention services tend to be of short duration.

A few DHBs are offering evidenced-based interventions

As defined by Dudley et al (2015), a limited range of evidenced-based FASD interventions, are offered in a few DHBs, namely:

- Parent Child Interaction Therapy (PCIT)
- A modified Alert Program is available for children with ADHD
- The Alert Program
- Language and literacy training, cognitive control therapy
- Parent Child Interaction therapy
- Children's Friendship training.

Other interventions mentioned include:

- A pro-social peer relationship skills training offered in schools
- Activ8 which works on pro-social and communication skills in the school sector
- Sparx programme which is an e-therapy programme for young people with mild to moderate depression
- Parent support network workshops for supporting parents and caregivers
- Mentoring and buddy programmes
- Right Service Right Time which is an approach to ensure the wellbeing of children and families, in particular to deal with anxiety issues
- Parenting programmes such as Incredible Years, Triple P and Circle of Friends.

A few individuals within Child Youth and Family (CYF) are seen to be leading the development of FASD resources

Child, Youth and Family social workers have a reasonable understanding of FASD and offer appropriate support to families. One regional CYF advisor has developed resources for families using cards with advice around support, structure, supervision, strengths and keeping it simple.

More resources are needed as neuro-developmental services are overloaded

Concerns were raised about fitting children and young people with FASD into already stretched services. Such a move was seen as diminishing the limited resources available for other children with significant needs. Given the complex nature of FASD, stakeholders are seeking more resources and not the reallocation of existing resources.

Transition services are lacking for young people with FASD

Transitional services for young people with FASD are particularly lacking. Stakeholders acknowledge appropriate interventions for young people can achieve positive outcomes.

Tailored support for families with children and young people with FASD is limited

Families with children and young people with FASD are setting up local support networks. These families can and are acting as the harm prevention workforce seeking to get the message out about the harm of alcohol in pregnancy.

New Zealand's alignment with best practice FASD principles is mixed

Feedback across New Zealand highlights the areas to strengthen alignment with best practice FASD principles (Dudley et al 2015) are:

- having assessment and diagnosis by a multi-disciplinary team
- having a family-centred approach
- having key workers
- offering long-term FASD specific interventions
- undertaking ongoing monitoring
- planning the transition to adulthood
- building interventions around an individual's strengths.

Why we did a stocktake of services?

This report presents a stocktake and gap analysis of services for children and young people with neuro-developmental delays, which may be providing support to children and young people with Fetal Alcohol Spectrum Disorder (FASD) and their families across District Health Boards (DHBs).

The stocktake is required by action 8 of the Taking Action on Fetal Alcohol Spectrum Disorder (the Action Plan). The findings in this report can contribute to action 8: developing a coordinated, consistent, accessible and appropriately resourced pathway for supporting affected people and their families, whānau and caregivers.

Twelve health professionals were interviewed across nine DHBs to inform the stocktake. The health professionals were asked to¹:

- Map services and supports across their DHB region for children and young people with neuro-development delay, which may be providing support to children and young people with FASD and their families (including health, NGOs, private sector and education)
- Assess the available support and service mix against best practice standards
- Identify if neuro-development/FASD interventions with a proven evidence-base are available.

The stocktake offers a high level overview of services and support available. The overview does not offer a complete list of all services and support available in all DHBs.

¹ Appendix one contains the stocktake tool.

Auckland

Understanding of FASD is not widespread

In Auckland DHB, widespread knowledge of FASD across health and other professionals is limited. Only a few clinicians have received training on FASD.

Auckland DHB does not have a defined FASD referral and assessment pathway

Child and Adolescent Mental Health Services (CAMHS) have a neuro-developmental assessment pathway. Children are mainly referred to CAMHS by their GP or via the education system. Less frequent referrals are received from NGOs and private sector practitioners. A child or young person cannot be referred by their parent/caregiver. Neuro-development assessments are mainly for Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

Children are not being assessed specifically for FASD. CAMHS is not resourced to do FASD assessments as FASD is not classified as a mental health condition. If a child presents with other mental health issues, they will receive a diagnosis and support for that condition. For example, if a child has ADHD as part of their FASD, they will receive interventions relating to their ADHD.

If a child is suspected of having FASD, they may be referred to general paediatric or developmental paediatric services depending on the severity of their developmental delays. In the paediatric service, the child and family receive a 45 minute appointment with a paediatrician to assess whether or not they have FASD. The assessment process does not follow with the Canadian guidelines of using a multi-disciplinary team (Cook et al 2016).

A private sector organisation is undertaking FASD assessment as per Canadian Guidelines

In Auckland, the Fetal Alcohol Clinic, a private practice, does assessments for FASD using the Canadian guidelines. Referrals to the private practice come from CYF, youth justice and self-referral. A wait list exists for new assessments. This organisation also supports Alcohol Healthwatch in their advocacy and prevention work. They also undertake FASD workforce training across New Zealand.

Fetal Alcohol Clinic offers some intervention services and support to families. A lack of funding stops the expansion of these services. A time limited follow-up service is offered using an intern psychologist. They go into schools to adapt the curriculum and work with the family.

Few FASD specific intervention services are available in Auckland

Services exist to support other neuro-developmental conditions. However, few FASD specific services exist. Few professionals are trained to provide FASD interventions.

Alignment with the Canadian guidelines is limited. The current structure of health and education does not enable the involvement of multiple professional disciplines in the delivery of interventions. Using a family-centred approach was identified as an area to strengthen.

Through contracts with the Ministry of Social Development, NGOs offer intervention services to children and young people with FASD and their families. For example, Youth Horizon offer programmes to youth in difficulty. These programmes have not been specifically modified for FASD. Stakeholders perceive therefore the programmes do not work well with young people with severe neuro-disabilities.

Incredible years and Circle of Security are available. Circle of Security works on the mother/child relationship and is based on detachment model therapy.

Limited evidence-based FASD interventions are being offered.

Of the list of evidence-based interventions identified (refer Appendix 1), only Parent Child Interaction Therapy (PCIT) and parenting support management is available in the Auckland DHB region.

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Counties Manukau

Referrals for general neuro-developmental concerns go to paediatric services or CAMHS

Counties Manukau has several pathways for children with neuro-developmental delays. Children can be referred by their GP, private therapist or education provider to the paediatric service and CAMHS. Self-referrals are accepted by CAMHS. Children with potential global developmental delays or intellectual disabilities are directed to developmental paediatrics. Emotional regulation and/or behavioural issues are directed to CAMHS or infant mental health dependent on the child's age.

FASD assessments are undertaken via an ongoing referral process drawing on multi-disciplinary information

Children referred to the developmental paediatrician receive a one-hour assessment. The paediatrician has an intake meeting before seeing the child to gather relevant multi-disciplinary information. Information is gathered from the school/pre-school, and NGOs working with the family. The paediatric nurse specialist calls the family to take a developmental history. After the assessment, the paediatrician refers, as needed, to other services such as education or audiology.

The paediatrician cannot complete the full FASD assessment across the 10 domains within the one hour assessment. The paediatrician looks at facial measurements, dysmorphism, history and screens for general development. The paediatrician refers, as needed, to other clinical specialists (i.e. psychologist, speech language therapist) to complete the FASD diagnosis. A diagnosis will be made if the child presents with the facial features of FASD without further referrals.

CAMHS can be difficult to access for school-aged children. Access can be impeded by the family's ability or desire to engage with the service. The service is overwhelmed by referrals. CAMHS focuses on diagnosis of emotional, behavioural and mental health issues. They offer short-term interventions for emotional regulation and behavioural issues. CAMHS do not have capacity to see children with intellectual disability. Children with developmental delays are referred back to the developmental paediatrics.

No FASD-specific interventions are offered in Counties Manukau DHB

Rather than offering specific FASD services, Counties Manukau DHB identify the specific needs of the child and offer interventions aligned to need (e.g. speech and language therapy). The child or young person is not supported from a holistic perspective.

General interventions are provided by a mix of public, private and NGO services

Infant Mental Health offer interventions such as Parent Child Interaction Therapy, Circle of Security and Watch, Wait and Wonder. They also provide child psychotherapy. This service is based on relationships between caregivers and infants. It offers a holistic approach.

CAMHS have a few therapeutic interventions including Anger Busters, Social Skills groups, and Incredible Years. The psychiatrist will prescribe anxiety medications, if needed.

The Child Development Team provide developmental therapies such as occupational therapy, speech and language therapy, physiotherapy, and a dietician. Children accessing these services tend to have global developmental delays or severe neuro-disabilities. Children with FASD can only access these services if they have a significant developmental delay.

Speech and language therapy are overwhelmed. Access to the service is prioritised to those with the greatest need (e.g. those under-two being able to swallow safely). For older school age children, the focus is ensuring access to the curriculum. As a result, the access criteria for speech and language therapy is set high and many children miss out. If they can afford it and are able to organise it, families may seek speech and language therapy privately.

Other NGO services offering interventions are:

- CCS Disability Action and Ohomairangi Trust who provide early intervention teachers and an ASD whānau outreach programme. Ohomairangi Trust also run Mellow Parenting which is a relational parental intervention focused on infant mental health.
- East Tamaki Health Care and Frequent Family Services who provide parenting support such as Triple P and Incredible Years.
- Frequent Family Services who offer family support and primary level interventions in Franklin such as Triple P and Incredible Years. They also have some psychological support.
- Anglican Trust for Women and Children who offer Mellow Parenting.

Feedback indicates these services need modification to be appropriate for children and young people with FASD and their families.

Privately, FASD services are available through the Fetal Alcohol Clinic and two private developmental paediatricians.

Eligibility to access funding impedes children and young people with FASD

Very few children with FASD meet the criteria for Ongoing Resourcing Scheme (ORS) funding in schools.

More information is needed about the services available for young people with FASD

The stakeholder interviewed was unable to comment on the services for young people with FASD and their families.

Evidence-based FASD interventions are generally not available

None of the domain-specific strategies or interventions listed in Appendix 1 are offered. Parent child interaction therapy is provided, and a similar strategy for two year olds called PCAT.

Waitematā

An ad hoc and virtual FASD diagnostic and intervention pathway exists

In Waitematā DHB, no formal or cohesive pathways exist for children and young people with FASD and their families. In the paediatric service, there is no clinical psychology resource, and assessments cannot be undertaken across the 10 FASD domains. Children with suspected FASD have an initial assessment with a paediatrician without clinical psychology input.

If the child or young person with suspected FASD presents with anxiety or other psychiatric issues, they can be assessed by Marinoto Child and Youth Mental Health Services (Marinoto). Marinoto provide mental health assessment and therapy for children and young people from 0-19 years who live in the Waitematā DHB area. Some staff in Marinoto have received training in FASD diagnosis.

Children and young people with suspected FASD and not mental health issues may miss out on receiving a full FASD assessment.

ASD and ADHD pathways exists

Neuro-developmental delays diagnosis and referral pathways are very good for ASD, but not for FASD. Waitematā DHB does have ASD and ADHD pathways. The ASD pathway does not have clinical psychology input. In extreme cases, the ADHD pathway has clinical psychology input. The ADHD service has reached capacity in West Auckland.

Private services exist in Waitematā DHB region

Private services in the Waitematā area include:

- A large group of educational psychologists.
- Speech and language therapy. Access to speech language therapy is available in the DHB to children under five and in education for those over five
- Fetal Alcohol Clinic (more details on page 8).

Ad hoc FASD interventions with limited access

CYF provide information for foster caregivers. Information cards were designed in collaboration with FASD specialists. Marinoto run an eight week parent group with children who have suspected FASD, in collaboration with CAMHS and CYF. There are plans to continue this programme.

The behaviour support team (Explore) is available across the age range for anyone with a disability, including neuro-developmental disabilities. Explore has a specialist team with clinical psychologist oversight. Explore provides in-home and school assessment. They provide behaviour therapy in the home with parents and children to understand what is driving the behaviour. Explore has a six month wait list and are a non-diagnostic service. Explore offers support to children with FASD and their families. Explore are accessed via Taikura Trust – a Needs Assessment and Service Coordination (NASC) for disabled people

0–65 years in greater Auckland region. Children with neuro-developmental delays who can access Explore can receive effective support and individualised interventions.

Education services are through the Disability Support Services. These services are limited.

Services for young people with FASD are very limited

Access to neuro-developmental interventions is variable and not FASD specific. Currently, the focus is ad hoc on providing parents and caregivers with resources, and liaising with schools.

Young people with neuro-developmental disabilities over the age of 15 cannot access services unless they have an intellectual disability.

Funding for the youth health clinic has been moved to support primary care to work with children and young people. With the discontinuation of the youth health clinic, there is no specialist care for young people with complex needs.

Transition services are lacking for young people with FASD

Clinicians supporting young people with FASD have no clear transition pathway. These young people can have significant alcohol and drug issues, relationship breakdowns and issues with the justice system.

Some evidence-based interventions are being offered for specific disabilities

The following evidenced-based interventions are available in Waitematā DHB region:

- A modified Alert Program is available for children with ADHD.
- Parent Child Interaction therapy is offered through CAMHS.

Other interventions available include:

- A pro-social peer relationship skills training offered by occupational therapists and social workers in schools. The training is not based on Children's Friendship Training.
- Activ8 which works on pro-social and communication skills. These groups are based in the school sector.
- Sparx programme which is an e-therapy programme for young people with mild to moderate depression.
- Parent support network runs workshops for supporting parents and caregivers.

Stakeholder feedback suggests these programmes could be modified for children with FASD.

Waikato

Across the region there are a range of diagnostic services

Paediatric medicine and developmental services have a level three regional neo-natal service. Babies born prematurely or with problems will come from around the five DHBs: Waikato, Lakes, Taranaki, Bay of Plenty and Tairāwhiti. Some babies will have been exposed to alcohol or drugs in-utero. These babies may not be identified, as people may not share alcohol and other drug use.

The general paediatric service and Child Development Service are for the Waikato DHB region. The services are for children aged up to 15. Some children with significant disabilities may stay with the service until they leave supported education between 18 and 21 years.

In Waikato DHB, Child Development Services are provided by the Child Development Centre. The service has psychology, occupational therapy, physiotherapy, speech therapy, social language and visiting therapy elements. The service does assessments when there are questions around disabilities and provides support to children with significant disabilities and their families.

For behavioural issues such as feeding or settling, the child and family go to general paediatrics. The exception is when there is evidence of development delay or ASD. Across the region, general paediatricians run outreach clinics. GPs, Plunket nurses or public health nurses will refer to the service. A paediatrician will review the child and their family in an outreach clinic. Depending on the problems identified, the paediatrician will arrange further investigations or management. Onward referrals to the Child Development Centre may be made.

The referral process of children with neuro-development delays is not clear cut

A child under six will be referred to Child Disability Services, where a child's behavioural concerns indicate ADHD. If there are suspected developmental delays, the child will be referred for an assessment through Child Development Services. If the child is aged over six and there is no question of developmental delays, they are referred to mental health services.

If a young person presents with a severe behavioural problem in CAMHS, they must be referred to general paediatrics. CAMHS continue to support the family focusing on their mental health. CAMHS' contract means they cannot provide services for behavioural problems. In contrast, general paediatric services do not have these constraints. If it is unclear where a child or family fits, they are likely to be accepted into general paediatric services.

Determining what service to refer a child to is not clear cut. As a result, children and their families can get moved between services due to the range of needs and differing eligibility criteria. Services are trying to manage extensive waitlists so they will refuse a referral if the

child does not fit their criteria. They will, however, seek to make an onward referral to a suitable service.

Funding for services is available through NASC and Good Start Funding

NASC ensures children receive appropriate disability allowances. In the Waikato, the local NASC is called the Disability Support Link. NASC have a limited and fixed pool of funding to cover infancy to geriatrics. NASC do needs assessments, assign resources to families and families find the services. For those in rural areas, this can be challenging as there may be no family or friends to offer support. For some families, the amount of support offered can be insufficient.

Good Start funding can also support families to negotiate their own packages of care. Good Start funding is currently being rolled out and is not widespread.

A range of age related intervention services are available

In Waikato, the early intervention services are provided by education and health providers and by two NGO providers: MacKenzie Centre and Conductive Education. The two NGOs have both education and health service contracts. The NGO services provide support for people with physical disabilities and increasingly support children with ASD and their families.

Once a child is aged over two and under five, the Mackenzie Centre, Conductive Education and Early Childhood intervention services will become involved through specialist education services. The family can only access one service. The family may have access to an education support worker funded by the Ministry of Education for use in early childhood centres. If the child is not at an early childhood centre, they do not receive this support.

Both services are delivered to people living in the Hamilton region. Those living more rurally do not have access to these services.

Children aged under two living rurally in the Coromandel, Tokoroa and Te Kuiti receive visiting therapy services from the Child Development Centre.

School-aged children with a neuro-developmental delay may be supported by RTLB

If a neuro-developmental problem is suspected, the school may refer the child to the RTLB for an assessment and to provide recommendations for interventions. A referral may go through to Special Education Services' Severe Behaviour Team. At some stage, a referral will be sent from the school or GP to the Child Development Service, general paediatrics or CAMHS. CAMHS tends not to be involved in the younger age group. Severe behavioural issues are more likely to be referred to paediatrics.

Schools may provide support to children with neuro-development delays from their teacher aide contract. Schools may also arrange speech and language therapy, occupation therapy or physiotherapy.

A range of non-FASD specific supports are available for family and caregivers

Consideration is also given to the family circumstances, and the presence or not of family violence, neglect or abuse. For very young parents or sole parents, CYF's Family Start may be involved. If the parents have an intellectual disability, support is also sought from CCS Disability Action, Community Living Trust, or IDEA services field workers. Community Living Trust and IDEA services are both agencies offering lifelong support of people and families with intellectual disabilities.

In Waikato, other family support services include the FASD NZ branch, FragileX association and ADHD group Ross Trevor House. These NGOs provide parent education and informal supports

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Taranaki

Mixed awareness and knowledge of FASD

Feedback from those offering training in FASD diagnosis note the paediatrician has attended specific FASD training. Community-based organisations are seen as having lower awareness of and knowledge about FASD.

Taranaki DHB does not have a specific FASD diagnostic pathway

Referrals to the paediatric service are perceived as being open and easy. Professionals within the health and education sector can refer a child with developmental concerns to the paediatric service. The referral is reviewed by the child development nurse or coordinator who determines the assessments needed, and where they are undertaken. Children with suspected FASD under seven years follow a similar path as children with other neuro-developmental delays.

Children under seven years are seen by the paediatrician. If the paediatrician determines a risk of FASD due to alcohol exposure during the pregnancy, a full scale assessment is recommended once the child is seven years or older. The delay in the full assessment is due to neuro-cognitive testing being more reliable in an older child.

One diagnostic pathway exists to assess children for FASD which is age and location dependent

A diagnostic FASD pathway exists for a limited number of children who are older than seven years and enrolled with the Ministry of Education's Severe Behaviour Team. Assessments are done in collaboration between the paediatrician in the Child Health Service and a psychologist from the Ministry of Education. The diagnostic process is:

- The coordinator at the DHB sets up the meetings and clinic appointments and collects information from the parents/caregivers and school.
- The paediatrician undertakes the medical and developmental assessments. The psychologist undertakes the psychology testing. A speech and language therapist or occupational therapist may be involved.
- A combined report is written.
- A diagnostic formulation meeting is held to discuss the outcomes.
- A meeting is held with the parents/caregivers or the family.
- A meeting may be held with the school to discuss appropriate school-based interventions.
- A report is produced with a list of recommendations, which may include further interventions in the school, speech and language therapy, occupational therapy or more developmental paediatric follow-up.

Those not in the Severe Behaviour Team and adolescents have no access to a multi-disciplinary FASD diagnosis pathway

For children not in the Severe Behaviour Team, the paediatrician cannot confirm a diagnosis except in the small number of cases where the child has the physical signs of FASD.

Currently, the Child Health Service does not have a psychologist. A full FASD assessment is therefore not possible. For these children, the paediatrician flags a potential FASD diagnosis.

Two potential referral pathways exist for adolescents with suspected FASD through youth justice or mental health. These young people tend to end up in CAMHS, which currently does not recognise FASD as a diagnosis. CAMHS will not collaborate on an FASD assessment. CAMHS will refer the adolescent to the paediatrician who can only undertake the medical and developmental assessment. The young person will not receive a complete FASD assessment.

Access to appropriate interventions is good for those in the Severe Behaviour Team and less so for others

The referral, diagnosis and intervention pathway works well for those children in the Severe Behavioural Team. The key benefit of this pathway is the ongoing involvement of the Ministry of Education's Severe Behaviour Team in providing support and services to the children within the school system. The Severe Behaviour Team also train other staff to be more knowledgeable about FASD.

Beyond this service, very limited intervention services exist that understand and have experience in working with children and young people with FASD. These children and young people are likely to have received services under other FASD associated diagnoses (e.g. ADHD or depression). Concerns were raised about the potential for harm from these services if they are not modified for people with FASD.

Other interventions noted as available in Taranaki DHB include:

- Within the school environment, RTLB and teacher aides, and speech and language therapists through special education. Access to speech language therapist is limited by strict referral criteria
- Iwi services with a focus on child behaviour and whānau aspects
- Services on social interactions of the child (e.g. Big Brothers/Big Sisters)
- NGO contracts for counselling
- Alcohol and other drug services
- CAMHS for mental health issues including referral to psychiatrist and crisis team
- For children with ASD there are Incredible Years and Triple P.

One evidence-based FASD intervention is available in the Taranaki region

Children's Friendship training is offered by RTLB in the Taranaki DHB.

Hawke's Bay

Hawke's Bay DHB is a demonstration site of good FASD practice

Hawke's Bay DHB is described as a demonstration site of establishing best practice diagnostic pathways for children and young people with FASD. Hawke's Bay DHB has a multi-disciplinary diagnostic team and has an FASD pathway within their existing system.

A dedicated diagnostic pathway of neuro-development delays exists

Hawke's Bay DHB has a paediatric service under the Women, Child and Youth Service directory. The Child Development Service covers learning and behaviour and disability services. The Child Development Service has speech and language therapists and occupational therapists who work with children with developmental difficulties.

The Child Development Service has a diagnostic assessment programme (DAP) to assess children with complex learning and behavioural needs. DAP is used to diagnose ASD, FASD and other neuro-developmental difficulties. The team is primarily focused on assessment and diagnosis. The service provides some education modules including FASD education modules to the community.

Children with suspected FASD are assessed after the age of eight to allow their cognitive functions to develop. Children cannot be assessed twice due to limited resources. The stakeholder notes too many false negatives occur if children are assessed too early.

The Child, Adolescent and Family service is an intervention service for children with moderate-severe mental health issues. This service may make a diagnosis, especially for adolescents. The service does some FASD assessments.

A range of intervention and support services exists in the DHB

The Disability Support Service is an intervention service offering occupation therapy intervention and/or speech and language therapy. The service does not have behavioural psychology support. The Disability Support Service offers speech and language therapy for children up to three years. The Ministry =

NASC brokers services for families and is based in the Disability Service. Children up to eight with a disability can access the service. A definitive diagnosis of intellectual disability is not needed to access the service. A paediatrician can make a referral if the child has global developmental delay or delays in at least two functional areas. When a child turns eight a definitive diagnosis is required.

A child with intellectual disability and NASC support can be referred to Explore who offer support. Child Development Services cannot refer to Explore.

Children with neuro-development delays can have a key worker. Delays exist in receiving a key worker which can delay access to interventions.

A range of services of variable quality exists in the NGO and private sectors

Children with FASD and their families can receive intervention and support services from a range of NGOs. Families are being referred to these services as they do not meet the tertiary services' criteria. NGO services include:

- BirthRight and FamilyWorks provide counselling support, social working support and parenting programs (e.g. Incredible Years, Strengthening Families). Strengthening Families brings the family and professionals together (i.e. paediatrician, allied health professional, teacher, social worker). A facilitator identifies the family's needs and strategies to strengthen the family are agreed.
- Iwi providers, Te Tai Whenua o Heretaunga, and Te Kupenga Hauora provide social work and parent support. Te Tai Whenua also offer mental health services.
- Awhina Whānau Services offer whānau counselling, and families for family violence. Families tend to be referred by CYF.

Stakeholder feedback suggests NGO services for children with FASD and their families are of variable quality. These services are not seen as having the same skill levels as the tertiary organisations. Children who have neuro-developmental difficulties and very complex social situations may be receiving inappropriate support.

A number of other services offer support service in the region:

- Gains Psychology & Consulting Services is a private service with psychologists who do some neuro-developmental assessments
- A few other private psychologists provide assessment and intervention services.

RTLB provide interventions including speech language therapy

RTLB are located in schools and have specific skills at adapting curriculum and managing behaviour. Three teams are organised in the region covering children and young people from two to 20 years. RTLB have psychologists and speech language therapist.

In the preschool years, RTLB provide some speech and language therapy or some early intervention in kindergartens, early childhood centres or occasionally in homes. In schools, RTLB have speech and language therapists who accept referrals for children up to nine years. After nine years, it is difficult for older children to access speech and language therapy. The barriers to accessing speech and language therapy may be overcome by seeking funding for private speech therapy from the Scott fund or WINZ.

Ministry of Education has a Severe Behavioural Team for children and adolescents

Children and adolescents with significant behaviour issues are referred to the Ministry of Education's Severe Behaviour Team. Through this service, children and adolescents have access to psychologists, teachers for the deaf, physiotherapists, kei te wānanga support, and occupational therapists.

The Ministry of Education's Severe Behaviour Team is primarily focused on working with the school on a focused issue for a short period of time. Once the goal is achieved the service is withdrawn. If other issues arise, the child/adolescent needs to be referred for that issue. Stakeholder feedback queried whether more flexibility is needed.

Some evidence-based neuro-development/FASD interventions available

Evidence-based interventions offered in Hawke's Bay DHB are: language and literacy training, cognitive control therapy, and the Alert program.

Eligibility criteria for services and funding can block access to services and support

High needs children can be referred to Higher Complex Needs which has significant funding attached. To receive this funding, evidence is needed on:

- the complexity of the need
- the exploration of other funding and support sources through the Child, Adolescent and Family service, and the Ministry of Education
- existing solutions not working
- the child remaining out of school with significant difficulties.

The Ministry of Education also have ORS funding for students with severe and ongoing needs for special education. The application for ORS funding is a collaborative effort between parents, educators and key workers.

Feedback from the stakeholder indicates children with FASD may not meet disability services or mental health services criteria. Very few receive high learning needs or ORS.

Hawke's Bay DHB is increasing support for families

Recognising the needs of families, Hawke's Bay DHB are recruiting a developmental coordinator to provide post-diagnosis and navigation support to families. A lack of respite care for families continues.

Young people with FASD miss out

Paediatrics goes up to 15 years. Beyond this cut off young people are moved into adult services. Stakeholder feedback indicates that young people with FASD tend to come in contact with CYF and youth justice.

Supporting the transition from childhood to young adult is well recognised for those with neuro-developmental issues. This transition is managed well for those receiving disability services but less so for others. Concerns were raised about access to sexual health services.

Wider Wellington region

Multi-disciplinary teams diagnose ASD and other neuro-developmental delays including FASD

In CCDHB, the child development service is for children aged 0 to 16 years. Unique for New Zealand, the service employs developmental paediatricians. The multi-disciplinary team includes a developmental paediatrician, occupational therapist, speech and language therapist, and a physiotherapist.

At referral, children under six with a question of developmental delays, including children with FASD, are triaged. The pathway coordinator goes back to the referrer and gets more information to ensure the service is right for the child. If accepted, the child is seen by a developmental paediatrician who does a standardised developmental assessment (e.g. the Griffith Scales).

If ASD is suspected, the child will have a formal assessment by a multi-disciplinary team of a paediatrician, speech language therapist and clinical psychologist. The composition of the multi-disciplinary team is flexible and structured to the child's potential development delays. For example, if there are motor delays or sensory integration issues then the team will be a paediatrician, occupational therapist and a physiotherapist.

Over the age of six, the child will be seen by a paediatrician and clinical psychologist who will do a standardised cognitive assessment. If a disability is diagnosed, the developmental paediatrician will follow-up with the child.

In CCDHB, the developmental paediatricians and paediatrician received training on diagnosing FASD. The Canadian guidelines are used to diagnosis children based on the four digit code.

Hutt Valley DHB has a developmental paediatrician based in the general paediatric department. The developmental paediatrician holds a developmental clinic, and multi-disciplinary assessments are undertaken.

In Wairarapa DHB, services are more limited. Paediatricians and a clinical psychologist are available to do supplementary assessments. Children can be assessed by a multi-disciplinary team.

Eligibility criteria for CAMHS a barrier to access for children with FASD

Children with FASD tend to straddle services due to behavioural difficulties and mental health issues. A child with FASD may not meet CAMHS' eligibility criteria.

To avoid children missing out, the developmental paediatrician triages all general paediatric referrals with a behavioural or developmental aspect. The developmental paediatrician works closely with the pathways coordinator and intake worker at Te Haika (Mental Health Contact Centre) to ensure the child is seen by the most appropriate service. The child and family therefore have access to developmental and behavioural paediatric assessment. The service does not have a clinical psychologist.

Hutt and Wairarapa DHBs are likely to have the same issue of children straddling services. At one stage, sub-regional services were considered. The stakeholder notes an ideal regional service would have four or five regional teams contributing to paediatrics, CAMHS, special education and speech language therapists.

Children with FASD (and children with fragile X) can miss out on funding and support in education as their needs do not meet the eligibility criteria for ORS. A particular challenge is ensuring education support recommendations from clinical psychologists are enacted. Barriers to action include limited resources in schools or recommendations not fitting within the school structure, particularly in high school where there are multiple teachers.

A range of interventions are available, but no FASD specific interventions

In CCDHB, children and families can access medication through the paediatrician or CAMHS psychiatrist. Some children with FASD respond to stimulant medication to manage their behaviour.

RTLB offers interventions through the school for a six-week duration. Due to the underlying trauma, a six week intervention will not address the behavioural issues for children with FASD. The interventions are acknowledged as useful. However, children with FASD get better gains from long-term interventions and support.

Outside of the DHB setting, a few paediatricians have a private practice in the Wellington region. None have a behavioural focus.

A few NGOs offer mentoring for behavioural difficulties. Some NGOs run Incredible Years which is important for pre-schoolers with behavioural difficulties. For older children with behavioural difficulties, there are few intervention services.

- The Boys and Girls Institute offer mentoring and buddy programmes for children and young people who are socially isolated
- Challenge2000 based in Johnsonville provide generic support. Often children with FASD do not fit well in the service.

Some agencies are social-work derived and offer family support. However, stakeholders do not see these as a good fit for children with FASD and their families.

Parent education groups are available

The Child Development Service introduced parent education and support groups for families. (e.g. feeding difficulties, sensory needs). The groups have four seminars over eight weeks and are run by clinical psychologists or psychiatrists.

Strengthening Families multi-agency meetings can be called where all providers offering services to a family get together and coordinate support and services. A series of four to six meetings is held over six to 12 months to collectively work together to strengthen the family.

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Canterbury

No formal FASD referral and diagnosis pathway exists

Canterbury DHB has no formal FASD referral and diagnosis pathway as defined by the Canadian Guidelines (Cook et al 2016). Following the Christchurch earthquake, the CAMHS capacity is stretched. All children with disabilities are being referred through the paediatric service. Without additional funding and new resource allocation, it is not feasible to establish a FASD referral and diagnostic pathway. ASD assessments currently have a wait list for assessment. Due to the existing pressures, Canterbury DHB does not want to introduce a new pathway that creates another wait list.

FASD assessments are currently done as part of the neuro-development assessments

Psychologists in Canterbury DHB are training in NEPSY (a Developmental NEuroPSYchological Assessment) to increase capability to do assessments for a FASD diagnosis. The developmental paediatricians have received training in Europe in identifying and diagnosing FASD.

Currently, children will receive a FASD diagnosis if they have a history of alcohol exposure and there are significant concerns about developmental, behavioural and learning issues. For those children where the diagnosis is not so clear further assessments are carried out.

The Child Development Service has the foundations for a multi-disciplinary diagnostic team

Canterbury DHB's Child Development Service consists of physiotherapy, occupational therapy, psychology and family support. More Child Development Coordinators would be needed to offer support and phone follow-up if multi-disciplinary FASD diagnostic team was established. Capability gaps include speech language therapists and psychologists.

Children's Teams are identifying children exposed to alcohol in-utero

Four Children's Teams are present in Canterbury DHB. Information shared in the Children's Team can raise questions about children and young people's fetal exposure to alcohol. The family focus and partnership approach of the Children's Team can be useful in FASD assessment and interventions.

Early interventions are a mix of public and private services

Access to interventions by children under six is based on need and is not dependent on a diagnosis. Around half of early interventions for children under six are undertaken by a collaboration of a neuro-developmental therapist at the Child Development Service (e.g. occupational therapist or physiotherapist) and the Ministry of Education staff. Other

children are seen in private practice including the Champion Centre², CCS Canterbury³, and Conductive Education. The allocation of children to the service is dependent on which service has a vacancy.

Right Service Right Time is an innovative approach to ensure the wellbeing of children and families, in particular to deal with anxiety issues. Parenting programmes such as Incredible Years, Triple P and Circle of Friends are available with a focus on addressing anxiety and building resilience. Right Service Right Time is perceived as not good at capturing school aged children and fostering links between health and education.

Limited availability of proven neuro-development/FASD interventions

Feedback suggests Ministry of Education's psychologists may offer Parent Child Interaction Therapy. Similar programmes to the Children's Friendship training may be offered. Language and literacy training may be offered by CAMHS Speech Language Therapists. It is not known if this is the evidence-based programme described in Appendix 1.

The Alert Program is not offered. However, the Alert Program is wanted due to its proven benefits for children with FASD and those with other neuro-developmental delays.

Children with FASD link into services and interventions via other diagnoses

FASD is not a recognisable mental health disability. As there is no defined FASD pathway in Canterbury, the focus is to 'join the dots' for children based on their symptoms to gain appropriate interventions.

A number of children with FASD are suspected of not accessing services

Transient families and those children being referred to the Children's Team may miss out on access to early interventions due to structural and other barriers. It is suspected children with FASD will be over-represented in the group missing out on services.

² The Champion Centre provides multi-disciplinary early intervention services to infants and young children with significant disabilities and their families in Canterbury. <http://www.championcentre.org.nz/> accessed 15 February 2017

³ CCS provide support and strengthen communities so people with disabilities are included in the life of their family/whanau and community. <http://www.ccsdisabilityaction.org.nz/regions/upper-south-island> accessed 15 February 2017

Southern

No referral and diagnostic services for children and young people with suspected FASD

There is no coordinated referral and multi-disciplinary diagnosis pathway for FASD in Southern DHB. The paediatrician can identify if there is a history of in-utero alcohol use and determine if children meet the criteria for FASD. However, assessing the extent of neuro-psychological damage is not possible. CYF seek to assessments for young people coming through their systems from outside the area.

Awareness of FASD and its impact is growing in Southern DHB. A collaboration between health, NGOs and the private sector are seeking to establish a referral and diagnostic pathway.

Existing criteria of health and disability services prevent diagnosis and access to services

Intellectual disability services may identify a child with a non-specific neuro-developmental disorder, and offer some assistance. However, only a small portion of children with FASD will meet the criteria for intellectual disability.

CAMHS have taken a position of not diagnosing children with FASD as they perceive the diagnosis places blame on the mother.

Limited and non-FASD specific interventions are being offered by NGOs and RTLB

Some NGOs are offering intervention using case management that seeks to bring the family on board (e.g. Mirror Counselling, ADL, and Otago Youth Wellness). The NGOs seek to work with parents/caregivers and the child. They will refer to paediatric services and work with what is identified.

Within education, RTLB have a role in offering specialist support. However, without an FASD assessment, tailoring of services to individualised need is not possible.

Otago Youth Wellness are offering a transition and bridging services for young people

Interventions to manage transitions for young people exist, particularly in managing schooling issues such as truancy. The effectiveness of the interventions is seen as limited by the lack of a detailed FASD assessment.

Services exist to support families who have children with FASD

Social support services are working with families where children have behavioural issues. The interventions are not specifically targeted to children with FASD. In Southern DHB, intellectual disability services have changed in the last year and services have been discontinued. As a result, these non-FASD specific services to families have been stopped.

Other DHBs

Northland

Those offering training in FASD diagnosis note that Northland DHB has a good network of community interest. They are trying to establish wrap around services for children coming to the service.

Bay of Plenty DHB

Feedback from those offering training in FASD diagnosis note there is a paediatrician who is actively involved in the FASD sector. However, they are unable to do evaluations and follow-ups. Feedback suggests they are working collegially with CYF and CAMHS but not in a structured way.

Nelson/Marlborough

Nelson/Marlborough have a paediatrician who is working to build a team.

Rotorua and Manawatu/Whanganui

Services are seen to be limited in the Rotorua and Manawatu/Whanganui areas.

South Canterbury

Feedback indicates the services and the management of children and young people with FASD and their families are similar to Canterbury DHB.

West Coast

Canterbury and West Coast DHBs share their management structure. Services remain independent. Feedback indicates the services and the management of children and young people with FASD and their families are similar to Canterbury DHB.

West Coast DHB is seen to be more vulnerable in maintaining key health professionals required for diagnosis and intervention.

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Appendix 1: Stocktake tool



FASD Service
Stocktake tool_08 12

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