

Hawke's Bay District Health Board Developmental Assessment Programme FASD Assessment Pathway: Process Evaluation

August 2015

A report commissioned by the Health Promotion Agency



ACKNOWLEDGEMENTS

The Health Promotion Agency (HPA) commissioned Paula Parsonage of Health and Safety Developments to undertake this process evaluation in order to understand more about the Hawke's Bay District Health Board Developmental Assessment Programme FASD Assessment Pathway model and explore considerations for replication in other regions.

HPA would like to thank the researcher and author, Paula Parsonage, for her work and dedication in undertaking this informative and insightful evaluation. The HPA commission was managed by Sue Paton, Principal Advisor Addictions, HPA.

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GLOSSARY OF ABBREVIATIONS AND ACRONYMS

ADHD	Attention Deficit Hyperactivity Disorder
ARBD	Alcohol Related Birth Defects
ARND	Alcohol-Related Neurodevelopmental Disorders
ASD	Autism Spectrum Disorder
CAFS	Child Adolescent and Family Mental Health Service
CDS	Child Development Service
CYF	Child Youth and Family
DAP	Developmental Assessment Programme
DHB	District Health Board
FASD	Fetal Alcohol Spectrum Disorder
FAS	Fetal Alcohol Syndrome
ID	Intellectual Disability
NASC	Needs Assessment Service Coordinator
PAEDS	Paediatricians
PFAS	Partial Fetal Alcohol Syndrome
RTL	Resource Teacher Learning and Behaviour

EXECUTIVE SUMMARY

Reducing harm for children affected by parental addiction is a priority for the Health Promotion Agency (HPA). The Hawke's Bay District Health Board (DHB) Developmental Assessment Programme (DAP) provides multi-disciplinary diagnostic assessments of children with complex developmental and behavioural concerns. Additionally the DAP provides training in developmental and behavioural conditions for those working in health, education and social service settings. One component of the DAP is a Fetal Alcohol Spectrum Disorder (FASD) Assessment Pathway for children with developmental and behavioural issues potentially related to pre-natal alcohol exposure. HPA commissioned an independent process evaluation in order to understand more about the DAP FASD Assessment Pathway model and explore considerations for programme replication in other regions.

The DAP FASD Assessment Pathway is provided by a multi-disciplinary team combining Paediatric, Speech language, Psychological and Social work assessment utilising the Canadian harmonisation of the Washington 4-digit code (Chudley et al, 2005). Key aspects of the pathway include assessment at home, school and clinic; collaboration with families, caregivers, teachers, referring paediatricians and others; synthesised assessment findings and recommendations provided in a single report and provision of feedback sessions to the family and to school personnel involved with the child. A team approach underpins the programme. The training component of the DAP develops capacity in the broader community to provide an effective response to children with an FASD and thus supports implementation of assessment recommendations.

Evaluation findings indicate that the DAP FASD Assessment Pathway is operating as intended and is successfully identifying children with FASDs, engaging families living in low decile areas and engaging a high number of Māori whānau. Further, the programme has a reach into homes and schools. The following are identified as linked to the success of the Pathway:

1. The Model. Essential aspects of the model have been identified as follows:
 - *Shared vision and values:* These include being child focussed, collaborating with families, whānau, other professionals and services and adopting a strong non-stigmatising approach that promotes respect for all. Additionally the model aims to be culturally responsive.
 - *Best-practice multi-disciplinary approach:* A best-practice approach to FASD assessment is used.
 - *A synthesised report and feedback sessions:* As outlined above.
 - *A team approach:* The DAP functions as a team, co-working and supporting the implementation of the Pathway together. A number of key DAP processes provide mechanisms by which the team approach is given effect.
 - *Close working relationship with Paediatricians:* Paediatricians provide ongoing oversight for the child and their family/whānau. Close working

relationships support the implementation of the DAP FASD Assessment Pathway and maximise the impact of the assessment findings and recommendations.

- *Strong effective relationships with other services:* The model relies on collaboration with other professionals and services to refer children, to provide input to the assessment process and to support implementation of the recommendations.
- *Building capacity through training:* The mandate to provide training to other professionals is essential to the working of the clinical component of the pathway.

2. Workforce, infrastructure and service context. The DAP FASD Assessment Pathway is provided by a highly skilled and experienced professional team supported by strong leadership. The Pathway is part of a broader assessment programme and the DAP is sited within a larger child development service and a robust organisation. This contributes to a high quality and sustainable programme. Situating the specialised assessment pathway within a child development service is widely viewed as a way of providing an effective continuum of service for children, enabling flexibility and effective use of resources and contributing to programme sustainably. Those delivering such a programme require specialist training in FASD assessment.

The evaluation highlighted a number of important considerations for replication of FASD assessment programmes. Foremost there is broad consensus that the lack of post-assessment support is a limitation of the DAP FASD Assessment Pathway. The approach would be strengthened by the addition of support for children and families in the post-assessment phase, similar to that provided by DAP for children diagnosed with Autism Spectrum Disorder. This would need to be enabled via funding provisions.

Further all stakeholders agree that the waiting time for the DAP is a significant challenge and that active ongoing management of the waitlist is required.

The following were also suggested as ongoing challenges:

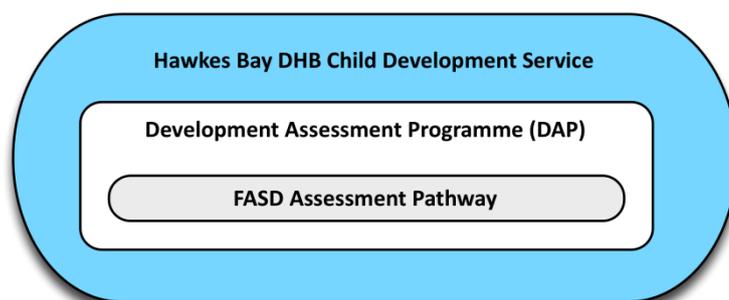
- The need to continue to refine the assessment reports so that they are both comprehensive and as 'user-friendly' as possible.
- The importance of ensuring culturally responsiveness. Stakeholders suggested partnering with Māori and Pasifika in the programme set-up phase to ensure all aspects of the programme are designed from the outset to maximise responsiveness.
- Stakeholders identified a mismatch between the health and education paradigms. Purposeful collaboration and partnership with the Education sector was recommended to mitigate this.
- A team culture characterised by strong professionalism, collaboration, collegial respect and openness must be developed and maintained. This includes ensuring there are opportunities for ongoing professional development for team members.

Stakeholders universally support expanding the provision of FASD assessment opportunities within DAP-type programmes. The experience that has accrued from the DAP FASD Assessment Pathway provides a useful blueprint for other programmes. The strengths identified, lessons learned and the expertise now available within the DAP could provide invaluable support for further development.

INTRODUCTION

The Hawke's Bay District Health Board (DHB) Developmental Assessment Programme (DAP), a service component of the Hawke's Bay DHB Child Development Service (CDS), provides multi-disciplinary diagnostic assessments of children with complex developmental and behavioural concerns. The DAP also provides training in developmental and behavioural conditions for professionals and para-professionals working in health, education and social service settings. One component of the DAP is an assessment pathway for children identified as potentially having developmental and behavioural issues related to pre-natal alcohol exposure. This pathway is referred to as the Fetal Alcohol Spectrum Disorder (FASD) Assessment Pathway. The service context is shown in Figure 1 below. The DAP FASD Assessment Pathway is unique in the New Zealand context and is viewed as highly effective by many stakeholders.

Figure 1. The DAP FASD Assessment Pathway in context



Reducing harm for children affected by parental addiction is a priority for the Health Promotion Agency (HPA). This aligns with New Zealand government priorities for identifying, assessing and connecting vulnerable children to services (Ministry of Social Development, 2012). As the DAP FASD Assessment Pathway appears well matched with these priorities, HPA commissioned Health & Safety Developments to undertake a process evaluation in order to understand more about the DAP FASD Assessment Pathway model, identify implementation successes and challenges and explore considerations for replication in other regions. The evaluation took place during the period from April to June 2015.

FASD

FASD is a non-diagnostic umbrella term used to describe the full range of adverse effects resulting from the pre-natal exposure to alcohol. The term includes conditions such as Fetal Alcohol Syndrome (FAS), Partial FAS (PFAS), Alcohol-Related Neurodevelopmental Disorders (ARND) and Alcohol Related Birth Defects (ARBD) (Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders, 2011; Chudley et al, 2005). Key adverse effects are linked to brain damage caused by alcohol. These vary from mild to severe and encompass an array of physical defects and cognitive, emotional and adaptive functioning deficits (Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders, 2011).

Such effects result in life-long disability. Early diagnosis is seen as a protective factor for the child, reducing the risk of further harms such as exclusion from school, criminal offending and mental health issues. Additionally, the assessment process engages and educates families and whānau and community services both in relation to effectively supporting the child and also in the harms associated with alcohol and pregnancy (Alcohol Healthwatch, 2011).

EVALUATION OBJECTIVES AND PROCESSES

The evaluation objectives were to outline:

- Core components and delivery mechanisms of the DAP FASD Assessment Pathway within the overall DAP context.
- Key implementation successes and challenges.
- Considerations for replication of an FASD Assessment Pathway in other regions.

Evaluation processes included:

- Review of key documentation: Relevant documentation on the development of the service and current operations was sourced in discussion with the CDS Clinical Leader, the DAP Consultant Neurodevelopmental Paediatrician and the DAP Coordinator. Documents were reviewed and relevant content is referred to in this report.
- Stakeholder key informant interviews: All DAP team members, other relevant Hawke's Bay DHB staff and external stakeholder representatives were invited to contribute to the evaluation by participating in a 1-1 interview. Informed consent procedures were followed with all those who elected to participate. A written summary of the interview was provided to each participant to verify accuracy. Interview results were analysed for key themes and these are summarised in this report.
- Analysis of relevant service data: Data pertaining to the client population and service utilisation was sourced via Hawke's Bay DHB. Key points from the analysis are outlined below.

NB. While the focus of the evaluation is the DAP FASD Assessment Pathway in many instances this component of the DAP is not distinguishable from other DAP service components and operational aspects of the DAP as a whole. Where it is meaningful to do so, findings that pertain specifically to the DAP FASD Assessment Pathway are noted.

RESULTS

DATA OBTAINED

Data were obtained as follows:

1. In total 22 stakeholder key informant interviews were undertaken, including all eight DAP team members and CDS Clinical Leader (referred to in this report as DAP key informants) and 14 others (referred to as External key informants) including a family member, non-DAP Hawke's Bay DHB staff (paediatricians; Māori health; child adolescent and family mental health service (CAFS) and Pacific Island liaison) and other professional external stakeholders representing the following services and roles that interface with DAP:
 - Ministry of Education Psychologist
 - Public Health Nurses
 - Resource Teachers Learning and Behaviour (RTLBs)
 - Needs Assessment Service Coordinator (NASC).
2. DAP data for 2010 - 2015 were provided by CDS for all children referred. Data include demographic characteristics, referral sources, diagnostic information and DAP recommendations relevant to each child.
3. Documentation: Documents reviewed included the following DAP operational documents:
 - *Excellence in Service Improvement: Improving Waitlist Management within the Developmental Assessment Programme* (Frechtling, 2014)
 - *Pathway for the Assessment of Fetal Alcohol Spectrum Disorder (FASD)* (Robertshaw, 2013)
 - *DAP Initial Family Visit template*
 - *Sketch of the DAP model*
 - *Ecological perspective overview*
 - *FASD making the connections in practice and collaboration*
 - *Your DAP Team Appointments For Your Child chart*
 - *DAP Process Checklist (checkpoints for running MDT case review meeting)*
 - *Bid for funding post-diagnosis 2013.*

HAWKE'S BAY POPULATION

As at the 2013 census 151,179 people are usually resident in Hawke's Bay, comprising the Wairoa District, Hastings District, Napier City, Central Hawke's Bay District and Chatham Islands Territory (Statistics New Zealand, 2013). In the main the Hawke's Bay DHB district lies within the territory of Ngāti Kahungunu, but also overlaps other iwi boundaries (Hawke's Bay DHB, Ngāti Kahungunu Iwi & Health Hawke's Bay, 2014).

Approximately 22% of people are aged less than 15 years compared with 20 % for all of New Zealand (Statistics New Zealand, 2013). Approximately 25% of the Hawke's Bay population are Māori (compared with 15% nationally), and approximately half of the Māori population are aged less than 25 years. There is a small but growing Pasifika population currently comprising approximately 4% of the population. More than 80% of the population live in the closely located cities of Napier and Hastings; 10% live in smaller centres and 10% live in rural and remote locations. Approximately 26% of the total Hawke's Bay population live in areas with a relatively high deprivation index (Hawke's Bay DHB & Health Hawke's Bay, 2012).

ORGANISATIONAL CONTEXT

As noted the DAP FASD Assessment Pathway is located within the Hawke's Bay DHB CDS, which is the umbrella service that fulfils the requirements of multiple contracts relevant to child development. These include:

- Child Development Service contract under the Ministry of Health Service Specification DSS1012 – Child Development
- Autism Spectrum Coordination Contract DSS221 (new since 2011)
- Gateway Health Assessment contract (new since 2013) funded by the Ministry of Social Development to provide health assessments for children under the care of Child Youth and Family Services (CYFs)
- DAP contract funded by Hawke's Bay DHB.

The DAP began as a pilot programme funded by the Ministry of Health in 2002 and was initially set up in the private sector. Over time responsibility for programme funding and management transferred to the DHB and in 2010 it was amalgamated with the CDS. The DAP is delivered by a "ring-fenced" sub-team within the CDS and DAP systems and management are embedded within the overall CDS. The FASD Assessment Pathway was initiated in 2010. To support the development of the FASD Assessment Pathway, team members undertook intensive training as a team in FASD assessment and diagnosis. Three team members travelled to Canada to attend an international conference and training at the Asante Centre in British Columbia¹. Post the initial training, ongoing training and supervision was coordinated via Alcohol Healthwatch².

THE DAP: CORE COMPONENTS AND DELIVERY MECHANISMS

As noted above the two key functions of the DAP are to provide:

- A. Clinical assessment: Providing multi-disciplinary diagnostic assessments of children with complex developmental and behavioural concerns. The FASD Assessment Pathway is one component of this function. The team also provides assessment for other developmental issues such as autism spectrum disorder (ASD).

¹ For further information see <http://www.asantecentre.org>

² For further information see <http://www.ahw.org.nz>

- B. Training: Providing training in key developmental and behavioural conditions for professionals and paraprofessionals working in health, education and social service settings. Since its inception the DAP has been mandated to provide training and up-skilling in the community to build community capacity to respond effectively to children with complex developmental and behavioural concerns. This component has evolved over time and is now provided in 2 x 2-hour Modules at the local Education Centre. The Modules provide a consistent approach and there is open access.

Other training is also provided as needs arise, for example in 2015 training has been provided to a 'cluster' of schools. Additionally DAP team members have provided training sessions for a group of Child Youth and Family (CYF) Social Workers to enhance their understanding of the impacts of FASD.

The DAP is delivered by a multi-disciplinary team comprising the following roles:

- A DAP Coordinator/Social Worker (1.0 FTE)
- Psychologist (1.6 FTE)³
- Speech Language Therapist (0.5 FTE)
- Consultant Neurodevelopmental Paediatrician (1.0 FTE)
- Occupational Therapist (0.4 FTE)^{*4}
- ASD Coordinator (0.8)^{*}

The DAP team has access to cultural support from a Kaitakawaenga from Hawke's Bay DHB Māori Health Service and the Hawke's Bay DHB Pacific Island Liaison Nurse.

In addition the programme receives administrative support from CDS administrative staff, some assistance from the CDS Therapy Assistant and overall leadership and management from the CDS Clinical Leader.

The programme operates during normal business hours, with the work schedule being planned to accommodate school terms (as school observations and school personnel are only possible within these time periods). The team aims to undertake ten assessments per school term per year (a total of 40 assessments annually). Data provided suggests that approximately 34% of these are FASD assessments.

Vision and Values

The DAP team operates under the vision and values of Hawke's Bay DHB. These and their application in the CDS of which the DAP is a part are summarised in Table 1 below:

³ Some psychologist time is utilized outside of the DAP within the wider CDS eg Mealtime Clinic, Cognitive Assessments, Behaviour Support and other MDT assessments.

⁴ * Indicates roles that are not involved in the FASD Pathway.

Table 1. Vision and Values⁵

Vision					
Hawke's DHB Vision statement	Bay of Plenty health services	Excellent health services	Reduce Health Inequalities	Improve health and wellbeing	Working in partnership
Application of vision in CDS/DAP	To provide a high quality service addressing the needs of the children & youth throughout Hawke's Bay	To provide culturally safe accessible service delivered by a Team respectful of and responsive to each individual child's/whānau needs	To deliver service in the right place at the right time to address the needs of the child/whānau	To ensure effective collaboration and integration within and across services and organisations	
Values					
Hawke's DHB Values	Bay of Plenty Tauwhiro	Rāanga te tira	He kauanuanu	Ākina	
Application of values in CDS/DAP	Delivering high quality care to patients	Working together in partnership across the community	Showing respect for each other, our staff patients and consumers	Continuously improving everything we do	
	A comprehensive assessment will have enduring impact. Do it once, do it well.	Ensure right team for each child/whānau Collaboration with others is fundamental including CYF, WINZ, NGOs	Recognise & incorporate the strengths of individual Team members	Encourage, listen to and learn from and act on the feedback from our consumers	
			Acknowledge the benefits of the body of knowledge	Actively pursue evidence based practices	

In addition to the above, internal stakeholders consistently commented that their work is underpinned by strong ethos of being child-focussed and non-stigmatising in their approach to families and whānau.

THE DAP FASD ASSESSMENT PATHWAY

The DAP FASD Assessment Pathway is targeted at those children who have significant developmental and behavioural problems and for whom there has been pre-natal exposure to alcohol.

⁵ Frechtling, 2014:9.

The FASD Assessment Pathway is described as a two-stage assessment model. Core components of the model are summarised below.

Stage 1. Screening and information collection

Stage 1 applies prior to acceptance into the FASD Assessment Pathway. It is however an integral and critical component of the model in that it provides essential screening and gate-keeping to ensure best use of the DAP resources, ensuring FASD assessment is offered to these for whom it is appropriate.

This stage applies when:

- A child has significant developmental and behavioural problems
- FASD is a consideration/question.

While initial referrals may be received from a wide range of sources almost all are screened by a Paediatrician before referral to the DAP FASD Assessment Pathway. Referrals fall into one of two groups:

- A. Children under the care of Hawke's Bay DHB Paediatrics:** For this group the Paediatrician discusses concerns with families/caregivers, obtains further history as needed including a detailed history of pre-natal alcohol exposure, data about growth, sentinel facial features and learning and behaviour problems. Where appropriate the Paediatrician then refers the child to the CDS for a fuller assessment (see below CDS Allocation Meeting).
- B. New referrals to Paediatrics or CDS:** For this group the diagnostic work up (as in A above) is completed by a Neurodevelopmental Paediatrician who then refers the child to the CDS for a fuller assessment. If insufficient information is contained within the original referral additional information is sought either via a Social Work visit or by using a Parent and a School questionnaire.

An FASD pro-forma is used as basis of the referral to guide the screening process.

The following apply:

- Alcohol consumption in pregnancy must be a documented concern.
- Parents and caregivers must be aware of the referral question.
- There is 'Clinical wait' for children under eight years of age⁶.

Stage 2. Definitive multi-disciplinary assessment

The following processes occur in chronological order:

CDS Allocation Meeting

Post screening, referrals are presented at the CDS allocation meeting which is attended by CDS, DAP representatives, Paediatricians, Child Adolescent and Family Services (CAFS)

⁶ Children are assessed for FASD after they turn eight years of age. This is based on best-practice in consideration of resource constraints (Robertshaw, 2013).

and Needs Assessment Service Coordinator (NASC) services representatives. Those at the meeting discuss the information and reach a consensus on the best pathway for the child.

Children referred to the FASD Assessment Pathway who are eight years old at the time of referral go onto the DAP waitlist and are seen in turn. (Generally children are not accepted onto the DAP waitlist until they are six years of age. Those under eight are assessed for FASD as soon after their eighth birthday as practicable).

Overall responsibility for the ongoing health care for the child remains with the referring Paediatrician.

Engagement: Initial visit (for those on the FASD Assessment Pathway waitlist)

Once accepted all children and the family/whānau are visited by the DAP Coordinator (a Social Worker) who undertakes a holistic social assessment, (including risk assessment), explores the family's strengths and concerns and links them with appropriate supports. This typically includes:

- Providing information about FASD and on behaviour management (if this has not already been given by the Paediatrician)
- Advising on eligibility for Child Disability Allowance
- Advising of eligibility for service through local services such as Options Hawke's Bay (NASC service) and Explore.
- Providing information re NGO support services e.g. CCS Disability Action
- Linking with the Early Intervention Team, Ministry of Education, where appropriate
- Linking with CAFS if required.

The DAP Coordinator may work with the referring Paediatrician to provide this package of care.

The DAP Coordinator role is pivotal in linking the family/whānau with the programme. The Coordinator provides guidance to the team as to the planning for the family determining how much the family can cope with, what is the best order of assessment processes, venue, delivery mode etc.

DAP Intake Meeting: Schedule/Plan provided to family

When an assessment place is available (once the child is eight years old if they have been referred at a younger age) team roles are allocated and a schedule/plan is developed at the regular DAP Intake meeting. The schedule/plan is provided to the family.

Assessment

The following assessment processes for each child are combined within the FASD Assessment Pathway:

- Paediatric assessment

- Speech language assessment
- Psychological assessment
- Social work assessment (gained over time).

The DAP FASD assessment process utilises the Canadian harmonisation of the Washington 4-digit code (Chudley et al, 2005).⁷

Wherever possible each child is assessed at home, at school and at the DAP clinic. The school observations are always undertaken by a team member who is not known to the child.

The average staff time (excluding Consultant Neurodevelopmental Paediatrician) required to complete FASD assessments is shown in Table 2 below:

Table 2. Estimated professional hours per FASD assessment*

<i>Discipline</i>	<i>Indirect time - Hours</i>	<i>Direct time Hours</i>
Social Work	4.7	4.9
Psychologist	5.3	8.1
Speech Language Therapist	2.9	3.6
Travel time	5	-
Total	17.9	16.6

*(J. Frechtling, personal communication, June 23, 2015).

This estimate is based on data from 20 recent assessments and is considered to be conservative, for example data on Paediatrician, administration and management hours were not included. It was noted by internal stakeholders that the time per assessment has reduced somewhat over time as team members have become more experienced and processes continue to be streamlined wherever possible.

DAP Formulation meeting

When all assessment processes have been completed and analysed the DAP team meet formally to discuss the assessment outcomes. The purpose is to evaluate “does this child meet diagnostic criteria?” Outcomes relating to all of the FASD diagnostic domains are confirmed, reviewed and discussed, a diagnosis is formulated by consensus and recommendations are similarly developed. The role of report writer is allocated to one team member. A base template is used, allowing input from each professional.

Other professionals involved with the child may be invited to contribute to the discussion, such as Resource Teacher Learning and Behaviour (RTL), Ministry of Education Speech Language Therapist, Public Health Nurses.

⁷ An Occupational Therapy (OT) Assessment is not undertaken in the DAP FASD pathway. At the recommendation of the DAP Occupational Therapist it was determined that it was not best use of the limited OT resource.

Comprehensive report

All assessment results, the diagnosis and recommendations are synthesised into the assessment report. An edited version of the report which excludes sensitive family information may be developed in discussion with family, before the report is shared with others, for example those in the education settings.

Feedback: Family and School Sessions

Once the report is written there is a Family Feedback Session delivered by at least two members of the team, most often the DAP Paediatrician and one other, generally the person with the strongest relationship with the family or particular expertise in the area for which the child has the greatest needs. The DAP interpretation of family is very broad incorporating whoever is important in the child's life.

The Family Feedback Session is educative in focus, to ensure key people in the child's life are given support to understand what the assessment/diagnosis and the recommendations mean for the individual child. Any recommendations involving referral to other agencies are discussed and consent is gained for the referrals to be made.

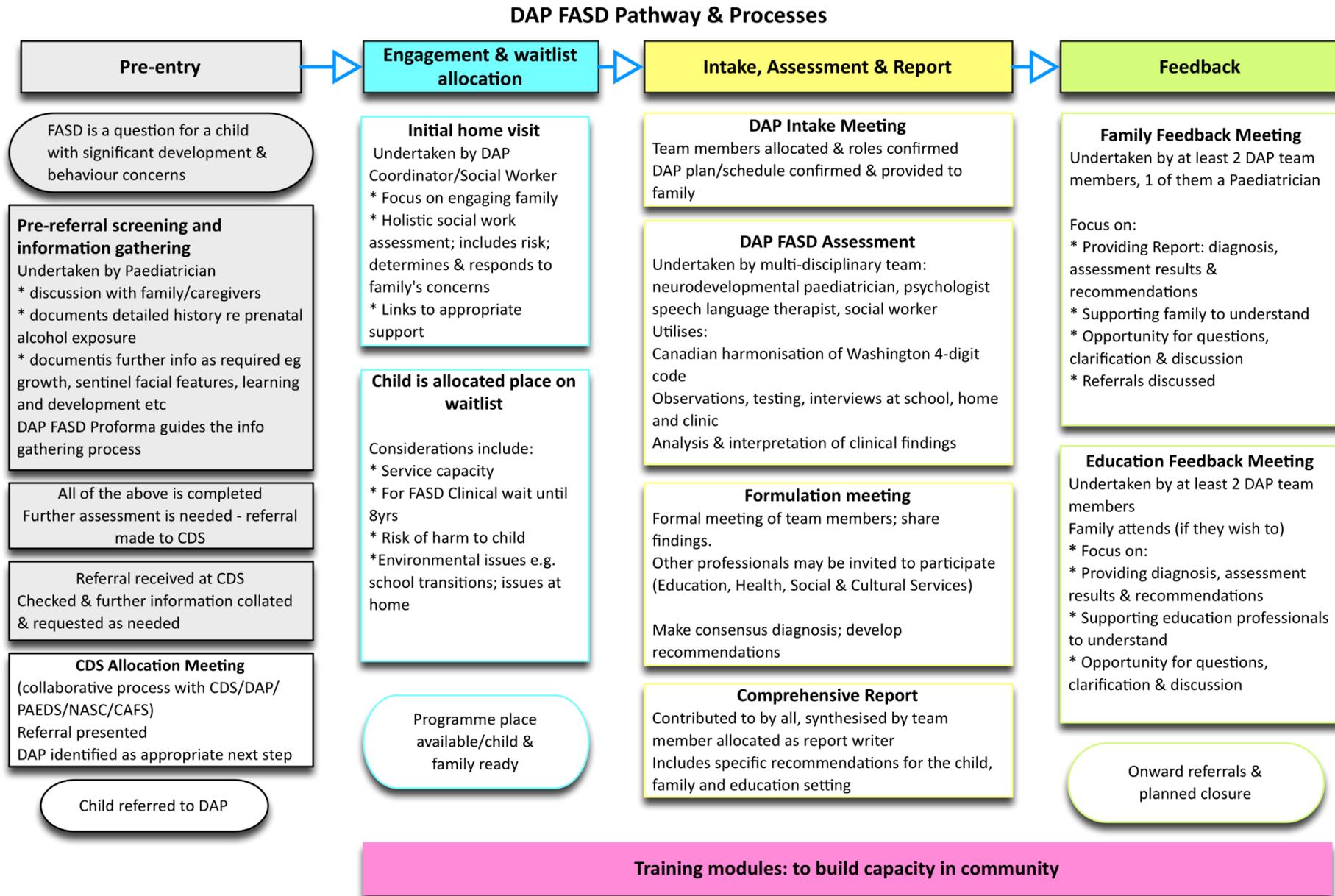
A School Feedback Session is provided to those in the school context and is delivered by at least two members of the DAP team. Family are present if they wish to be. Other professionals such as a Public Health Nurse may be invited with permission of the family.

For some children and families/whānau who live some distance from Hastings the assessment and a family feedback session will be completed in a block. Accommodation is available via a local charitable trust to support this process. The families/whānau stay in the accommodation for 2 – 3 nights while the assessment is completed and they have an initial feedback session prior to the report being written. They are provided with a one-page summary of the assessment findings.

The Feedback sessions provide an opportunity for further discussion and clarification for all concerned and represent the conclusion of the DAP programme for the children. The DAP Coordinator may remain involved for a short time to follow through with referrals.

An overview of the DAP FASD Assessment pathway is shown in Figure 2.

Figure 2. DAP FASD Assessment Pathway and Processes



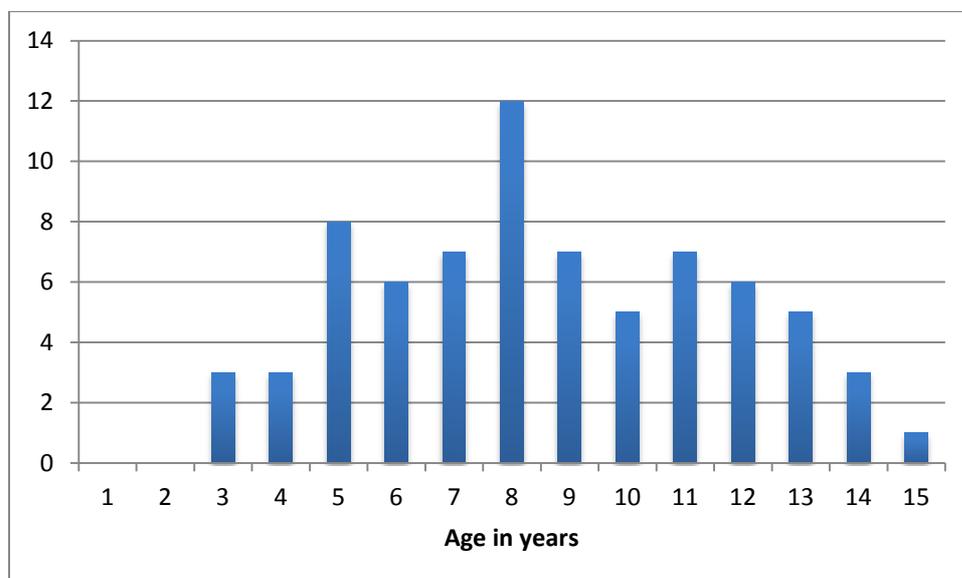
THE DAP FASD ASSESSMENT PATHWAY CLIENT GROUP

Data, information from documentation and information from stakeholders has been compiled and analysed to provide a profile of the client group served by the FASD Assessment Pathway.

Client Demographics

Data pertaining to children on the FASD Assessment Pathway for the period 2010 – 2015 provides a snapshot of those assessed, showing that a total of 74 children have accessed the DAP FASD pathway, with 74% being boys and 26% girls. A majority of children are Māori, being 73% of the group. Data on the ethnicity of those who are non-Māori were not available. As shown in Figure 3 below, ages of those referred range from three years to 15 years⁸, with approximately 61% of children being aged eight or older at referral.

Figure 3. Age of children at referral to DAP FASD Pathway, 2010 - 2015

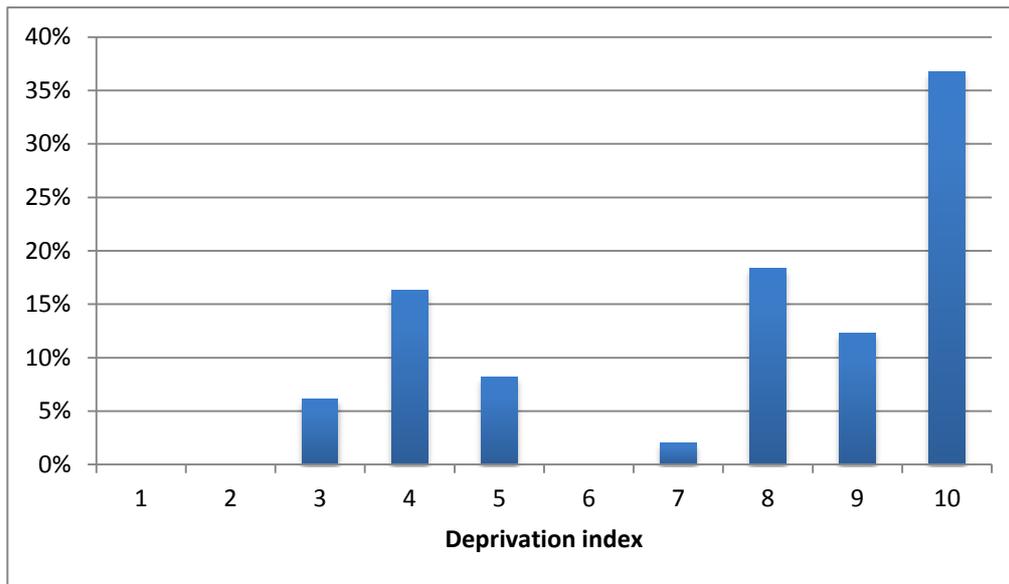


Data pertaining to deprivation index were available for 49 children (those whose assessment process is completed or almost completed). These show that most of the children live in areas with a high deprivation index⁹ for example 69% live in areas with a decile rating of 7 or higher, with 37% living in a decile 10 area (the highest level of deprivation). Data are shown in Figure 4.

⁸ The age of one child referred before birth was not included in the chart.

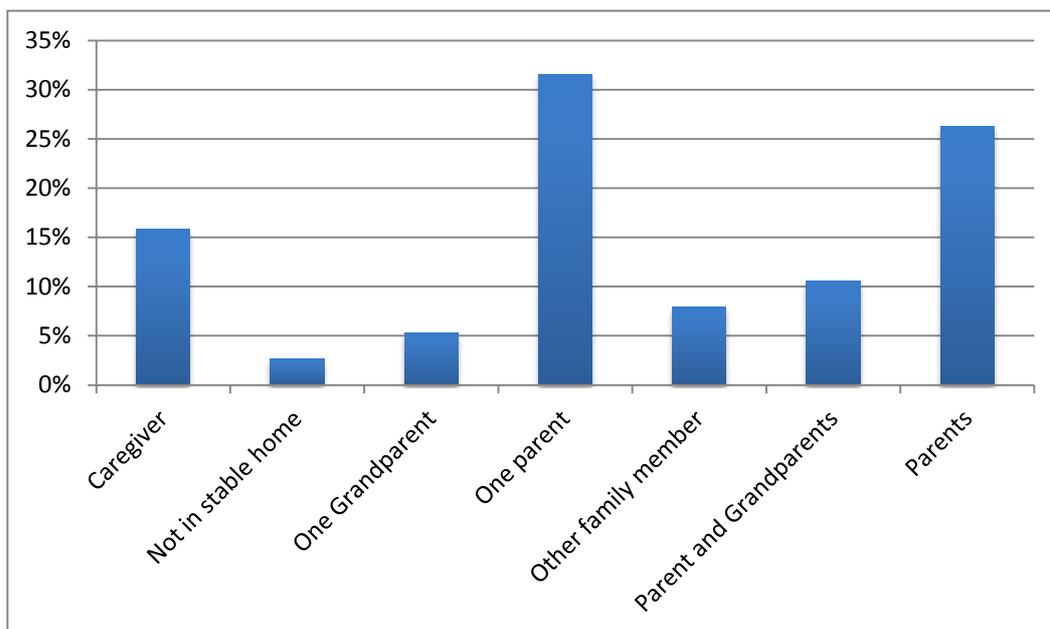
⁹ The New Zealand Deprivation Index is a measure of the level of socioeconomic deprivation in small geographic areas. The index ranges from 1 to 10. A score of 1 indicates that people are living in the least deprived 10 percent (decile) of New Zealand. A score of 10 indicates that people are living in the most deprived 10 percent. The deprivation index uses Census data for car and telephone access; receipt of means-tested benefits; unemployment; household income; sole parenting; educational qualifications; home ownership and home living space. Salmond et al. 2007 cited in <http://www.odi.govt.nz/resources/research/outcomes-for-disabled-people/nz-dep.html>

Figure 4. % FASD Assessment Pathway Children by deprivation index



Data for the same group also show that a wide definition of family and whānau applies. A minority of the children (26%) live with both parents (this includes birth parents and adoptive or whangai parents), 32% live with one parent and a further 11% live with a parent and grandparents. A further 13% live with another family member or grandparent, 15% live with a caregiver and one child was not living in a stable situation. This is shown in Figure 5 below.

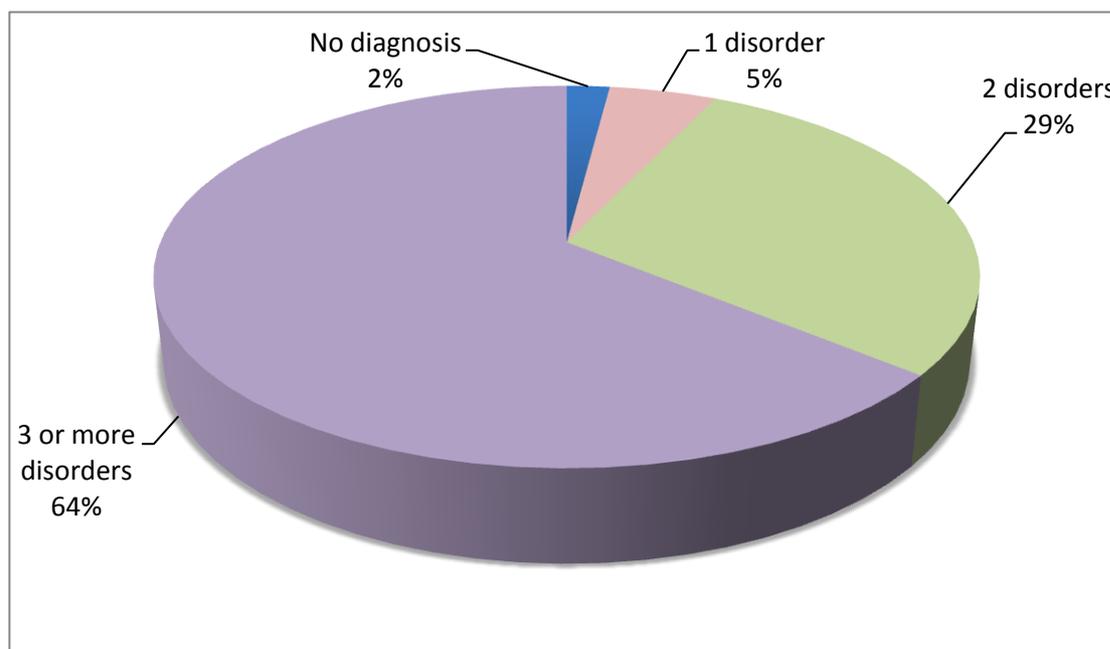
Figure 5. % FASD Assessment Pathway Children living with parents, family, whānau and others



Assessment outcomes

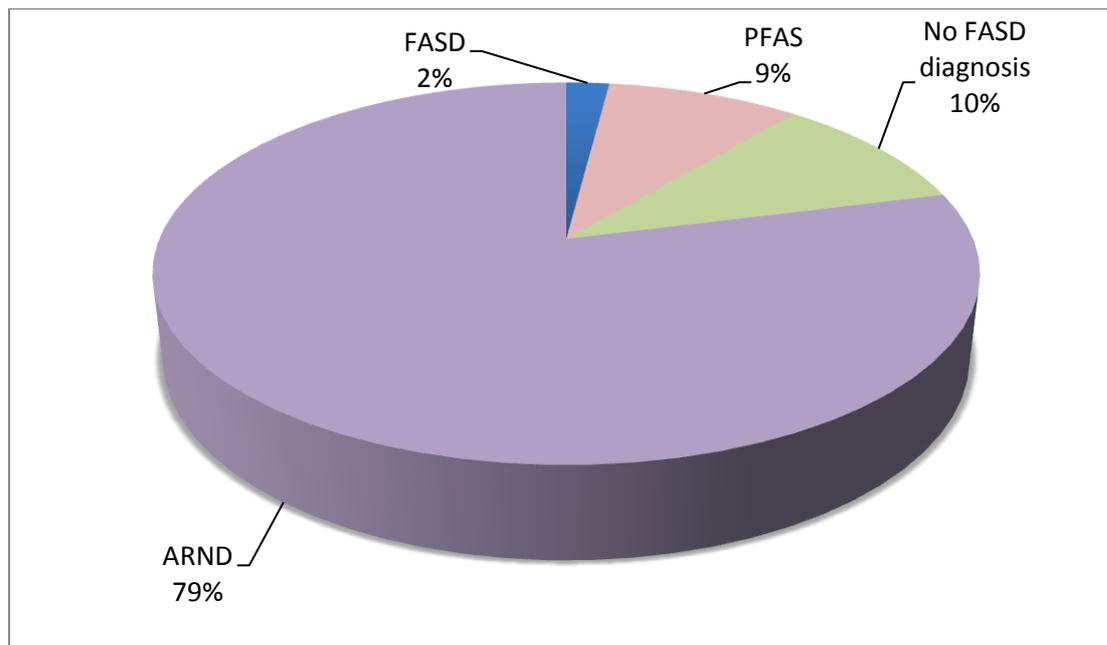
Data on FASD assessment outcomes were available for 42 children. Figure 6 below shows that all but one child were assessed as meeting the criteria for one or more disorders, and 93% of the children were assessed as having more than one disorder including FASD, Attention Deficit Hyperactivity Disorder (ADHD), Intellectual Disability (ID), Language Disorder, Attachment Disorder and Adaptive Behaviour limitations and Cerebral Palsy.

Figure 6. Assessment outcomes: % of children on FASD pathway diagnosed with a disorder



A total of 38 children (90% of those for whom assessment has been completed) met the criteria for an FASD. Of this group 33 (a majority of the FASD group) were assessed as having ARND, four (11%) met criteria for PFAS and one was recorded as meeting criteria for an FASD with no further specification. Results are shown in Figure 7.

Figure 7. Assessment outcomes: % of children diagnosed with FASD on FASD pathway



Data also show that 21 children (50% of those on the FASD Assessment Pathway for whom data were available) were assessed as having an ID, with most being assessed with a moderate ID (12 of the 21 children) and a further five of the ID group being assessed as borderline.

Results from a small study undertaken by the DAP team comparing the DAP client group in 2007/08 and 2013 indicate that the client group has become more complex in terms of the children's development, family circumstances and environment (J. Frechtling, personal communication, June 23, 2015). The study compared two randomly selected groups of DAP assessments, 18 cases from 2007-08 and 20 cases from 2013 and applied a complexity matrix (Bernie, 2008) to measure complexity in a number of domains. Results showed that six of the 18 children in 2007-08 group were assessed as having no diagnosis as compared with zero children in the 2013 group. In terms of environmental and family complexity there was a shift to more complexity in each domain measured with a general increase in complexity overall. These findings suggest that the DAP is being accessed by those for whom it is intended i.e. those with complex needs.

ACCESS TO THE FASD ASSESSMENT PATHWAY

As noted a total of 74 children have accessed the DAP FASD Assessment Pathway between September 2010 and June 2015. Of these, 49 have had assessments completed or almost completed and a further 25 are in process or waiting for assessment. As a broad indicator of capacity this equates to an average of approximately 14 FASD assessments per 12-month period.

Data confirm that mostly children access the DAP FASD Assessment Pathway post-screening via a referral from a Paediatrician (88% of referrals) and a very small number of children gain access via other health professionals and services including Child Adolescent Mental Health, Psychologists and the DAP Coordinator.

Before being screened by the Paediatrician, referrals originate from a range of sources both internally from the wider CDS or Gateway team members and externally from Ministry of Education professionals such as RTLB, educational psychologist, teacher, family or whānau member, public health nurse, general practitioner, child and adolescent mental health service, child youth and family (CYF) and from those working in non-government organisations.

Time from referral to report back

Data indicate that the time from referral to final report back varies considerably with the shortest time recorded as four months and the longest as 3 years and 11 months. The wait time for those on the DAP FASD Assessment Pathway is not straightforward as there are several factors at play. The age of the child is a key clinical factor. As noted above, FASD assessments are not undertaken until a child is eight years of age, so any child younger than eight must wait under the care of a Paediatrician until they are old enough to be assessed. The child's education and social context are also factors for example, a child may be transitioning from one school or home environment to another, school holiday's have to be factored in to enable school based observations and the family context may be such that they are not in a good place to participate in the programme. A further factor is the capacity of the DAP team.

All stakeholders raised the wait time as a key challenge for the DAP and this is discussed in more detail below (see *Waitlist* page 34).

Nature of the recommendations made in FASD assessment report

Incomplete data pertaining to the recommendations made in the FASD assessment report were available for 40 children. These are indicative only as aggregate data on recommendations is not routinely reported. Data indicate that approximately 78% of children assessed were referred for paediatric follow-up. Additionally application for or continuation of the Child Disability Allowance was recommended for 78% (15% of these children are already receiving the allowance). Approximately 50% of children were referred to a NASC (Needs Assessment Service Coordination) service either for assessment of eligibility or continuation of the service. An Individualised Education Plan was recommended for 30% of the children. A range of other health, education and social well-being related recommendations were made relevant to the needs of the individual child, these included for example, referral to other health and social services such as Te Taiwhenua O Hereataunga, audiology services, mental health services etc.

STRENGTHS OF THE APPROACH

There was a high level of agreement among stakeholders regarding the strengths of the DAP and the FASD Assessment Pathway. Key themes are summarised below. Where findings apply specifically to the FASD Assessment Pathway this is identified.

Robust Multi-disciplinary Assessment Process

The nature of the FASD assessment process was regarded as a key strength by all stakeholders. Four aspects of the process were consistently raised as being strengths:

- The assessment is multi-disciplinary and comprehensive.
- The assessment occurs in the home and school as well as the clinic and includes families, education, health and other professionals.
- The information and understandings gained in the assessment are synthesised into a single coherent report.
- The process provides a plan and/or guidance for supporting the development of the child at home and school.

The following comment summarises these themes which are expanded on below:

DAP provides a detailed assessment. The children are assessed in multiple places – school, home, clinic. The assessment pulls together lots of different strands of the story, lots of information and provides a plan.

External stakeholder

Multi-disciplinary approach

The multi-disciplinary nature of the FASD assessment is viewed by all stakeholders as a defining key strength of the FASD Assessment Pathway. It enables comprehensive assessment of the whole child and reflects best practice in FASD assessment. For example the following comments are typical:

The whole team approach the child with a wide lense; look at the whole family context. Everyone works to support the child to achieve their maximum potential.

Internal stakeholder

It's a very good service. Once the child gets to the DAP it's an in-depth process, looks at needs of child, family and school.

External stakeholder

The multi-disciplinary approach allows for triangulation of information providing more robust assessment and diagnostic formulation.

External stakeholder

Assessment occurs in multiple environments

All stakeholders highly valued the inclusion of observations of the child in the context of their education and home environments and also the inclusion of interviews and discussions with parents and care-givers, teachers and other professionals. Both internal and external stakeholders regard this as a highly effective assessment approach that provides reliable and useful results and is well matched to community needs. The following comments illustrate these widely expressed views:

All children seen by DAP are seen by at least 3-4 of the team in two to three settings, so it is a robust diagnosis process.

Internal stakeholder

The home and education observations are so enlightening. You get much more than you get [from] just using the tools, even the gold standard tools.

Internal stakeholder

They're flexible. They come out to the school, go to the home – get much more out of the assessment process [than if they see the child only at the unit].

External stakeholder

The DAP team know their communities. They come out in to the community and this is vital for our at risk families. If they stayed in the hospital I think they would miss a lot. They wouldn't get the same understanding of the child. They come out into the school and the home and the children can be so different [in those contexts].

External stakeholder

A synthesised report is developed

All stakeholders viewed the synthesising of information into one report as highly useful. Internal stakeholders highlighted the level of analysis and discussion required to reach a consensus and ensure that all aspects of the assessment are accounted for, that it makes sense as a whole and that the report and the recommendations are clearly supported by the assessment findings. External stakeholders also commented on the value of having the information integrated into one report, particularly for families. The following comments provide examples:

Multi-disciplinary programme – looks at the whole child; synthesising information.

Internal stakeholder

Provides understanding of the holistic needs. The MDT is very good; everyone is looking at the person at one time and this is better for families. Other families [not under DAP] get really annoyed.. you have to see this one then that one....gets very hard. Having a group of people working collaboratively is better for families.

External stakeholder

Families and schools receive guidance tailored to the needs of the child

External stakeholders commented on the value of the assessment as a plan or guide for their own work with the children and families. For example:

The assessment is very thorough and can be used as a platform for service delivery.

External stakeholder

[The DAP team] assesses a variety of areas that can be a barrier to accessing the curriculum at school for that child. It is important to know what the problems are and how these impact in the school environment.

External stakeholder

The Assessment Process is an Intervention

Linked to the point above, there was agreement among stakeholders that the assessment process is itself a therapeutic intervention rather than being a solely diagnostic process. Through the assessment those involved in the day to day life of the child deepen their understanding of the child's needs and abilities and how best to respond to and work with the child. For example:

Information about the child is made visible to the family/parents. The assessment is part of the therapeutic process. Important to see the assessment as a process. Parents have the opportunity to hear explanations and to ask questions and have them answered as early as possible.

External stakeholder

We assess needs and functions to develop a diagnosis/report which builds understanding of the child's development and gives direction to those who are involved with the child. The assessment provides individualised information.

Internal stakeholder

Family and School Feedback Sessions Extend Learning

The Family and School Feedback Sessions provide an extension of the learning from the Assessment process and report. These sessions are considered a strength of the programme by stakeholders. For example:

Family education is a huge part of the process. A diagnosis is no use without understanding.

Internal stakeholder

They work so well as a team. E.g. They came to school - I was invited to the meeting. Three members of the team came and gave feedback to the school, with the parent there. I thought this is amazing. There was no sense of alarm, they worked through the points and what needs to be done. It was very clear and very nice. I thought 'this is how health professionals should be all of the time. Giving people the information that they need and in an accessible form.'

External stakeholder

[With the feedback process] You get a group discussion which is useful – it's not just a report in the mail.

External stakeholder

Team Structure and Roles

The overall structure and roles within the DAP were noted as a strength. All roles are viewed as important and, importantly, the key professional disciplines required for FASD assessment are represented in the team.

Internal stakeholders commented that having the CDS Clinical Leader to support the management functions of team and work alongside the DAP Consultant Paediatrician to provide overall leadership supports the work of the team very well.

Additionally the DAP Coordinator role is seen as critical. The DAP Coordinator is a key point of contact for the families and other stakeholders and is responsible for managing the clinical work flow, tracking all referrals and team processes. The overall management of the waitlist falls to the Coordinator who maintains an overview of the whole client population from the point of acceptance into the programme, and typically is aware of those in the pre-entry phase. The DAP Coordinator can expedite referrals if there is an identifiable need to do so, eg if a child is at risk of harm. For example:

DAP structure works well. Clinical Leader/ Consultant Paediatrician, Overall Coordinator to manage work flow and track all the referrals, assessment processes, report writing and feedback [the pathway]. This role is a natural fit for a social worker.

Internal stakeholder

The social work [initial] visit spearheads the whole process, preparing families for the length of time the process takes.

Internal stakeholder

The social work role is very important. It is a critical role; the programme couldn't function without it. It provides a bridge to other services. They can work intensively. They provide the glue, the liaison with families and schools, they reiterate the key messages and advocate for the child.

External stakeholder

Both internal and external stakeholders commented on the value of having a Paediatrician involved in the programme. For example:

We look to [the Consultant neuro-developmental paediatrician] for guidance.

Internal stakeholder

It's a health assessment - having a Paediatrician involved - that's got to be a good thing.

External stakeholder

Teamwork

Many stakeholders commented that the DAP team members truly work together as a team rather than working as a group of individuals in a nominal team configuration. This teamwork is seen as a significant strength of the programme, promoting quality and sustainability. Team members and others consistently reported a strong spirit of teamwork, supporting each other, challenging each other and sharing responsibility for the performance of the team in delivering a good service.

As a team we can sort out confusing presentations. Do it once and do it well. We get the best possible analysis.

Internal stakeholder

The team approach is a strength, you still have some autonomy but I love the team approach.....you get such good information. You can't get it all in an hour.

Internal stakeholder

There is a sense of team responsibility, team accountability "haul each other up"; team support.

Internal stakeholder

Pulls all the disciplines together. The team works together towards one child's needs, bring all their clinical strengths together.

External stakeholder

Team Culture, Vision and Values

Linked to the point above, internal stakeholders universally reported that the culture of the DAP team is a major contributor to the effectiveness of the approach. The culture of the team in this instance refers to:

- Shared vision, values and expectations
- A culture of reflection and flexibility,
- Professional respect and trust.

For example:

Tasks and processes are easy to describe but it is the other stuff that makes the programme work. The shared values, beliefs, attitudes and expectations.

Internal stakeholder

Develop a shared vision. Be flexible thinkers; have flexible thinkers in management. Be willing to be flexible with the spending.

Internal stakeholder

It is evident that the team share a strong client focus and an anti-stigmatising position in relation to the children, families and other professionals and services. For example:

The drive is within, it's for the kids. This is true for every team member. It's one of the few things that we all share.

Internal stakeholder

The heart and the passion of the DAP team members. They are so passionate about what they do. This is so important.

External stakeholder

....have a non-stigmatising approach, have compassion – these are very important.

Internal stakeholder

It's a hard area to work in. We see a lot of abuse and neglect – care and protection issues – you have to be open to understanding why and be willing to get on with it. There are not a lot of resources. You have to work in a non-stigmatising way – especially with the birth mums – you have to believe everyone wants the best for the child – not point the finger.

Internal stakeholder

Stakeholders commented that a further strength of the team culture is the value placed on reflective practice and flexibility. The team and the broader service strives for continuous improvement, both in refining processes and practices and participating in ongoing professional development. A willingness to be flexible is necessary to support programme refinements. All internal stakeholders referred to these aspects of team culture and these views were supported by comment from those external stakeholders who work more closely with the team. For example:

Its client focussed. There's constant streamlining. We develop, put things into place, reflect and refine.

Internal stakeholder

It's a place for developing ideas. It's blossoming.

Internal stakeholder

The team is reflective. It's an evolving service and everyone takes turns to give it a nudge. Everyone looks after their own profession.

Internal stakeholder

Ongoing CPD [Continuing Professional Development] is a priority. We have journal club, in-service presentations, we host visiting experts, all staff attend 'Engaging Effectively with Māori', we have had a noho marae. We are working on developing a cultural competency pathway for staff.

Internal stakeholder

The team is constantly reflecting and refining processes to improve practice. This is the culture of the service.

External stakeholder

All internal stakeholders spoke of the high level of professional respect and trust within the team. This is viewed as a significant strength of the programme that ensures a high quality assessment process and supports effective teamwork. This in turn allows for efficiency, minimising duplication of effort, and supports ongoing professional and programme development. The following comments are typical:

There is respect and trust for colleagues in the team. There is a lot of joint working. They give each other feedback.

Internal stakeholder

There is room for disagreement. It is safe to disagree. You are able to show vulnerability – you don't have to know it all.

Internal stakeholder

There are strong personalities who are willing to challenge each other. There is a high level of communication.

Internal stakeholder

Professional expertise

The high level of professional expertise within the DAP team was consistently noted by all stakeholders. Team members have advanced professional skills and significant professional experience. A number of stakeholders noted that the DAP is not a place for new graduates. For example:

Team members have high-level professional skills; at the top of their field.

External stakeholder

Team is populated with strong professionals. They are making tough decisions – this risks producing defensiveness. [The DAP team members] have the ability to be questioned and to defend their clinical knowledge.

Internal stakeholder

Clinically they really know their stuff. You can ask them for information and you know it will be solid.

External stakeholder

I think it is a case of 'success breeds success'. They have been able to recruit good people. They have excellent clinical leadership.

External stakeholder

They are experienced and able to work in the community. [DAP is] not new grad territory.

Internal stakeholder

Additionally the importance of the training that the team received in FASD assessment and diagnosis was seen as essential. For example:

You need the training. Psychologists come with different levels of expertise in neuro-psychology. [For example] I didn't understand the gaps the issues related to executive functioning without an intellectual disability. Team training is important – everyone needs to be on the same page.

Internal stakeholder

Any SLT [Speech Language Therapist] could do the role if they are trained.

Internal stakeholder

Accessible Programme and Approachable Professionals

A number of external stakeholders commented that the programme can be easily accessed and that DAP team members are approachable and available to answer their queries and support them in their work. This was viewed as a strength. For example:

Approachable, adaptable and compassionate. People working in an institutional setting can be very removed from reality. They get down with people.

External stakeholder

There is an easy path in to the programme.

External stakeholder

They're so contactable. If you hear a family are going 'a bit wobbly' it is really easy to link in with the team if needed.

External stakeholder

It can give you a sense of confidence. Sometimes it's a sigh of relief because you have that health perspective and expertise. There may be things you have not seen – there is a sharing of responsibility.

External stakeholder

There is quite a bit of interaction with the team, “not just a report mailed out”. They offer professional support.

External stakeholder

Training Component of the Programme

Many stakeholders highlighted the training component of the DAP as a key strength. Both internal and external stakeholders value the professional development provided by DAP to those working in the community. This is widely viewed as being an effective way to share the knowledge and to build capacity in the community to support children with FASD.

It was further identified that the training component supports the clinical component in that the FASD Assessment Pathway relies on other professionals involved with the child to be knowledgeable and open to working effectively in consideration of the issues that the child faces. Again, the training is seen as building community competency and capacity.

Examples of relevant comments include:

It's a programme – not just a clinical service. This means that education activities and community liaison are built into the job. This enables us to do so much more.

Internal stakeholder

They spread the knowledge.

External stakeholder

Approachable team/ good connection with community: having the wider brief to provide education to community groups and professionals is a strength as it supports good communication with others [that the child/family is involved with].

External stakeholder

Linkage with Paediatricians

Close linkage between the DAP and the Hawke's Bay DHB Paediatricians was noted by many as crucial to the success of the approach, both in terms of shared processes and co-location. For most of the children assessed for FASD the Paediatrician is providing general health oversight prior to and after the assessment. Close linkage enables the two groups to work effectively together for the benefit of the children and families, supporting mutual understanding of respective roles, functions, resources and constraints. For example:

Linkage with Paediatricians: co-location with the Paediatricians and having the programme sitting in Paediatrics rather than in mental health is a strength of the programme.

Internal stakeholder

Links to Paediatricians: DAP was originally set up to support the work of the Paeds. It links in well. Co-location and “sharing a lunchroom” really help.

Internal stakeholder

Close contact with paediatricians. This is partly facilitated by co-location and partly by having a dedicated developmental paediatrician. Co-location allows easy access and consequently the timely “conversations in the corridor”. Having a dedicated developmental paediatrician helps to bridge the gap between the DAP and the paediatricians.

External stakeholder

Organisational Context and Leadership

The organisational context, i.e. being situated within a Child Development Service within a DHB was noted as a strength by internal stakeholders. The wider team and the wider organisation provide important support to the work of the programme in terms of management and clinical systems, access to the wider workforce and to workforce development systems such as training and supervision. For example:

The DAP is not a stand-alone service; it sits within a bigger context – it can draw on a bigger skill base; there is close working, better support and access to others for discussion.

Internal stakeholder

Part of a bigger service so you get outside perspectives [not just a small isolated diagnostic team].

Internal stakeholder

The DAP service was a stand-alone service but is now integrated into the Child Development Service. This is very important as allows the whole team to have a shared understanding of respective skills of team members.

External stakeholder

You need a Child Development Service staffed by a multi-disciplinary team. The DAP is the top storey on the house – you need to build the bottom storey. It is not a stand-alone service.

External stakeholder

Many noted the leadership of the programme as a strength and DAP team members were very positive about the leadership and management of the team. Some also noted that the leadership and support for the programme extends beyond the team and the CDS to the leadership of the Hawke’s Bay DHB Women Child & Youth Service.

The DAP is nurtured by the leadership.

Internal stakeholder

The leadership live to the values of the service and model these; provide support. We are acknowledged as professionals and supported.

Internal stakeholder

We get great support for ongoing professional development – it's a two way street; we know we are supported so we are very reasonable in our requests.

Internal stakeholder

There is a vision and a strategy; the team and programme is looked after.

Internal stakeholder

Linked to this it was noted the “ringfencing” of the programme in terms of function and funding was important to the sustainability of the programme. For example:

There is a real commitment to keeping the programme ring fenced; it's a firm boundary; we always bring it back to core business. It makes it possible to keep the momentum.

Internal stakeholder

Being a ring-fenced service is a strength but there is also a question....does this make the funding vulnerable? That has been suggested by others in the past. However it needs to be there when setting up the service.

Internal stakeholder

Community Partnerships and Connections

The focus on developing and maintaining collaborative partnerships with community stakeholders is seen as a key strength. Examples relevant to the FASD Assessment Pathway include the Inter-agency developmental disorders group and the FASD consultation forum. Building partnerships supports development of shared understanding of roles, facilitates co-working, avoids duplication, enables the team to generate more support for the children who are assessed and supports the team to maintain their own knowledge of community resources.

DAP team members also commented on the value of connecting with national and international bodies and groups that are involved in FASD prevention, identification and service provision.

The following comments provide examples:

The relationships with our partners are very important; this strengthens the value of the report. It builds buy-in and a greater level of comfort and this is much better for families

Internal stakeholder

We have developed the FASD consultation forum – it has developed a DRAFT 3 year action plan. We are working with Māori health and pulling together initiatives. 70 – 80% of the FASD children are Māori.

Internal stakeholder

The professional closeness really benefits the children. Years ago I wouldn't have dreamed of phoning a paediatrician and asking for advice. They have more understanding of our

constraints and we know the assessment takes time. It is worth the wait. We can pre-warn the families.

External stakeholder

Collaboration is the name of the game. It's an inter-agency process. The community must be open to it. I could see it working in other areas. It's a good tool.

External stakeholder

All the other services play their part. Public Health Nurses need knowledge of where to channel the referrals. All the cogs of the wheel need the professional development. Everyone has to wrap around the family and be accountable. If the family are not turning up to appointments I know it is my job to support that family and bridge the gap. It can be very scary for a family.

External stakeholder

CHALLENGES IN PROVIDING THE FASD ASSESSMENT PATHWAY

Stakeholders were asked to comment on the challenges of providing the programme. Key themes are summarised below. As with the section above many of these themes apply to the DAP overall.

Waitlist

Feedback from stakeholders indicates that the waitlist (ie the length of the waiting time from referral to assessment) is the most significant challenge for all involved in the DAP, including families, referrers, other professionals and the DAP team. The following comments are typical:

The waitlist is hard to live with. It is a shared responsibility but it's hard on the social workers.

Internal stakeholder

The wait time is difficult for families. Even though they are still receiving therapy, everyone likes to have an answer.

External stakeholder

Awesome service but too long to wait.

External stakeholder

Alongside this there is widespread acceptance that the demand for the programme outstrips capacity and that given the resource constraints the programme is well managed in this respect. There is also acknowledgement from both internal and external stakeholders that the quality and reputation of the programme generates increased demand.

For the DAP FASD Assessment Pathway the "Clinical wait" until the child is eight years old confounds the picture somewhat. Further, assessments are sometimes delayed to accommodate needs that are unrelated to service capacity e.g. the family is undergoing upheaval or the child is about to go to a new school. Stakeholders underscored the need for

an effective system to manage the waitlist, with the ability to prioritise and expedite referrals as required. Within the DAP, expediting of referrals is very carefully considered as the waitlist is long and the DAP Coordinator is highly aware of the team responsibility to manage access for all children. The following comments illustrate these themes:

[The wait list] is partly self-generating – the more people know about the service the more referrals DAP receives.

Internal stakeholder

They see a lot of children and they are good at getting through the numbers.

External stakeholder

The wait time: we understand the reasons for this. In a perfect world it would be great to have no wait time.

External stakeholder

The waiting time is an issue. Because it is such a good service it is a victim of its own success, but they have a good process for prioritising and I'm never really unhappy about it. It is a time consuming assessment and there are only so many hours in a week. We try to control access by allocating to the Paediatric clinic first, so we can get a good history.

External stakeholder

They are under huge pressure. There is a huge waitlist. Partly because it is a very thorough programme. The team give 110%. If there are particular concerns you can contact them and the social worker will visit. They are responsive within their capacity.

External stakeholder

The initial social work visit is a key part of mitigating the wait time and ensuring that families are as well supported as possible during this time. Linked to this are strategies to ensure education and partnerships with the wider CDS and other services are developed and importantly that referrers and others understand processes and issues related to limited capacity.

Its important to educate the bigger team, you can support the bigger team to get things going while kids are waiting for a diagnosis.

Internal stakeholder

The DAP team and the CDS Clinical Leader, in collaboration with the Paediatricians, continuously look for ways to minimise any negative impacts of the waiting time on families. For example:

We have looked at cutting the assessment time. A very small proportion of the kids on the FASD pathway do not get an FASD diagnosis. But it is not about the diagnosis it is about the understanding that the assessment provides.

Internal stakeholder

It's a horrible aspect of the programme; we give support to people on the waitlist - nobody is nowhere.

Internal stakeholder

In 2014 the programme won a Hawke's Bay DHB Excellence in Service Improvement Award for their *Improving Waitlist Management* project. Strategies for improvement addressed several domains including the child and family; referrers; the DAP and the CDS.

Data from consumer satisfaction surveys shows that family concern with wait times and support during that wait period are decreasing. For example consumer satisfaction surveys show that the proportion of those who stated the wait time was far too long has dropped from 75% in 2010 to 12% in 2011. Further the proportion of those who reported they had no services during the wait time dropped from 40% to 11% in the same period (Frechtling, 2014).

Lack of Post-assessment Support for the FASD Assessment Pathway

Almost all stakeholders explicitly referred to the lack of post-assessment support for children, families and schools as a critical issue and a limitation of the FASD Assessment Pathway model. Many of those with an FASD face limited understanding in the community and limited or no access to ongoing support. There is more support available for those with an FASD who have an intellectual disability.

You get the diagnosis, then the explanation and then what? For FASD there is an epidemic and a major gap in services. It is complex work and there are no resources. Some can get support and some can't [depending on the nature of the disability]. Families are struggling. This is a concern – it is not the DAP team's fault.

External stakeholder

Being an assessment only service you get a better understanding of the needs but there are limited therapy options. This is a gap.

External stakeholder

FASD is a sticking point. [Service is not available] if they don't have an ID. Previously the situation was the same for people with ASD; now ... those kids [have access to services and supports] and I daresay this will happen with the FASD kids in future.

External stakeholder

DAP is not an ongoing therapeutic process, the point is to put the recommendations in place. Case by case they are pretty good at being involved.

External stakeholder

Assessment Reports

Linked to the point above many stakeholders commented on the lengthy and complex nature of the assessment reports and discussed concerns about the extent to which families and

school personnel can understand and make use of the information contained in them. The role of professionals in supporting the families in an ongoing way was noted. For example:

The assessments can be very wordy. Families need support to understand.

External stakeholder

Sometimes the recommendations come through and schools don't really read the report. They take a long time to read and schools don't have the time. Sometimes they don't have the understanding to make the report meaningful.

External stakeholder

It can be difficult to bring all of those disciplines together [professional perspectives] in one report. The report used to be lengthy – I know they are working on that.

External stakeholder

Helping the families understand the issues can be a challenge. Families tend to be more towards the lower socio-economic, lower health literacy end of the continuum. Communicating the findings of the assessment process can be a challenge. The family gets the report and the feedback session (1 hour with 2 professionals) – the feedback to the school is very important because the school has a longer relationship and can help families with the understanding.

External stakeholder

Those in the DAP team described ongoing efforts to make the reports “user friendly” and also the tension between this and the need to ensure the evidential information is presented in such a way as to demonstrate that the assessment findings are sound and that all facets of the assessment are fully reported. Internally this is an area that the team are continuously striving to improve on. For example:

Streamlining the reports can be hard.

Internal stakeholder

Do the assessments follow the child?.....There can be tensions in developing a report that is professionally acceptable (meets professional standards) and is user friendly. There is a balance - I think we are growing in our ability to write the report for the child/family - shorter and more user-friendly.

Internal stakeholder

Team support

The need for team support was noted by some Internal stakeholders. Key issues include the challenge of managing team dynamics in a small team that works very closely; the need to support staff who are working in the challenging area of FASD, the importance of access to external supervision and the challenges in finding supervision and ongoing professional development opportunities in such a specialised field. The following comments reflect these themes:

Personalities can be a challenge. The team needs to work very closely and develop a lot of trust. It can be challenging.

Internal stakeholder

The FASD cohort can be challenging. Clinicians need to be held/supported. There is a lot of neglect, abuse, parents are not OK, teachers are stressed. A lot of clinical time is needed to work with all the people involved. One phone call is now four. There is a lot of emotional baggage attached to FASD – this is new for [those in my profession].

Internal stakeholder

Clinical supervision can be hard to access. No one does this work here. It's a consideration for professional practice requirements.

Internal stakeholder

It can be a struggle to get training opportunities. You have to find ways to do it yourself. E.g. on-line linking and information sharing with [other professionals] overseas working with FASD.

Internal stakeholder

Disconnect between Health and Education Approaches

The differences between the health and education sector approaches was raised as a challenge by both internal and external stakeholders. The focus on diagnosis is predominant in health sector approaches and is not a comfortable fit with the education sector approach where the focus is viewed as being more on functional impact in the learning environment. This is sometimes seen as a “mismatch”. There is acknowledgement on both sides that ongoing collaboration and communication are critical to ensure best use of resources. For example:

Getting a label sometimes leads to the teacher saying “I’m not qualified to work with this.” Sometimes attitudes and beliefs come through. With FASD children it can be hard for schools to get their heads around it.We focus on presence, participation and learning. DAP do different assessments from us, working together and sharing information is helpful. We do ecological assessment looking at the student’s needs and the school environment and identifying if there is a mismatch – we don’t do testing. Sometimes the DAP reports and the education reports are a mismatch. Sometimes DAP reports can set lower expectations. This is just my experience – tomorrow I could have a different experience...you really have to work at

understanding each other. There has to be open communication, you can't be precious. You have to reflect on your own practice.

External stakeholder

....Eg. the inter-agency developmental disorders group – working with Ministry of Education to build understanding of respective roles, identify areas of agreement and common ground. These relationships build over time. It is important to give a service-level message of collaboration. It's important to get your consents working so that you can share information. Co-author reports with Education – it avoids duplication. It is easier to do this in smaller centres.

Internal stakeholder

Engaging families

Stakeholders commented that it can be a challenge to engage families for a range of reasons including fear of the assessment, having different priorities from professionals and being transient or highly mobile. It was suggested that support from those outside the DAP is essential to assist in these issues and this underscores the importance of developing strong community networks and working collaboratively. The following comments illustrate this point:

Some families are very hard to engage. Some you need to work with for a long time to know their limits. Quite often we work as a conduit [eg. between DAP and family].

External stakeholder

[DAP] don't know the families well so they don't always get how limited a family is in their understanding and their ability to follow through. It needs to be very simple.

External stakeholder

There is a fear of the unknown [for families] initially but once they get to sit down its non-threatening and not stressful. Sometimes it's not what the parents want to hear but they accept it. They get pre-warning...some warm-up.

External stakeholder

The mobility/transient population is a problem. Families move and they can be difficult to contact. A lot of time and effort can be wasted. Being connected to the community is a big help with that. Networks are important.

External stakeholder

Family and professional priorities are sometimes not the same.

External stakeholder

Cultural responsiveness

Stakeholder feedback indicates that the DAP team work well with Māori whānau and with families of all cultures. All stakeholders also acknowledged that there is always scope for further development. There is agreement that cultural responsiveness is a vital aspect of the DAP. For example:

They work quite well cross culturally. They try to offer alternatives.

External stakeholder

Working with Māori: They're [DAP team members] very careful about making sure they are meeting everyone's needs in relation to the testing. They're quite tuned in to that.

External stakeholder

Most of the families are Māori – there is no issue there.....its the other culture..... gangs, poverty etc

External stakeholder

I think they're good. Never any complaints from parents.

External stakeholder

For Māori its about seeing the culture, feeling respected, feeling connected and about caring. Hospitality is important – a cup of tea. It would be good to have Kuia and Kaumatua more involved.... We have used the whare for the family feedback session. This was good. It's a good place for the family to be supported when they are getting the feedback.

External stakeholder

Internal stakeholders commented that working effectively with Māori is an area of ongoing development for the DAP team and that this is a priority. For example the CDS is working with the Māori Health Service to develop a cultural competency pathway for staff.

Both internal and external stakeholders noted that previously there was a designated Māori Kaitakawaenga role integrated within the CDS and that role is now located in the DHB Māori Service and operating at a more systemic level. It was acknowledged that there are benefits and downsides with either approach and that when the role was within the team there was opportunity for more “on the spot” involvement. It was suggested that in setting up any new programme consultation with Iwi Māori at the outset would strengthen the programme.

Additionally co-working with the Pacific Island liaison nurse is viewed as working well. It was suggested that Pasifika families need support to promote their engagement in the programme and it is useful to have a Pacific health professional involved. For example:

Having the Pacific Island liaison role is important – you need a nursing background, so you can explain to the family why the child must attend the clinic. If you have the nursing background/qualifications you have the credibility with the community. Otherwise they are saying “who are you to tell us what to do.”

*Encourage Pacific families to step up and be responsible, then give them the tools to do it.
Families need to know what they need to do and why so they can help their child in the home.*

External stakeholder

Other challenges

Other challenges were highlighted by individuals or small numbers of stakeholders. These include:

- Cost: It was noted that the overall DAP model is resource intensive and therefore staff costs are high, however it was seen to be a model that is worth the investment.
- Professional role satisfaction: There is a need to ensure that professional roles are sufficiently rewarding. This is an area that the CDS and DAP strive to address through active management which seeks flexibility for staff while ensuring that the imperatives of programme delivery are paramount.
- Stigma: There is a significant and unhelpful level of stigma associated with FASD, particularly for the birth mother. The DAP team operates from a strong non-stigmatising position and ensure a high level of sensitivity in all communications.
- Invisibility of the FASD population: Linked to the point above, there is a lack of understanding and a lack of research in the area of FASD.

STRONG SUPPORT FOR REPLICATING THE APPROACH IN OTHER AREAS

All stakeholders support more DAP-like services, including the FASD Assessment Pathway, being offered in other parts of New Zealand. The programme is seen as highly valuable in supporting children, families and whānau and professionals and services across education, health and social service sectors to respond effectively to children with significant needs. For example:

Definitely DAP teams should be available in other areas. I talk to RTLBs in other areas and they are very envious of what we have. I can speak for my colleagues on this – we are very lucky in Hawke's Bay to have this resource.

External stakeholder

Support like this service is definitely needed in other parts of the country. Early detection and early intervention is essential. Families are under pressure.

External stakeholder

I absolutely support replication of the DAP Programme in other areas. You need to get the right personalities. They are respectful of everybody. The culture in that place would be hard to replicate.

External stakeholder

DISCUSSION AND CONCLUSION

The information summarised in this report suggests that the DAP FASD Assessment Pathway provides an example of a best-practice approach that contributes to reducing harm and promoting health and well-being for children at risk. Findings indicate that the DAP FASD Assessment Pathway is operating as intended and is successfully engaging the intended target audience. The model aligns with government goals for improved outcomes for children as outlined in the *White Paper on Vulnerable Children Volume 1*, which calls for approaches that identify, assess and link our most vulnerable children to services early and effectively (Ministry of Social Development, 2012). The DAP FASD Assessment Pathway provides a highly specialised service that is not available to children, families and whānau in all areas of New Zealand.

An outcomes evaluation would be needed to provide further information about the outcomes for those who participate in the programme, however on the basis of the information available at present a number of conclusions may be drawn as outlined below.

CORE COMPONENTS LINKED TO SUCCESS

The DAP FASD Assessment Pathway is clearly identifying children with FASDs. It is engaging children and families living in low decile areas and engaging a high number of Māori whānau. Further, the Pathway has a reach into homes and schools. The following components have been identified as being linked to the success of the Pathway.

1. The Model. Critical aspects of the model have been identified as follows:
 - *Shared vision and values:* These include being child focussed, collaborating with families, whānau, other professionals and services and adopting a strong non-stigmatising approach that promotes respect for all. Additionally the model aims to be culturally responsive.
 - *Best-practice multi-disciplinary approach:* The DAP FASD Assessment Pathway reflects a best-practice approach to FASD assessment as supported by the Canadian Guidelines (Chudley et al, 2005).
 - *A synthesised report and feedback sessions:* The provision of a comprehensive report and face-to-face feedback sessions are crucial to the effectiveness of the programme.
 - *A team approach.* The DAP functions as a team, co-working and supporting the implementation of the FASD Pathway together. Shared vision and values, the DAP Intake meeting, the multi-disciplinary assessment process, the consensus based DAP formulation process, the synthesised report and the co-presented Feedback Sessions all provide mechanisms by which the team approach is given effect.
 - *Close working relationship with Paediatricians:* This is an essential component of the approach. Paediatricians provide the ongoing oversight for the child and their family/whānau. Close working relationships support the implementation of the FASD Assessment Pathway and maximise the impact of the assessment findings and recommendations. Co-location is optimal if this is possible.

- *Strong effective relationships with other services:* The model relies on collaboration with other professionals and services to refer children, to provide input and support the assessment process and to support implementation of the recommendations.
 - *Building capacity through training:* The mandate for the DAP to provide training to other professionals, thus sharing the knowledge, is essential to the working of the clinical component of the pathway.
2. Workforce, infrastructure and service context. The DAP FASD Assessment Pathway is provided by a highly skilled and experienced professional team supported by strong leadership and is sited within a larger child development service and a robust organisation. This contributes to a high quality and sustainable programme. Specific training in FASD Assessment is essential. It would not seem possible or advisable to provide an FASD Assessment Pathway as a stand-alone programme. Situating the specialised assessment pathway within a child development service is widely viewed as a way of providing an effective continuum of service for children, enabling flexibility and effective use of resources and contributing to programme sustainably.

LESSONS LEARNED AND CONSIDERATIONS FOR REPLICATION OF THE APPROACH

The following provide important considerations for replication of FASD assessment programmes.

Waitlist management. Active waitlist management is likely to be required. The DAP experience demonstrates that providing an early social work visit to assist families and whānau who are waiting for assessment is one important element of waitlist management. Additionally it is important to maintain strong relationships with referrers and other services. This supports all stakeholders to understand and live with service constraints so that the programme does not become overwhelmed, programme staff do not become overly demoralised and families are not left isolated and without support.

Post-assessment support to assist in implementation of recommendations. There is broad consensus that the lack of post-assessment support is a limitation of the DAP FASD Assessment Pathway. Those diagnosed with Autism Spectrum Disorder (ASD) by the DAP are supported by an ASD Coordinator in the post-assessment phase (via a contract under the Ministry of Health Service Specification DSS221). If this could be mirrored in the FASD Pathway the pathway would be significantly strengthened. This would need to be enabled via funding provisions.

Streamlining reports. The DAP team and external stakeholders have all identified the need to continue to refine the assessment reports so that they are both comprehensive and as 'user-friendly' as possible. Any similar assessment programme will face this challenge. Consulting with the Hawke's Bay DAP team to draw maximum benefit from their experience is likely to be helpful.

Cultural responsiveness. Any FASD assessment programme needs to demonstrate cultural responsiveness to Māori, Pasifika and people of all cultures. Partnering with Māori and Pasifika in the programme set-up phase is recommended to ensure all aspects of the programme are designed to maximise responsiveness.

Ongoing development of partnerships. An effective FASD Assessment Pathway must work across sectors, and the involvement of the Education sector is critical. Stakeholders have highlighted the challenge in aligning the health and education paradigms and the DAP experience of purposeful collaboration and partnership development appears to be making good headway.

Team support. The FASD Assessment Pathway relies on a skilled and experienced team of professionals who are prepared to work closely as team. The evaluation has highlighted that this is not a typical way of working and that it relies on a culture of strong professionalism, collaboration, collegial respect and openness. This culture needs to be supported and built. Careful consideration needs to be given to supporting a specialist team and providing opportunities for ongoing professional development.

CONCLUSION

Stakeholders universally support expanding the provision of FASD assessment opportunities within DAP-type programmes. The experience that has accrued from the DAP FASD Assessment Pathway provides a useful blueprint for other programmes. The strengths identified, lessons learned and the expertise now available within the DAP could provide invaluable support for further development.

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