

Evaluation of the Fetal Alcohol Assessment & Support Team

Summary Report

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Dr Fiona McGruer, PHD.

Dedicated to
Dr. John P. McClure (MBE)
In memoriam



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Executive Summary

1. Background

- Fetal Alcohol Spectrum Disorder (FASD) is a key national concern:
 - FASD **may affect up to 6% of children and young people in Scotland**
 - FASD is the most common cause of neurodisability in the Western world.
 - It is present at around 3-6 times the rate of Autism Spectrum Disorder in the UK.
 - FASD remains vastly under-reported and under-diagnosed in Scotland.
- The NHS Ayrshire and Arran Fetal Alcohol Assessment and Support Team (FAAST) were tasked with piloting an assessment and diagnosis pathway for those affected by FASD (**Figure 1**).

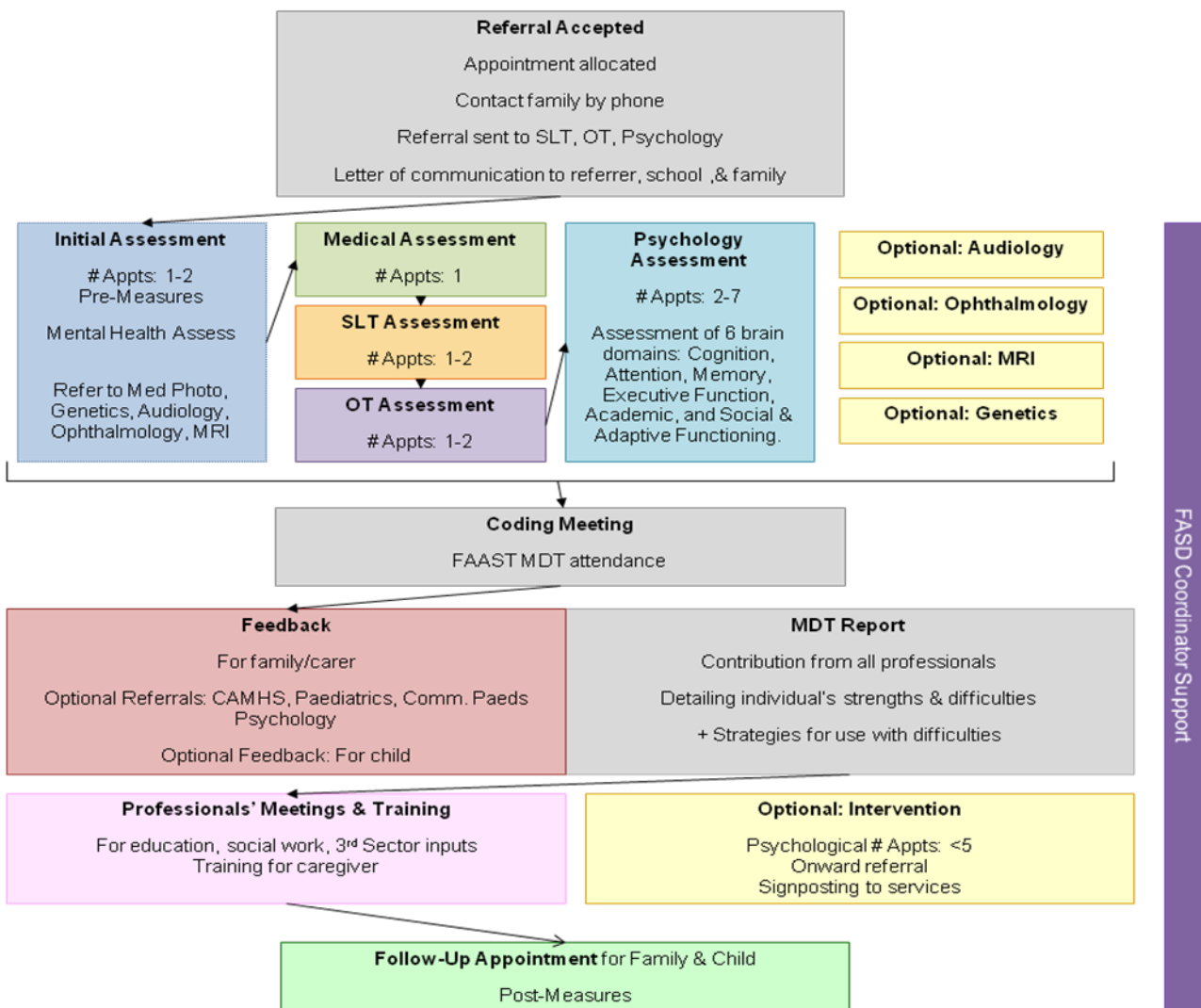


Figure 1. FAAST Clinical Pathway

- This multidisciplinary team comprises a Paediatrician, Clinical Psychologist, Occupational Therapists, Speech and Language Therapists and FASD Co-ordinator (**Figure 2**).

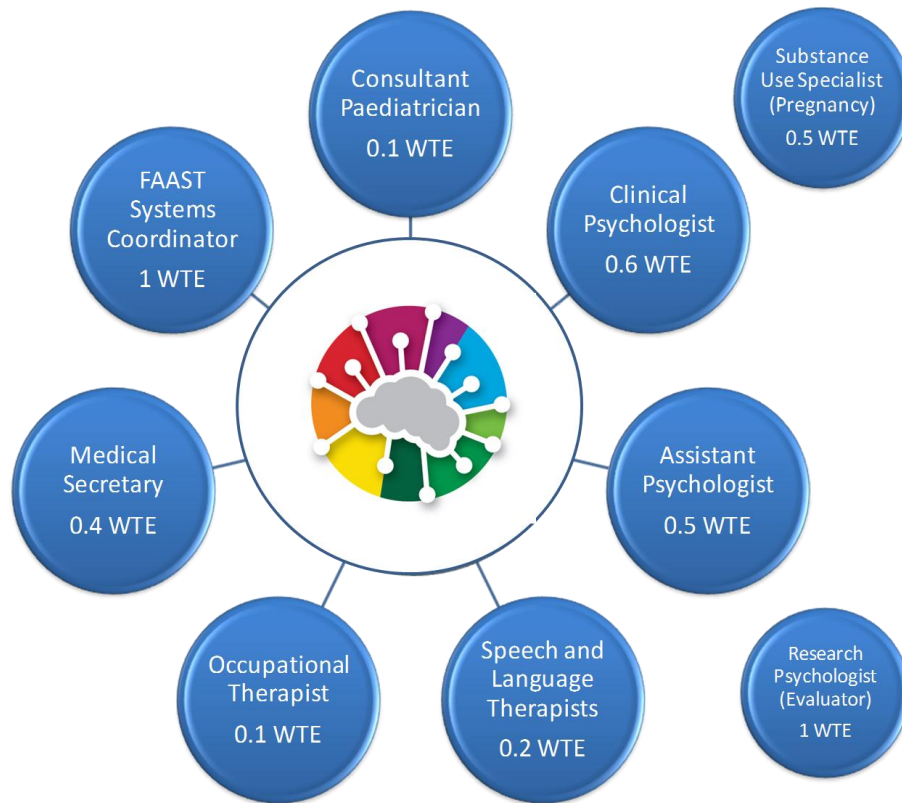


Figure 2. FAAS Team Members

2. Methods

- A ‘trident’ approach (Ellis and Hogard, 2006) was used to evaluate the FAAS Team (Figure 3).
 - This approach involves:
 - Describing and analysing process.
 - Measuring outcomes.
 - Sampling the views of stakeholders.

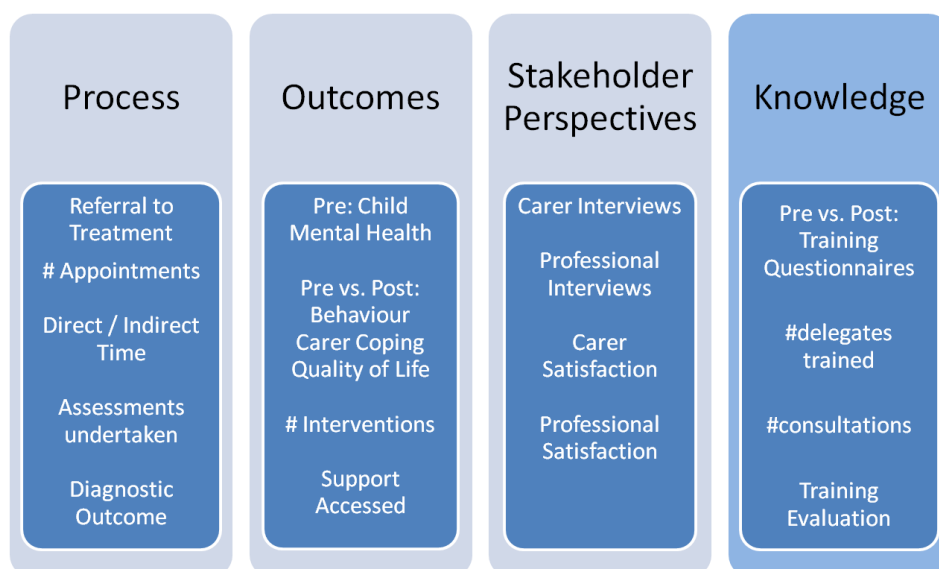


Figure 3. Final Framework of Service Evaluation

- This was carried out for two pathways available to children prenatally exposed to alcohol – assessment and support through the FAAS Team pilot and through ‘treatment as usual’ services (CAMHS and Community Paediatrics).

3.1. Process

- **Approximately 200 children have been assessed currently or historically in relation to FASD in NHS Ayrshire and Arran.**
- These children and families come from all over Ayrshire.
- The majority are looked after and accommodated.
- Many have additional difficulties arising from trauma, neglect, and abuse.
- They may or may not have a formally confirmed alcohol history.

- **Affected children have a history of multiple referrals to services - FASD is not necessarily considered on their first referral.**
- The assessment process varies greatly between FAAS services and each separate ‘treatment as usual’ service (CAMHS and Community Paediatrics).
- Children are often referred between services even once in the healthcare system for assessment.

- **Assessment of neurodevelopmental strengths and difficulties is central to accessing appropriate supports for these children.**
- Comprehensive assessment of FASD requires inputs from several multidisciplinary professions.
- This assessment can require up to 15 hours of clinical time.
- Children in both services were assessed using a robust and diverse range of measures.
- Services took a great deal of time to assess and diagnose these children.
- Treatment as usual services may struggle to access multidisciplinary staff for their cases.
- Children affected by alcohol exposure often require mental health risk assessment and management alongside neurodevelopmental assessment.

- **Affected children meet criteria for diagnoses across the FASD spectrum.**
- Treatment as usual services are not as likely as FAAS to give a formal diagnosis related to prenatal alcohol exposure - this may be due to fewer children having notable impairments, or it may be that clinicians are less confident conferring these diagnoses.
- Children can also meet criteria for other diagnosable difficulties, such as Autism Spectrum Disorder or Attention Deficit Hyperactivity Disorder (ADHD).

- **ADHD is a very common additional diagnosis often conferred before the child’s FASD diagnosis.**
- Other biological and non-biological contributions to a child’s presentation should always be considered in formulating their difficulties.

- The FAAS Team helped children and families gain access to many different forms of support and intervention.
- Both teams were slow to discharge these children; however reports were an area of particular difficulty for the FAAS Team.
- The FAAS Team's PDSA cycles suggested that:
 - **Both children and carers of this population can require risk assessment.**
 - Referral processes and delivery of FASD assessments must be carefully considered
 - Affected children and carers require ongoing support and intervention.
 - There remains a training need around FASD in Ayrshire and Arran.

3.2. Mental Health and Wellbeing Outcomes


- **Affected children report less resilience, less achievement and more risk taking than other children.**
- They do not seem anxious or depressed on screening, but **around a third of pilot children** (under 12 years old) **expressed suicidal ideation.**
- Carers of children who are alcohol exposed can cope well with parenting their children.
- Carers experience relatively low depression, anxiety and stress, despite reporting a high amount of difficult behaviours in their children.
- It is important that services which work with these children have the resources to understand and manage this risk.

3.3. Stakeholder Perspectives

- Carers reported a **history of struggling to access services for their child.**
- Stakeholder perspectives spoke to a high satisfaction with the FAAS service.
- They felt that both their parenting and their child had been judged in the past.
- In contrast, they **felt heard in the FAAS service** and welcomed an understanding of their child and the opportunities that diagnosis could bring.
- Education professionals felt a **need for more strategies to work with these children** and for strong collaboration between clinicians and educational professionals.
- They described **barriers to adapting to meet the needs of affected young people.**

4. Implications and Recommendations

- Whilst the FAAS pilot project completed good work, **their work is not sustainable.**
- Times when resources were reduced had a large impact on service provision.
- Risk management was difficult in a team with only one qualified mental health professional. Additionally, the awareness and need for FASD assessment is growing nationally.
- This service evaluation therefore proposes that **FASD be managed in the context of wider neurodevelopmental services and mental health teams** in mainstream services.

- 
- In NHS Ayrshire and Arran, **child FASD assessment and diagnosis has now been fully integrated into Child Services (CAMHS and Community Paediatrics)**.
 - This has been achieved as a result of FAAS Team training and consultancy.
 - Ongoing training and consultancy will likely be required to support this implementation.
 - The FAAS Team efforts have largely focused on professionals in Child Services in this health board. **Given that FASD is a lifelong condition there remains a need for training and consultancy in Adult Services**, in order to facilitate diagnosis later in life and support for those affected as they age.
 - Additionally, as those involved with the criminal justice system are a high risk population for prenatal alcohol exposure, there is **a need for training and consultancy for Forensic Services**.

 - **Equal provision of FASD services is not yet in place across NHS Scotland.**
 - The Team are aware of families in other Scottish health boards who have been unable to access services for their child.
 - Health, education, and social care professionals across Scotland may lack knowledge and confidence about FASD assessment and diagnosis, as was the case in NHS Ayrshire and Arran prior to the work of the pilot team.
 - Service pathways across NHS Scotland may not support the broad multidisciplinary neurodevelopmental assessment provision recommended for FASD cases.
 - Given the impact that a lack of access to services has on carers and their children, **it is suggested that FASD care becomes available nationwide**.
 - This directive will require a dedicated training and consultancy resource, regarding not only identification, assessment, and diagnosis, but also intervention and support, and service pathway design.

Chapter Summary: Process

Characteristics of Children Assessed

- There are approximately **200 children known to have accessed assessment in relation to PAE** in NHS Ayrshire and Arran.
- FFAST (36) and TAU group (18) children differed by their gender and they area of Ayrshire they lived in (**Figure 4, Figure 5**).
- **Most children under assessment for FASD are looked after and accommodated.**
- **80-90% of each group had a known / confirmed alcohol history.**

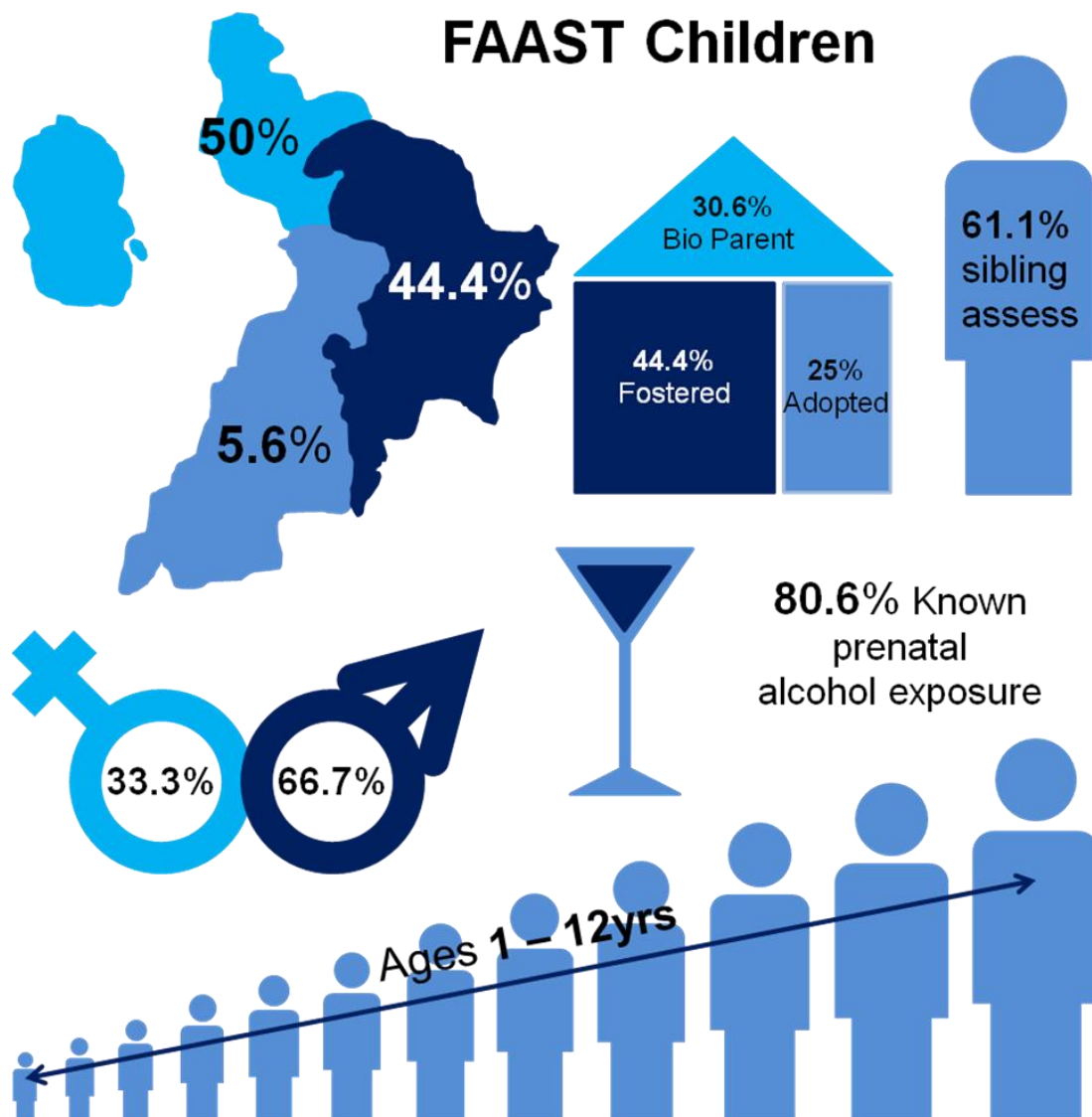


Figure 4. Demographics of FFAST Pilot Children

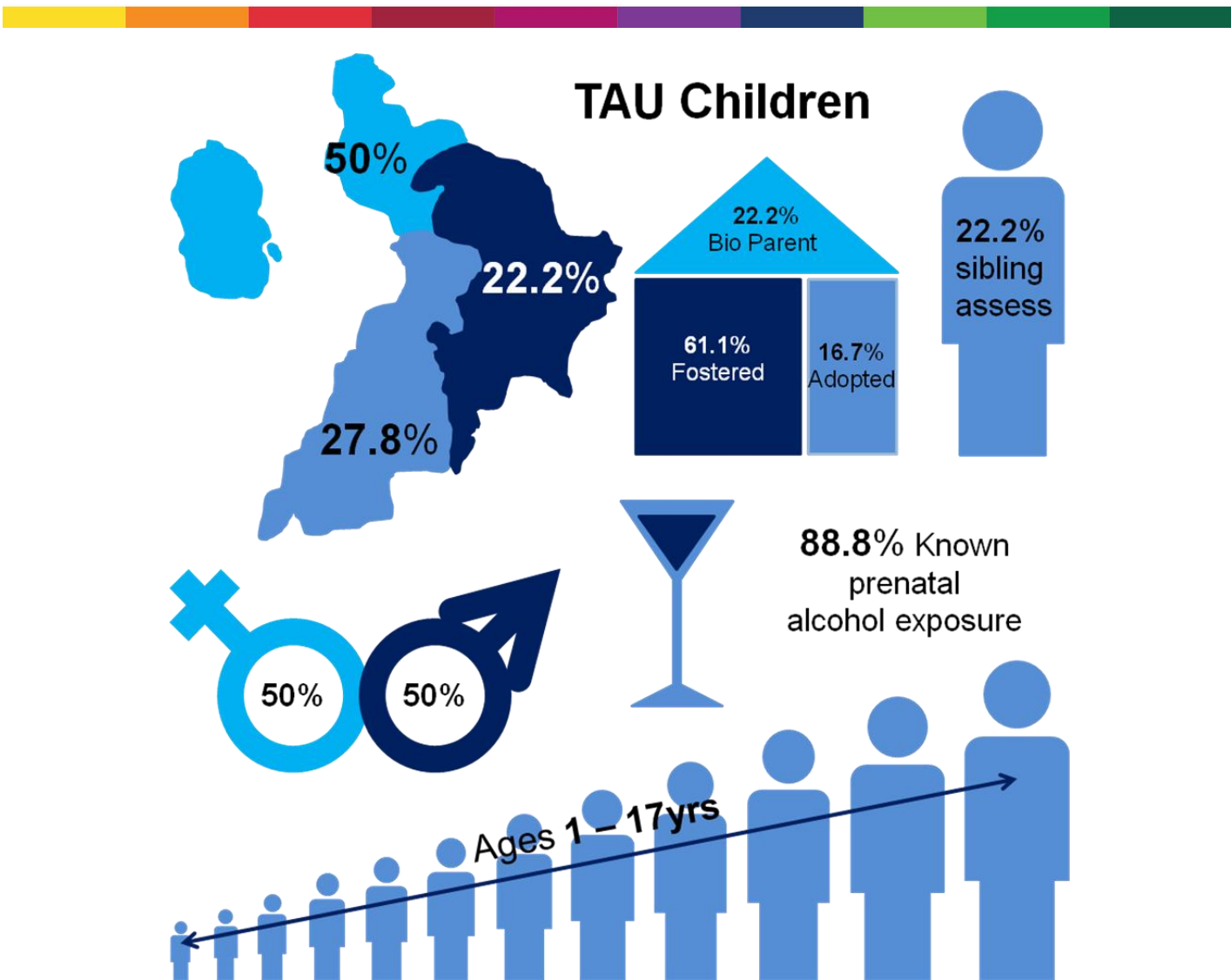


Figure 5. Demographics of TAU children

- FAAST group children often had a **history of trauma, neglect, or attachment difficulties** (see **Figure 6**).
- The overall process of assessment and intervention was **different between FAAST services and each separate TAU service**.
- Children were **often referred between TAU services**, so their process reflected aspects of each of these services (CAMHS and Community Paediatrics).

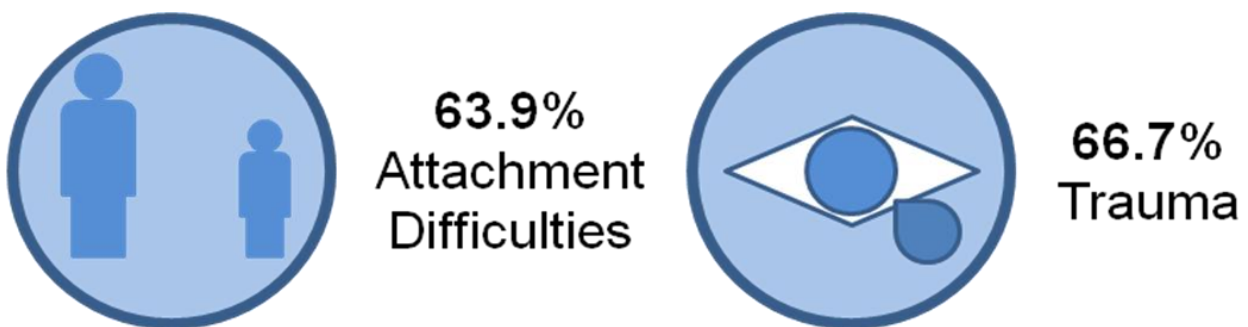


Figure 6. Attachment Difficulties, Neglect, and Trauma in FAAST Group Children

The Process: Referral

- Referral sources were similar between groups (**Figure 7**).

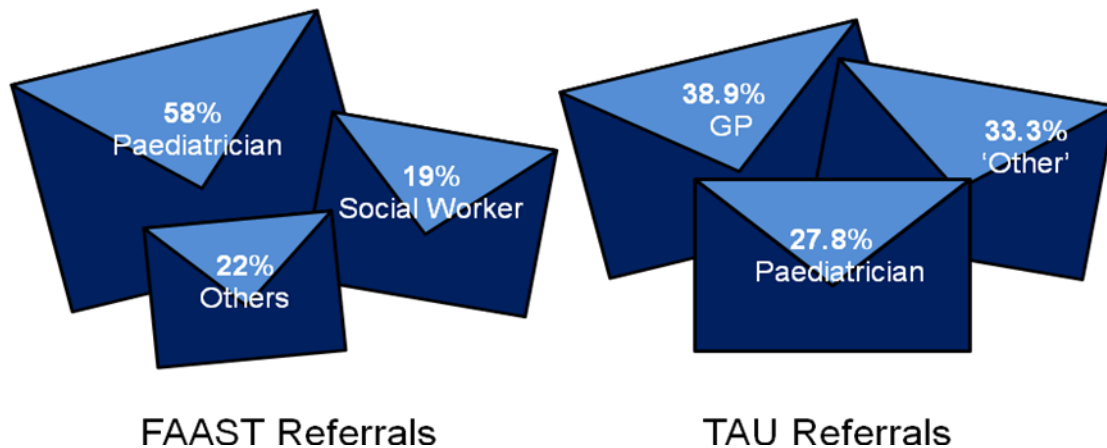


Figure 7. Referral Sources for FFAST and TAU Cases

- 50% of children in TAU services had been **referred previously** and the **mean time between these referrals was ~2 - 4 years** (**Figure 8, Figure 9**).

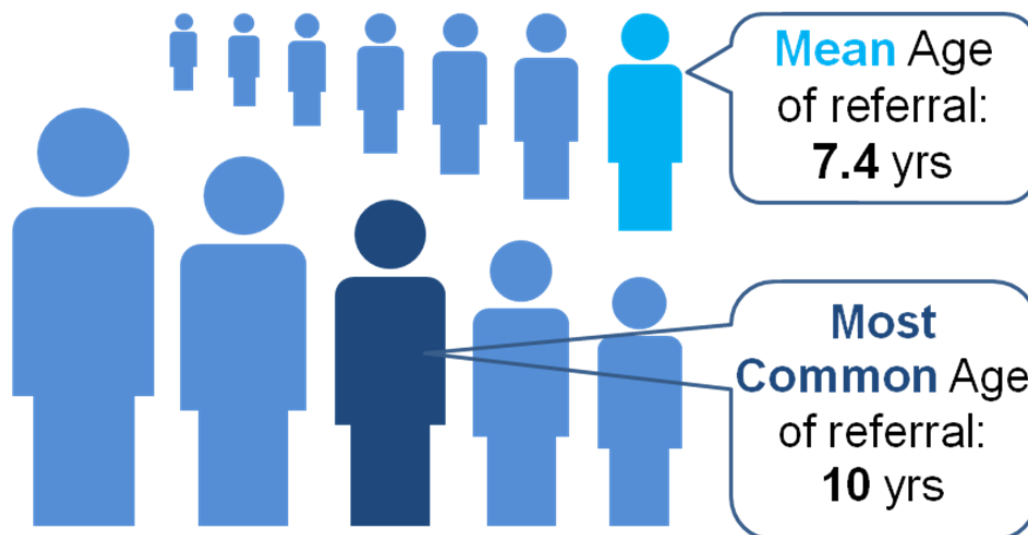


Figure 8. Age of FFAST Cases on Referral

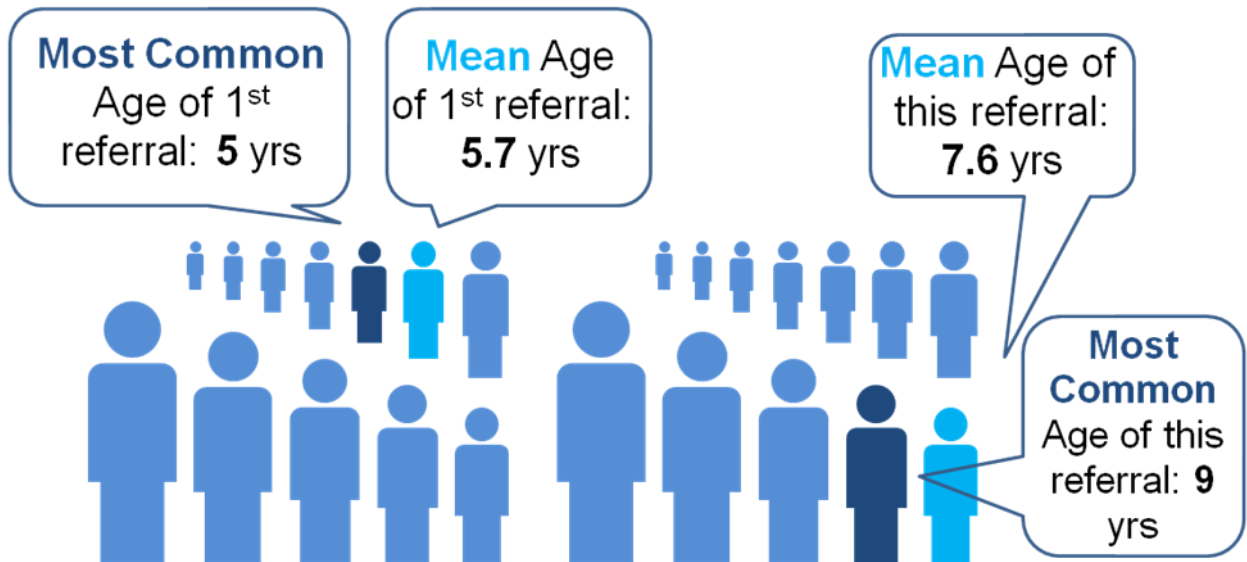


Figure 9. Age of TAU Cases on First Referral and Relevant Referral

- **Female children were typically referred later in life** than male children.
- The referral to initial assessment wait was similar for FFAST and TAU services.

The Process: Assessment

- Full assessment of FASD took **12.9 hours** for those assessed by FFAST and **15 hours** for those assessed by TAU services (Figure 10).
- In both services, **psychology assessment comprised the most direct clinician time.**

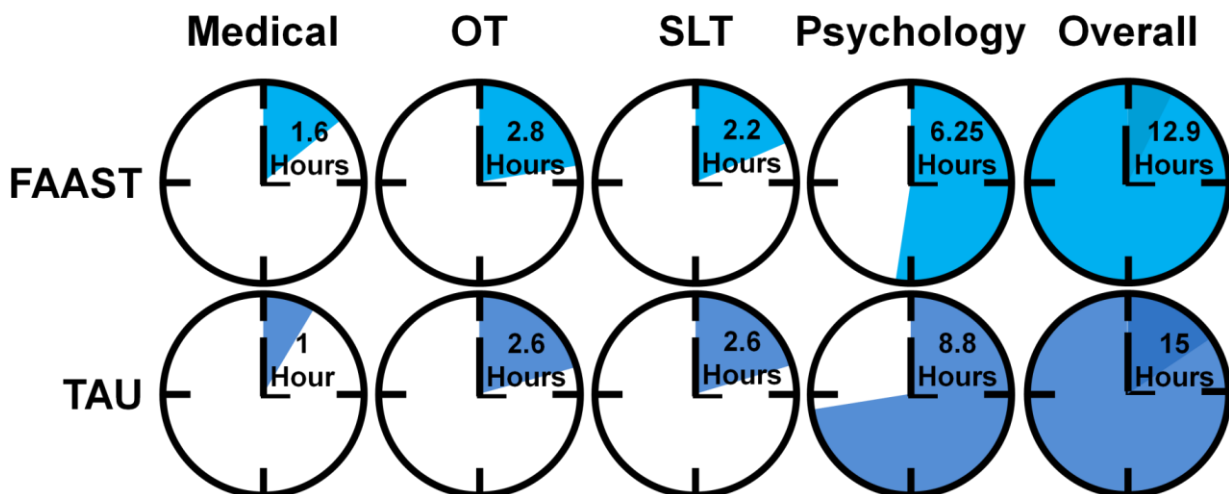


Figure 10. Overall Assessment Time by Assessment Discipline and Overall

- Children in FFAST services had access to more assessing disciplines.
- DNAs had a large impact on all assessment timing.
- Children in TAU services had their medical assessment a lot later into their process.
- FFAST children **received more medical onward referrals** than TAU children (Figure 11).

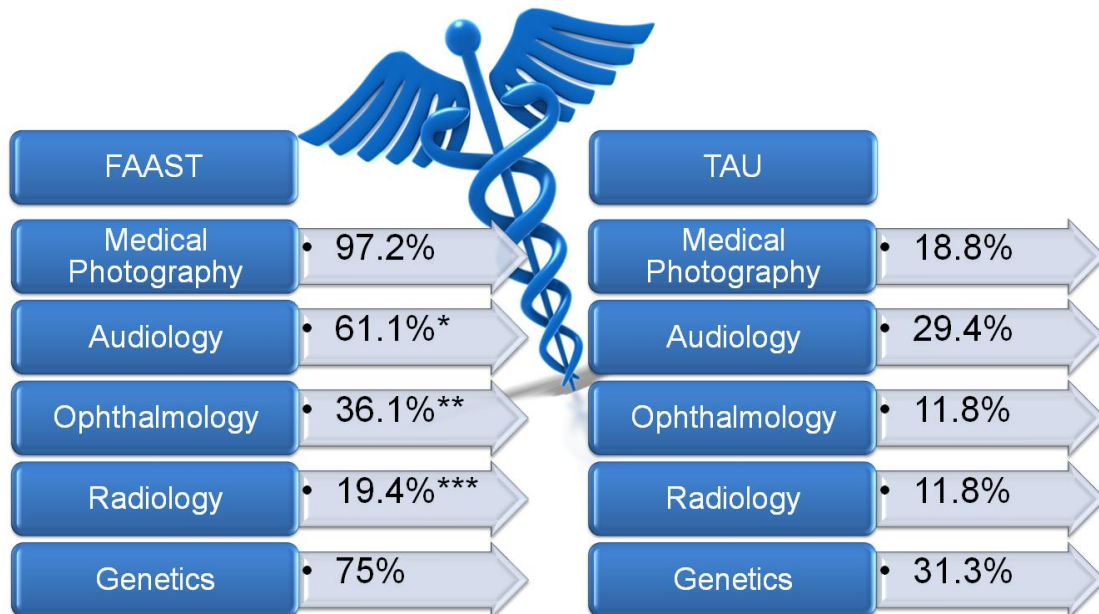


Figure 11. Onward Referrals from Medical Assessment

- TAU children typically had OT assessment later than FAAST children.
- Some TAU group children had more OT assessments than FAAST children (**Figure 12**).
- TAU children were less likely to have a sensory sensitivity assessment by OT.

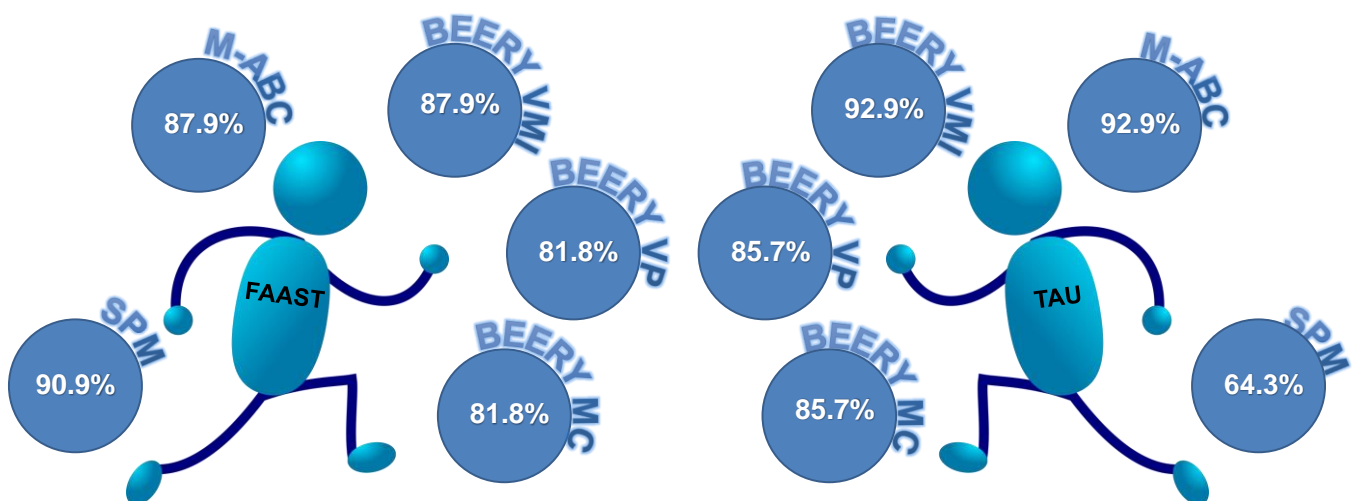


Figure 12. Formal Assessments Used by Occupational Therapy

- TAU children typically had SLT assessment later than FAAST children.
- TAU group children had more SLT assessment time than FAAST children.

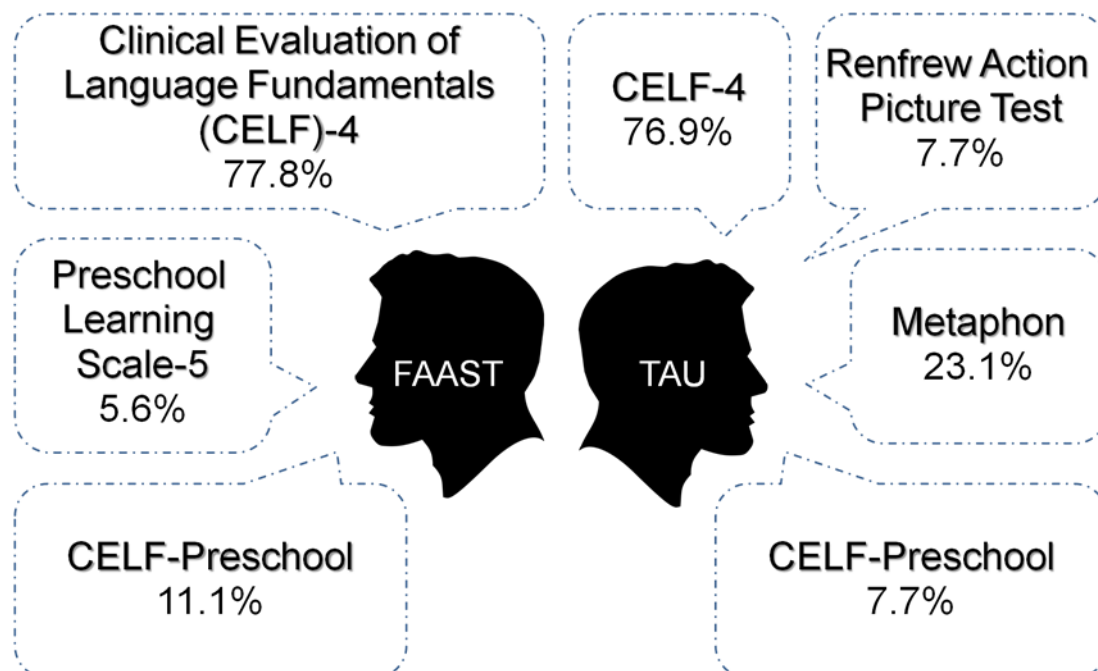


Figure 13. Formal Assessment Used by Speech & Language Therapy

- Many TAU **group children had received psychological input prior to FASD assessment.**
- TAU group children needed more psychology assessment (this likely reflects case complexity and mental health risk)
- Some TAU children had a large wait from initial assessment to psychology assessment. This was due to children who had intervention prior to clinicians being aware of the need for neurodevelopmental assessment.
- **Children in both services were assessed using a robust and diverse range of formal/standardised assessment measures.**
- The FFAST pilot project aimed to provide very comprehensive neuropsychological assessment, using formal assessment tools wherever possible (**Figure 14**). Children in TAU services received selected neuroassessment when this was clinically indicated (**Figure 15**).



Figure 14. Formal Assessment Used by Psychology for FFAST Group Children

- Figures 14 and 15 show the brain domains assessed (structure, academic performance, adaptive function, executive function, memory, cognition, attention, and social perception) and which neurodevelopmental tests were used to formally assess these.
- The use of formal executive function measures was higher in the FFAST group.



Figure 15. Formal Assessment Used by Psychology for TAU Group Children

The Process: Intervention

- **TAU children had more extensive psychological intervention.** This was likely due to the limited resource of the FAAS Team - several FAAS children were either referred to CAMHS or already received CAMHS intervention (by Psychology or Psychotherapy).
- Many TAU children had accessed Psychiatry input (55.6%), mostly for ADHD management.
- Many FAAS and TAU children had accessed Psychotherapy.
- **A large amount of Psychotherapeutic resource was used prior to the child's strengths and difficulties being understood,** this could reduce the efficacy of this intervention.

The Process: Diagnosis

- FAAS group children were coded more quickly following assessment, likely due to easier access to coding meetings.

- Few children met criteria for Fetal Alcohol Syndrome, many more met criteria for Fetal Alcohol Spectrum Disorder.
- **Children affected by prenatal alcohol exposure (PAE) can meet criteria for other diagnosable difficulties (Figure 16, Figure 17).**

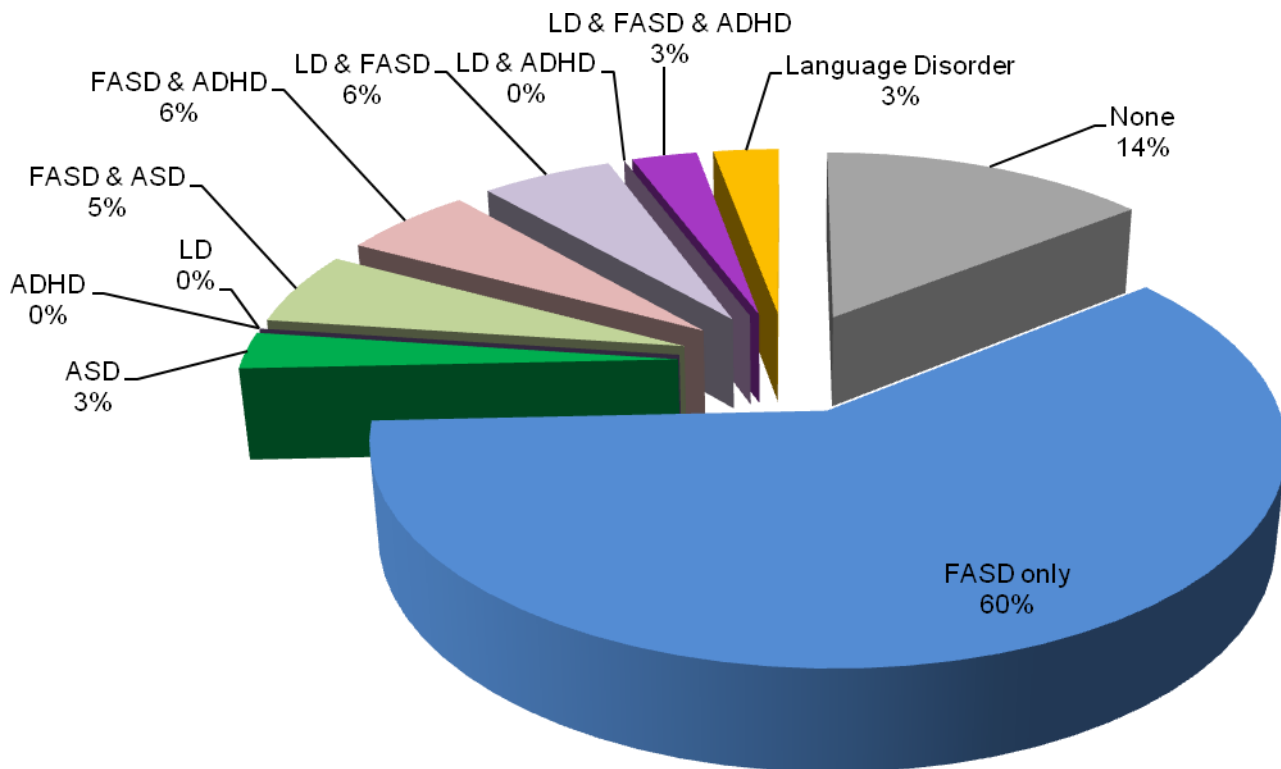


Figure 16. Outcome Diagnoses for FFAST group

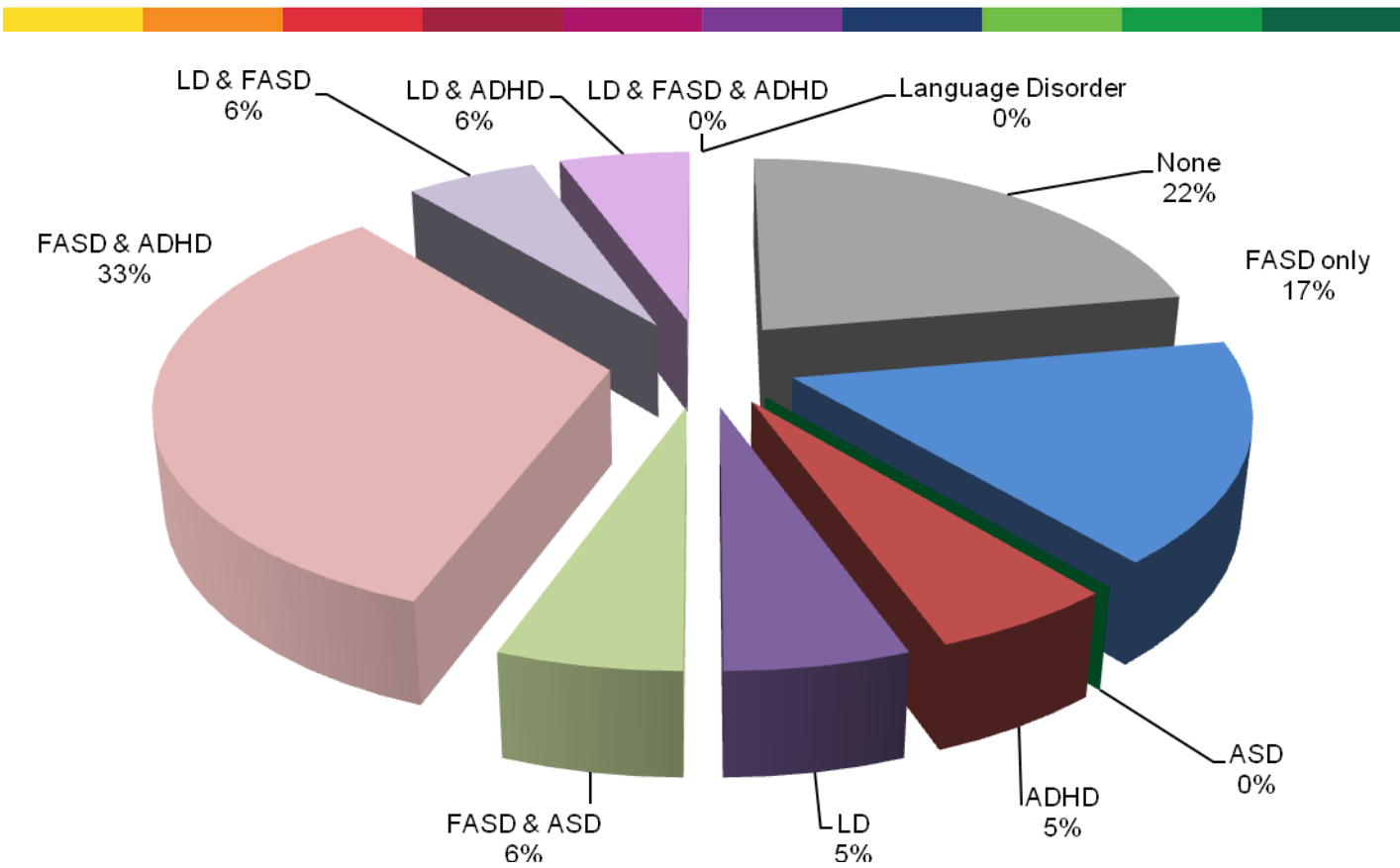


Figure 17. Outcome Diagnoses for TAU group

- **TAU services are not as likely to give a diagnosis related to PAE** (this may be due to fewer children having notable impairments, or may be due to less confidence giving these diagnoses).

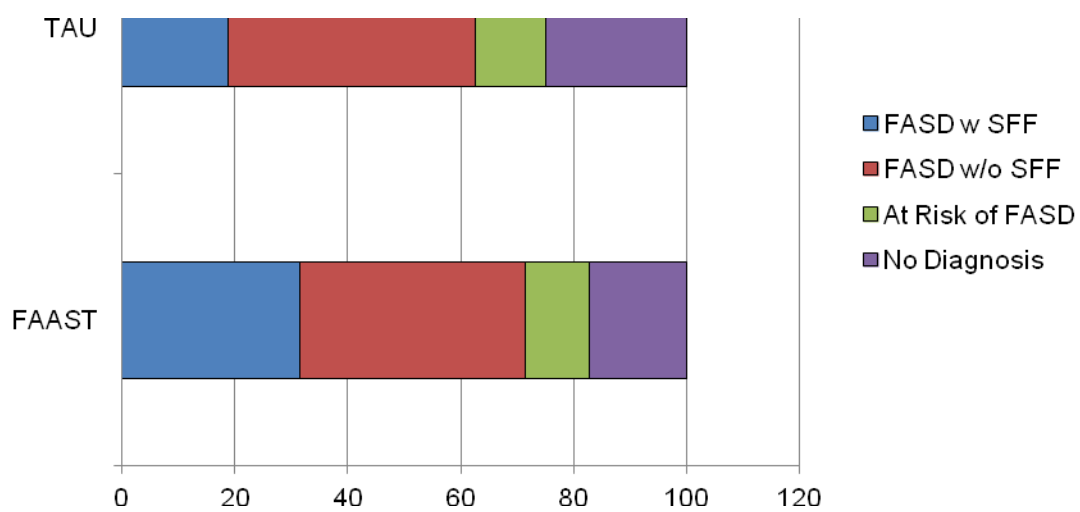


Figure 18. Cook et al (2016) Canadian Diagnosis per Group - FFAST vs. TAU

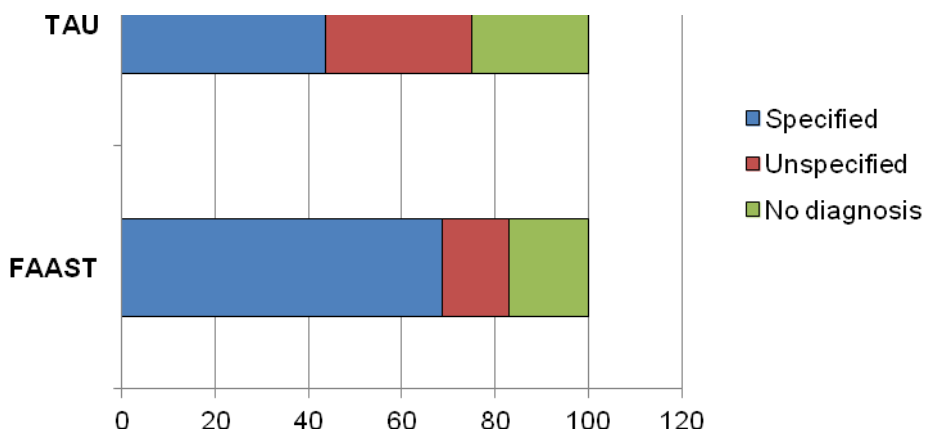


Figure 19. DSM-V Diagnosis per Group - FFAST vs. TAU

- Other, biological and non-biological, contributions to a child’s presentation should be considered in formulating their difficulties.
- More FFAST children receive their own feedback about their strengths and difficulties.

The Process: Supports

- Both services offered input to other professionals in the child’s life.
- **FFAST cases had much greater access to the FASD Coordinator**, as was intended.
- **The FAAS Team helped children and families gain access to many different forms of support and intervention.**

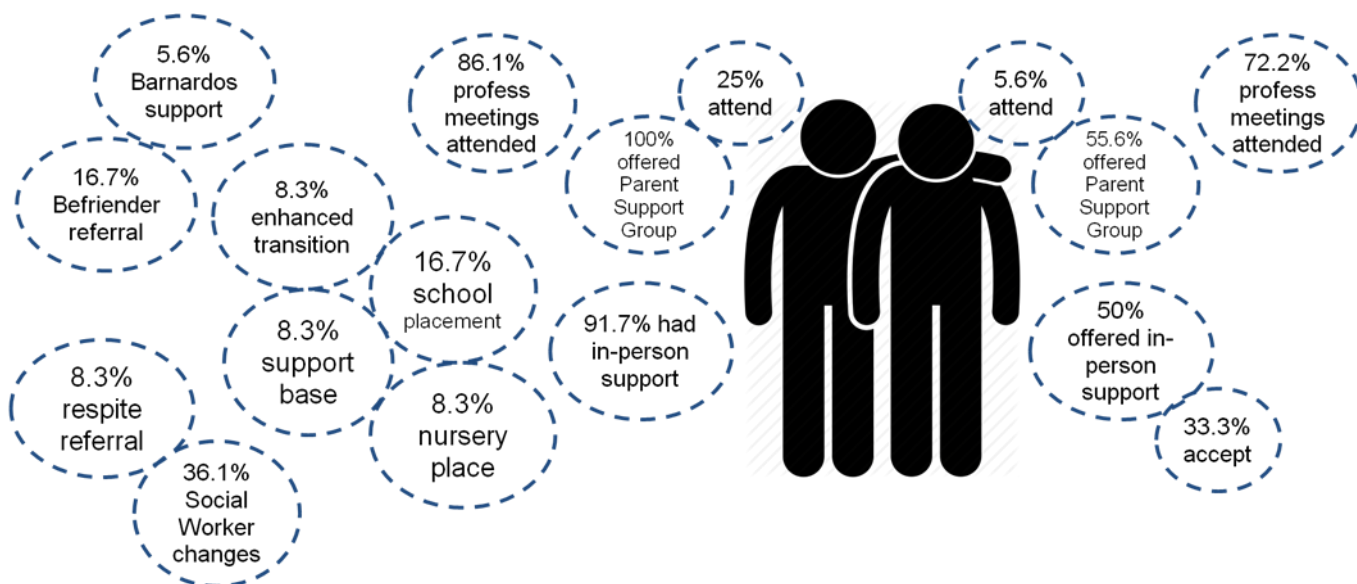


Figure 20. Supports provided in FFAST and TAU cases



The Process: Reports and discharge

- Reports were an area of particular difficulty for the FAAS Team - **only 50% of FAAS case reports had been sent out.**

PDSA Cycles

The cycles of change generated Learning Points to assist with the progression of the Pilot Project.

Learning Points:

1. Strict inclusion criteria should be agreed by each service to ensure children referred are suitable for FASD assessment.
2. Support should be offered to clinicians in generic series to establish inclusion criteria.
3. CAMHS cases should be open to a Care-Coordinator to ease access of treatment for co-existing mental health difficulties.
4. Consideration must be given to Child Protection and risk concerns.
5. Mental health of carers and children should be routinely checked upon.
6. The assessment process can be implemented within the design of existing services i.e. Paediatrics/CAMHS.
7. Learning points reiterate the need to embed the assessment process in generic services.
8. Some children will require referral to CAMHS for continued support and for ongoing care.
9. Families may require ongoing support following their child's assessment and diagnosis of FASD, to accept and understand the diagnosis and their child's strengths and difficulties.
10. Provision of FASD resources and a local support network is essential.
11. Schools and other professionals require training and support to implement strategies to help children with FASD.
12. FASD training continues to generate momentum indicating the need for training provision.
13. Multidisciplinary FASD training provision should be made available to all staff.
14. Evaluation of training will be available

Chapter Summary: Mental Health and Wellbeing Outcomes

Child Mental Health

- Children affected by prenatal alcohol exposure (PAE) may not present as more anxious or depressed than other children.
- However, these children perceive themselves as less resilient, less risk avoidant, and less achieving than other children.
- They report that they struggle with peer relationships.
- These children may be at risk of harm to themselves: **31.8% had thought about killing themselves, 4.5% would want to kill themselves.**
- This risk may only be apparent through more in-depth assessment.
- They may require CAMHS referral to manage risk (16.7% of FFAST cases).



Figure 21. Summary of FFAST Child Quality of Life and Mental Health Outcomes

Child Behaviour

- Carers report **significantly more difficulties in their children** than in the general population – in emotionality, peer relationships, hyperactivity, and antisocial behaviours.
- These difficulties have a **big impact on their child's life**.
- The level of these difficulties is related to carer coping.



Figure 22. Summary of FFAST Carer Behaviour Report, Coping and Mental Health Outcomes

Carer Coping

- Carers of these children **may not be significantly depressed, anxious or stressed**.
- Input from professionals may reduce carer depression, anxiety and stress.

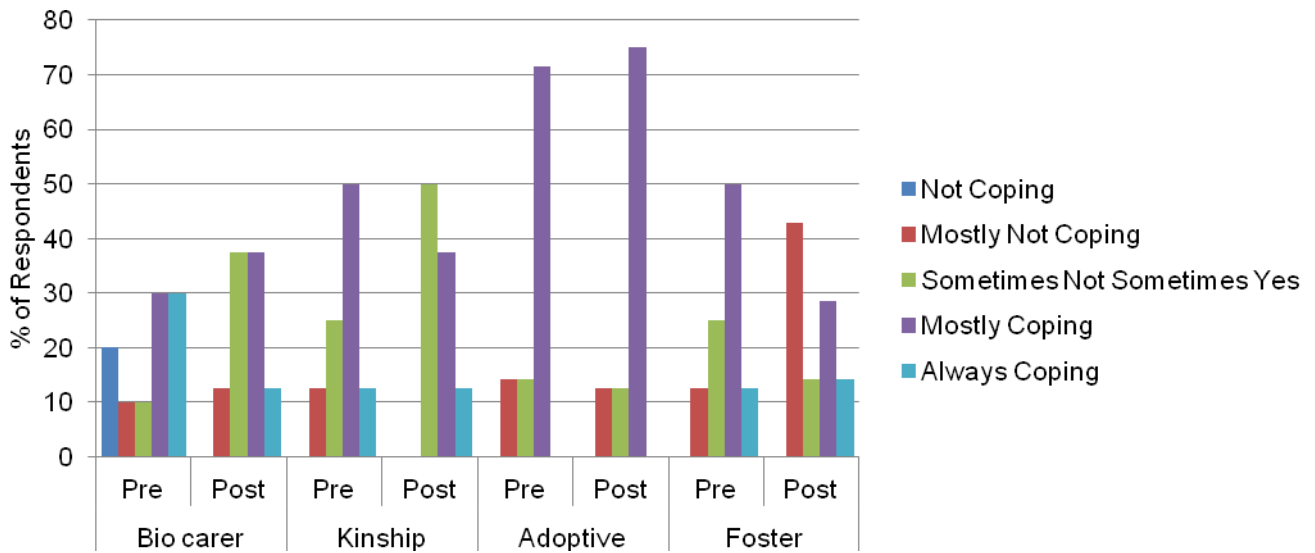


Figure 23. Parental Coping Scales Scores Pre- and Post-FAAST input by Carer Group

- Carers of these children typically **report a high belief in their ability to cope with parenting their child** and in their efficacy as a parent.
- Their depression, anxiety and stress levels are related to their belief about coping with parenting and the efficacy of their parenting.

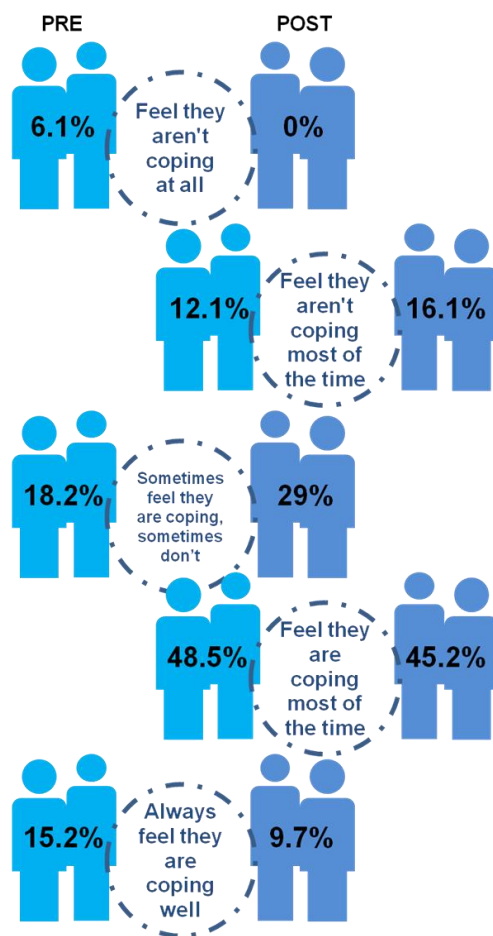


Figure 24. Overall Parental Coping Scales Scores Pre- and Post-FAAST input

Chapter Summary: Stakeholder Perspectives

Carer Satisfaction

- Carers were largely happy with the FAAS Team, giving them high overall scores.
- Their main criticism regarded the speed of the assessment process and of receiving an outcome report.
- They mainly valued feeling heard and access to assessment and diagnosis.

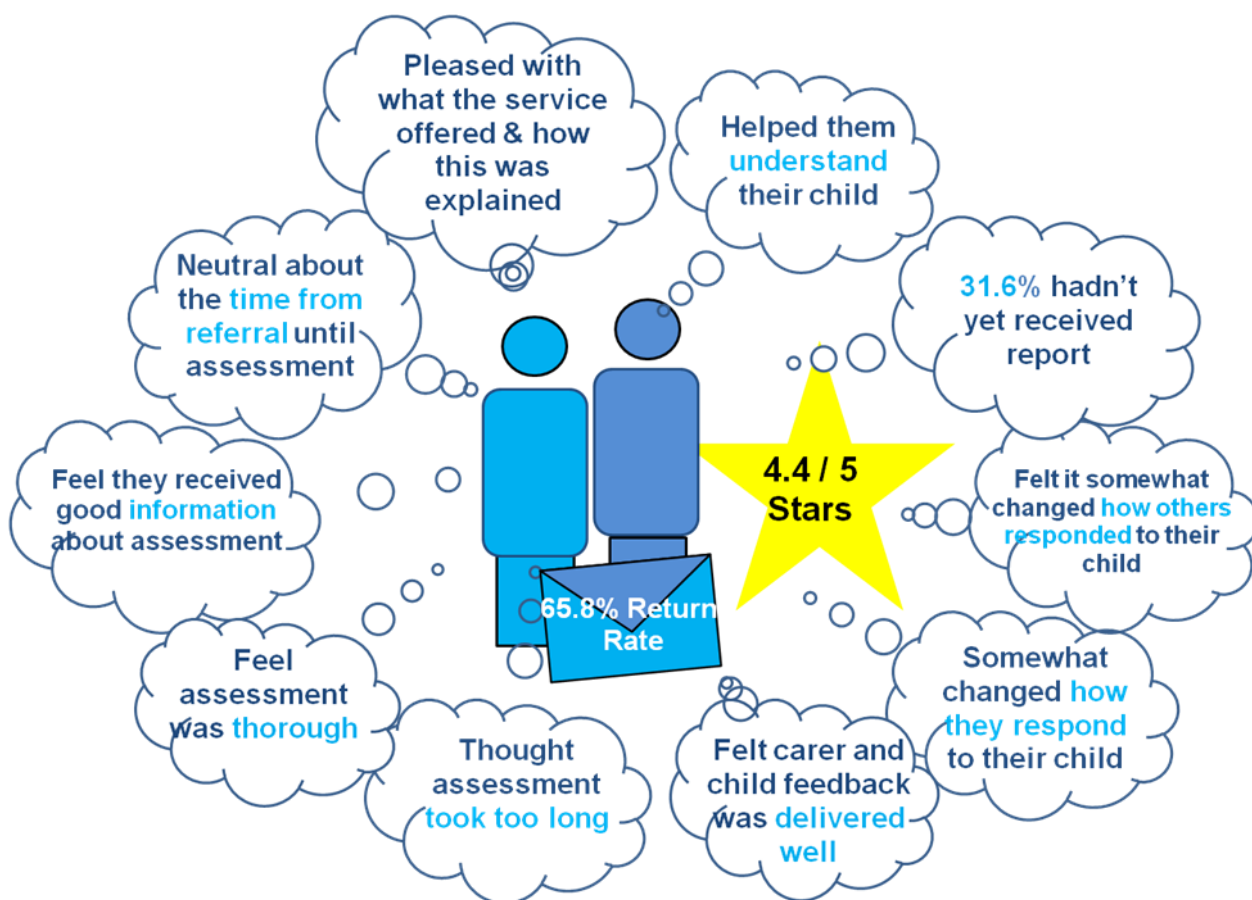


Figure 25. Carer Satisfaction Regarding the FAAS Service

Professional Satisfaction

- Professionals were largely satisfied with the FAAS Team, giving them moderate to high overall scores.
- The main criticisms were centred on sometimes limited communication, the speed of the assessment process and of receiving an outcome report.
- Professionals valued training and consultancy from the team. They felt that FASD assessment and diagnosis was beneficial for a child.

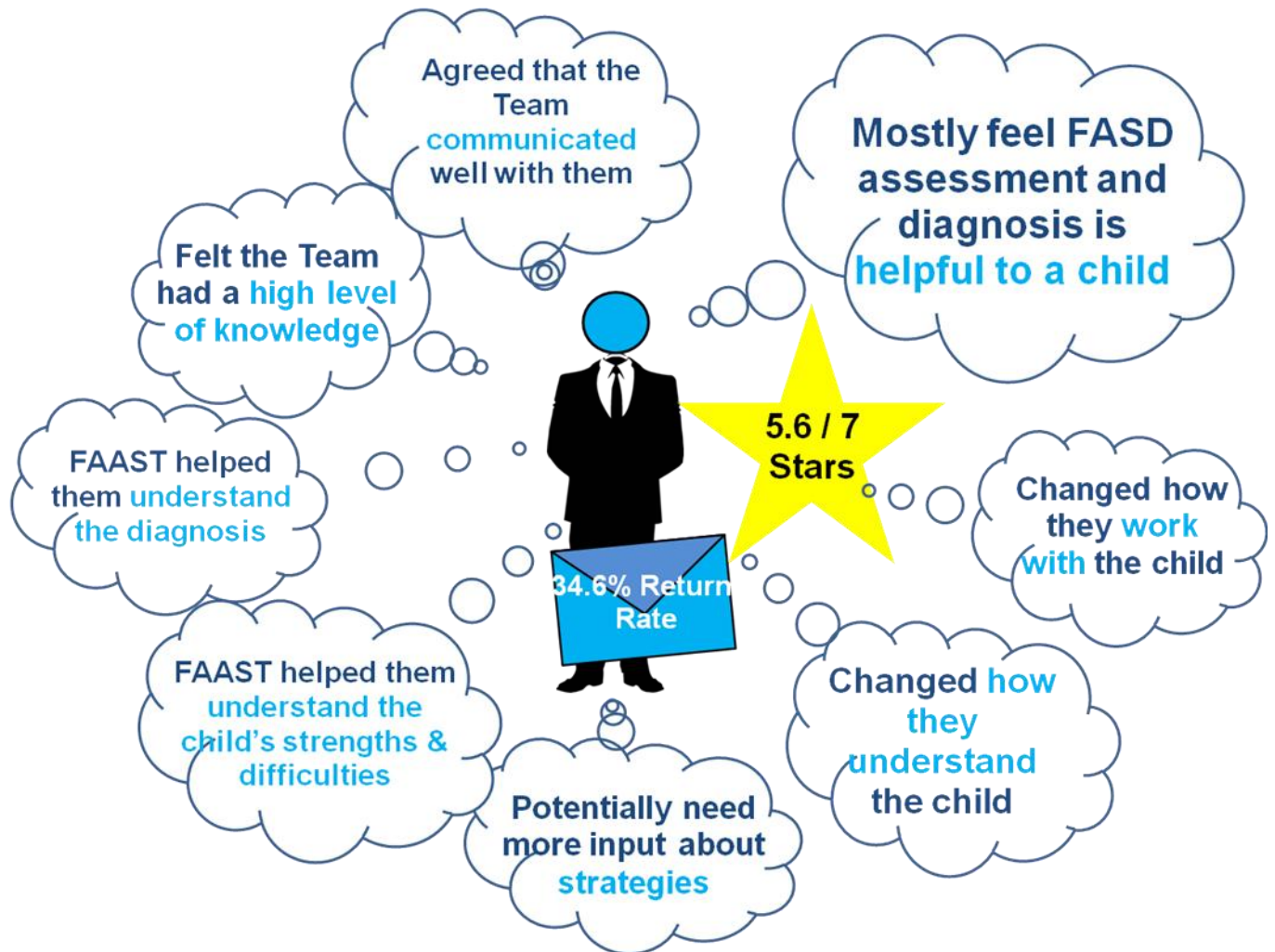


Figure 26. Professional Satisfaction Regarding the FAAST Service

Carer Perspectives

- Carers reported that they were constantly **fighting services to start an assessment process for their child**.
- They said that **no-one wanted to listen to them** and hear their concerns and they were **sometimes actively denied access to services by other services**.
- They **felt doubted and judged as parents**, often misidentified by others as the source of their child's difficulties.
- **Their child was misunderstood and judged as a 'bad child'**.
- They spoke about their children being lost, and unable to understand themselves.

- In the FAAST process, they felt that they were **finally being heard**, but this was conditional on them feeling that FAAST was **open and supportive with them** (most carers felt FAAST were open and supportive).
- They felt that the **process of assessment was slow and intensive**, and **at times felt invasive**. However, they also praised its thoroughness.
- They seemed **reluctant to criticise the FAAS Team due to their gratitude in receiving any service at all**.
- Carers **felt validated by feedback around their child's diagnosis** – they said they had **always known that something was different**.
- Carers reported other **services having a new positive understanding of their child**.
- They saw a diagnosis as a **gateway to services** and as **protective, against those who judged their child and themselves**.
- They also felt that **feedback directly contradicted the views of professionals who had not supported them in the past**.
- Biological parents **worried about how others would view them in light of the diagnosis**.
- Carers felt that **information was power in moving forward**, but **feared a future of fighting for their child alone again**.

Professional Perspectives

- Educators reported **feeling powerless when children were awaiting assessment and when education was awaiting feedback**.
- They were **anxious about managing mental health and behavioural risk** in schools.
- When they receive comprehensive feedback, as they feel they received from the FAAS Team, they **struggled to know how to translate this information into strategies**.
- Education **showed remarkable flexibility in their strategies in working with young people with additional needs**.
- However, they reported needing **timely input from health services**, and **would value close and intensive multiagency team working to implement strategies**.
- They felt that there was a **huge personal impact of working with FASD cases** – on themselves, the child, and the family.
- Educators **felt there were significant barriers to implementing strategies**:
 - They felt that **staff attitudes can harm young people's outcomes**.

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- That **multiagency staff attitudes prevent effective collaboration.**
 - That **restricted resources negatively impact the service young people receive across all agencies.**

Chapter Summary: Professional's Knowledge, Confidence, and Attitudes

- The FAAS Team had recorded delivering training to a total of **3980 health, education and social care professionals** across the period November 2015 to March 2018.
- This was over 160 training sessions.
- **An average of 137 professionals were trained each month**, with an increase in the number of professionals being trained per month each year.
- This suggests that want for training increased across the pilot, knowledge of FAAS Team training increased across the pilot, or both.
- The vast majority of training was delivered by the FASD Coordinator in collaboration with the Substance Use Specialist (Pregnancy).

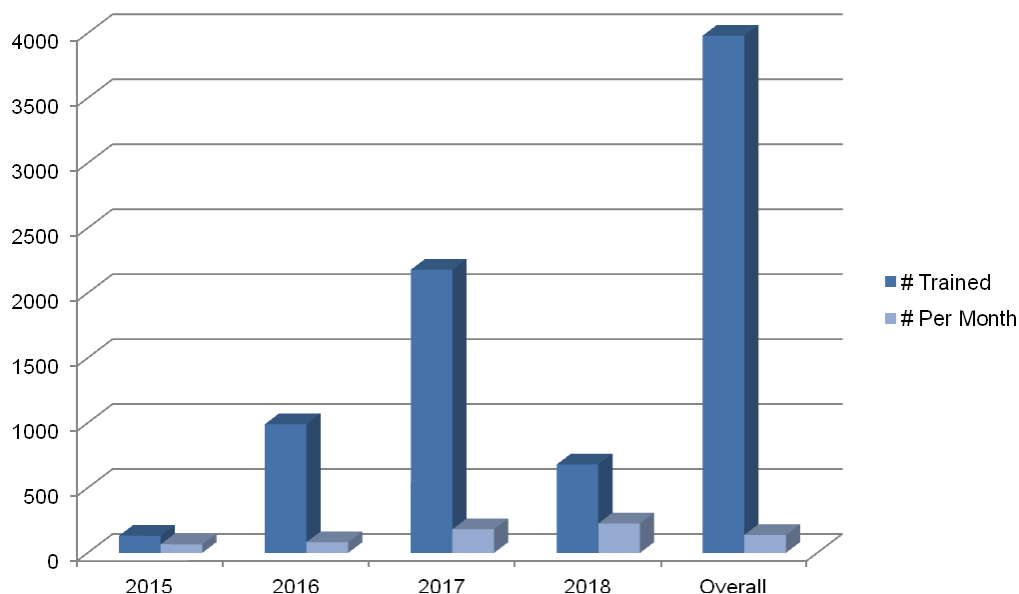


Figure 27. Professionals Trained Across the FFAST Pilot Period

- One potential avenue for increasing the Team's training capacity would be to **increase the number of professionals trained on each occasion** – FFAST training was delivered to a mean of 24.9 professionals at a time.
- This varied by professional:
 - The FASD Coordinator/Substance Use Specialist held smaller awareness sessions and thus trained an average of 21.1 attendees per session.
 - The Principal Clinical Psychologist or Assistant Psychologist trained an average of 46.9 attendees per session
 - The Consultant Paediatrician trained an average of 56 attendees per session.

A further supplementary report is available, detailing Professional Changes across the Pilot Timeline, Professional Changes through Training Sessions, Evaluation of the Training Sessions, and Professional Changes through the 2017 Conference 'Making Sense of FASD'.

Chapter Summary: Consultation

Although the author endeavoured to track all consultation undertaken by the team, this proved to be difficult as the team had no centralised recording for consultations. As a result, the author has aimed to summarise consultation activity below.

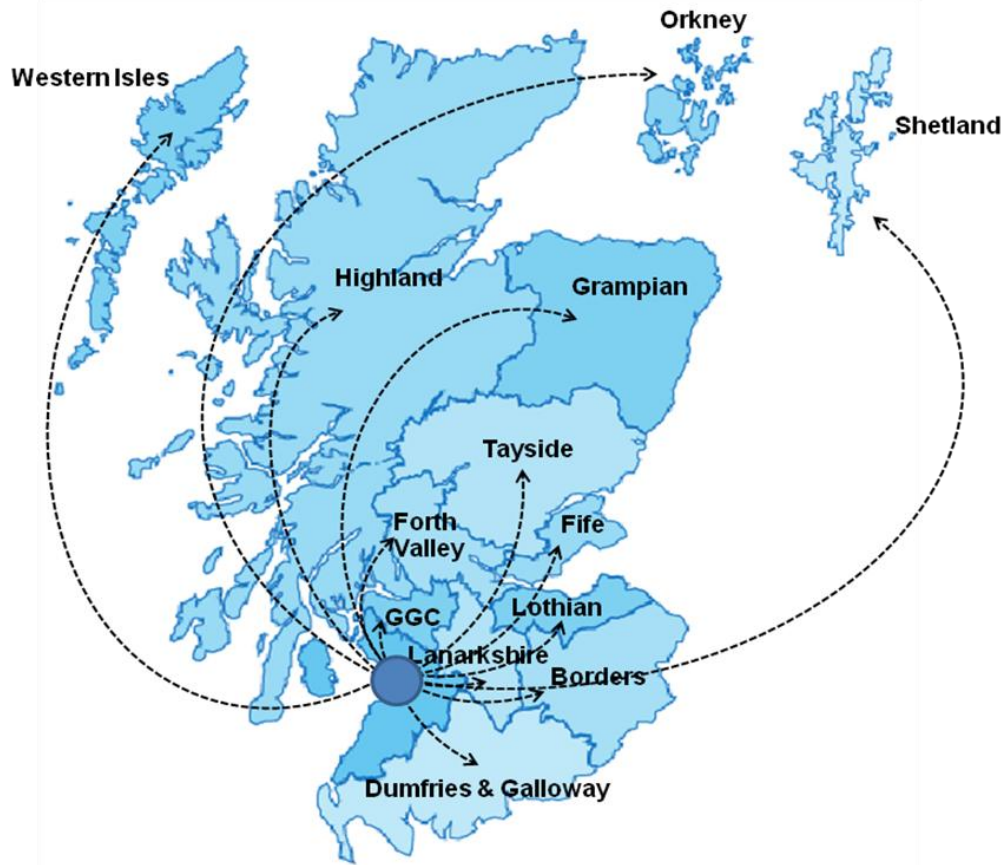


Figure 28. FAAST Consultation and Training to NHS Health Boards

- Team members undertook consultation to:
 - i. Professional colleagues in their own health board (e.g. Dr Shields consulting with psychologists in NHS Ayrshire and Arran).
 - ii. Other professionals in their own health board (e.g. Dr Brown consulting with Psychiatrists in NHS Ayrshire and Arran).
 - iii. Professional colleagues in other health boards.
 - iv. Other professionals in other health boards. Other professionals included those outside health, in education (including Educational Psychology) and social care.
- This consultation could comprise discussions on specific cases, diagnostic information and guidance, or around supporting service pathway development and implementation.
- The FAAS Team consulted with professional colleagues in **all regional NHS Scotland boards**.
- This consultation mostly comprised those in Child Services, although the team made contact with adult, learning disability, and forensic services.
- Additionally, the team consulted with **specialist NHS boards**: NHS Education for Scotland, The State Hospitals Board for Scotland, and Healthcare Improvement Scotland, specifically with the Mental Health Access Improvement Support Team (MHAIST).



Chapter Summary: Implications and Recommendations for Policy and Practice


This section was written in collaboration between Dr Fiona McGruer and Dr Jennifer Shields, FAAST Principal Clinical Psychologist.

Capacity and Sustainability of the Pilot Project

- Pilot FAAS Team were able to assess and diagnose 36 children and support treatment as usual FASD assessments across NHS Ayrshire and Arran. This was an admirable use of small resource.
- Children in the pilot service may have been negatively affected by the capacity of this small team:
 - Pilot had to reduce the number of cases they planned to take.
 - There have been long waits.
 - Speed of service was very much impacted by staff periods of leave or absence.
 - Only one pilot professional was appropriately experienced in managing complex psychological and mental health risk.
- These capacity concerns should be taken into account in future planning for FASD services.
- Assessment for FASD has been implemented in child services in NHS Ayrshire and Arran.
- It is hoped that NHS Ayrshire and Arran CAMHS and Community Paediatric clinicians could become relatively self-sustaining.
- In future, the team may consider having input to cases through consultation and coding (diagnostic) meetings.
- It may be beneficial for the team to pursue:
 - 1) A Train the Trainers model for awareness of FASD training
 - 2) Diagnostic training for other professionals throughout Ayrshire and Arran to alleviate the need for consultancy from the FAAS Team
 - 3) Input with early career professionals / trainees, in order to reduce need when these clinicians come in to practice.
- The team is hopeful that FASD support services can arise separate to the pilot team.

Necessary Conditions for this Project to be Embedded in Care

- Ongoing strong national 'No Alcohol No Risk' message.
- Awareness and endorsement of this message across all health and social care contacts.

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- Increased professional knowledge of FASD (across health and social care). Awareness-raising of FASD on a population level would be welcome to reduce the need in services.

Proposed Models of Service Delivery for those Affected by FASD

The Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Pathway

- The Pathway initiative offers guidance for the identification of individuals affected by prenatal alcohol exposure (PAE) pre-birth to 18 years of age.
- This pathway utilises the GIRFEC framework to describe steps to be taken by statutory and voluntary agencies where alcohol exposure is suspected.
- Recommended that the above pathway be considered for augmentation at several points.
- The pathway's success relies on universal services professionals having had training and having competence in:
 - i. taking an accurate alcohol history
 - ii. sensitively care co-ordinating referral for an FASD assessment
 - iii. holding multiagency meetings to discuss alcohol exposure.
- We are aware that professionals' perceptions of knowledge and competencies are low so there is limited evidence that the above steps could be carried out by the current workforce.
- We are acutely aware of the need for sensitive management of cases from when alcohol is suspected to when FASD is confirmed - this requires a high level skill set.
- Professionals should consider the child/family's individual needs when deciding to utilise widely shared documentation and the involvement of multiple professionals.
- As there are no existing specialist FASD diagnostic provisions nationwide, professionals will likely have to draw upon existing child health service structures in the form of Community Paediatric Departments, CAMHS or specialist CAMHS teams.
- Children affected by PAE often exhibit both paediatric and mental health concerns, so services may not currently be configured to meet the specific needs of children with FASD.
- Service provisions do not currently have staff trained in FASD-specific assessments or supports.



Neurodevelopmental Assessment and Diagnosis Pathways

- Many CAMHS and Community Paediatric services moving towards the use of broader neurodevelopmental assessment and diagnostic pathways.
- Neurodevelopmental service pathways can run in Child Health Services as specialist clinics, ideally spanning both CAMHS and Community Paediatrics in a “virtual hub” hosting the necessary skill set required by each child.
- Offer a single point of entry for all neurodevelopmental concerns, with assessment and input from multidisciplinary professionals, leading to a team diagnostic conclusion.
- NHS Ayrshire and Arran Community Paediatrics and CAMHS assess and diagnose FASD under the neurodevelopmental pathway umbrella as part of treatment as usual services.
- Seemingly appropriate given the common overlap of features of other common neurodevelopmental conditions.
- Given the high incidence of physical health disorder, mental health disorder and risk in these populations, it is recommended that children be referred to a central point of access, and that referrals are then appraised to ascertain which service structure is the best fit.
- It is therefore strongly suggested that services consider the concept of a neurodevelopmental hub which transcends and contains specialists from both paediatrics and CAMHS. This model of care would allow needs to be met in a safe and efficient way.

Recommendations for Policy and Practice


Prevention:

- All NHS and Integrated Health and Social Care Partnership (IHSCP) agencies should be aware of the ‘No Alcohol, No Risk’ during pregnancy message.
- All NHS and IHSCP agencies should deliver this message in their work with all women of childbearing age.
- The ‘No Alcohol, No Risk’ message must be *consistently* delivered by all professionals to pregnant women and women of childbearing age, to ensure there is not conflicting advice.
- Midwives should screen and discuss alcohol with all pregnant women.
- Midwives should deliver an Alcohol Brief Intervention (ABI) when appropriate. An antenatal ABI strives to motivate women to abstain from alcohol for the duration of their pregnancy. This should be recorded electronically for reporting purposes.



- **Identification:**

- Multiagency professionals should be aware that children who were prenatally exposed to alcohol may come from any socioeconomic background, and may present to any service with concerns (health services, social work, and education).
- LAAC services should be very aware of the potential of FASD affecting this group. LAAC children may be disproportionately affected by prenatal alcohol exposure, both internationally and in the UK.
- Neurodevelopmental contributions should be considered in all children presenting to CAMHS. Children prenatally exposed to alcohol may initially present to services with mental ill-health and risk.
- ADHD pathway clinicians should be aware of whether the children they assess have been prenatally exposed to alcohol. Children prenatally exposed to alcohol may often present to services with inattentive behaviours and subsequently be accepted into ADHD assessment pathways.
- A robust family history should be recorded for children under neurodevelopmental or FASD assessment. This can reveal siblings who are affected by antenatal alcohol exposure and may therefore i) contribute to consideration of an FASD diagnosis in the child under assessment or ii) clarify the need for referral of another child in the family. Many children in FFAST and TAU services had siblings who were also found to be affected by FASD.
- All services must i) take a comprehensive history of alcohol use in pregnancy, ii) consistently document this history, and iii) ensure that this information is available in the child's file as well as the mother's file. This information should be detailed (amounts, type, pattern of use, frequency of use). Many pilot children lacked a robust and specific history of prenatal alcohol exposure following their acceptance on to the pilot project, despite services being sure one would be forthcoming. Many of these children's files provided insufficient details of maternal drug and alcohol use such as "mum used substances and drank". This can be a barrier to accessing diagnosis.
- Services must be careful to show sensitivity to biological families, particularly when taking an alcohol history or considering a query around FASD. Cases should ideally be conceptualised as a broad neurodevelopmental assessment until FASD is the prominent factor in the child's formulation and a more specific diagnosis is appropriate.
- Services must be aware that parents may previously have been wrongly assured about alcohol use in pregnancy by professionals. Information around FASD can be




delivered in the context of Scotland's relationship with alcohol (that many individuals consume alcohol) and the changing views of the safety of alcohol consumption in pregnancy (that previous advice was not 'No Alcohol, No Risk').

- **Service Pathways:**

- Services should be willing and able to accept all cases of neurodevelopmental atypicality, of which FASD is the most common. Many pilot families had struggled to previously access assessment for their child in relation to prenatal alcohol exposure.
- Children who receive an FAS diagnosis at birth or an 'At Risk of FASD' designation in the early years should receive follow-up later in life to assess their strengths and difficulties, should difficulties arise. Their information must therefore be robustly recorded and communicated to all future relevant professionals to allow this to be considered.
- These children may be best assessed under a general neurodevelopmental pathway to avoid their repeated use of separate disorder-specific pathways and allow them to be fully understood. FASD can present as similar to other neurodevelopmental conditions, and children frequently have co-morbid diagnoses.


- **Assessment:**

- Neurodevelopmental service structures must have the clinicians confident in mental health, risk assessment, and risk management. Children prenatally exposed to alcohol presenting to neurodevelopmental assessment services may have underlying mental health risk.
- Clinicians should be aware that assessment for these children can be impacted upon by their mental health and risk. They may require input around this as a priority.
- Carer mental health and coping should be monitored and supported. The difficulties these children can present with may have a high impact on carer wellbeing.
- FASD assessment work may best sit with clinicians with a high level of specialisation in working with complex and high intensity cases.
- Clinicians may need to facilitate children and families' participation in the assessment process through reasonable adjustments (e.g. assessment offered at school, in the community). Families in which a child may be affected by FASD can have a high DNA rate – this may be due to many barriers to accessing services (financial constraints, child behaviour, carer coping, or child or carer's feelings towards the assessment process).

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- Services should offer clear and frequent communication throughout the assessment process. This is reassuring for families and may reduce the rate of DNAs.
 - Children affected by FASD should ideally have input from a MDT – current diagnostic guidelines suggest school aged children are formally assessed by a Paediatrician, Occupational therapist, Speech and language therapist, and Clinical Psychologist (Cook et al, 2016). If these resources are not available, this should not be a barrier to completion of assessment using those resources that can be utilised (e.g. screening, clinical observation).
 - The MDT should come to a joint understanding of a child affected by FASD. We recommend that the disciplines have assigned time to interpret assessment findings and discuss whether brain domains are significantly impacted. Impairments in one domain (e.g. language and communication) will impact on another domain (e.g. cognition). This indirect time must be included in the costing for MDT professionals.
 - It is our experience that a one-off assessment appointment is not the most suitable model of assessment. Assessment can be extensive, and children can present with concerns around mental health risk, which can require ongoing monitoring. Affected children tire easily. Both carers and young people may require extra time to come to terms with the journey and what an FASD diagnosis may mean.
 - A full formulation and understanding of the child should be placed in the context of their social history. In addition to impairments due to prenatal alcohol exposure, many pilot children also experienced difficulties related to adverse childhood experiences.
 - We recommend that affected children are assessed in the context of a wider team, with dedicated time allocated to indirect clinical tasks. The intensive nature of indirect clinical work for these children meant that the FAAS Team resource struggled to complete work in a timely manner.
 - Teams working with children affected by FASD should consider providing ongoing feedback throughout the assessment process. This can enhance carer understanding and allow carers and education to implement strategies as soon as possible.

- **Diagnosis:**

- Both carers and young people may require additional support to come to terms with a diagnosis of FASD, particularly considering that it is a lifelong condition.

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- Both carers and young people may require additional support to understand a complex profile of strengths and difficulties. This can be facilitated through the provision of additional feedback sessions or meaningful visual communication methods.
 - A diagnosis should be contextualised by factors in the child's life, and any other existing conditions.
 - Clinicians should consider which formal diagnosis would be most beneficial for the child and the family. For some families, a diagnosis of FASD may not be appropriate. In other cases, families may be unwilling to disclose an FASD diagnosis to other agencies. In such cases, diagnosis of Specified Neurodevelopmental Disorder may be more appropriate.
 - Clinicians should understand that it is the profile of strengths and difficulties and not the diagnosis that best informs intervention and supports. This information should be fully communicated to relevant persons around the child. It is this profile, not the diagnosis that should be the focus of communication with other professionals.
 - Clinicians may confer a diagnosis of Unspecified Neurodevelopmental Disorder where neurodevelopmental concerns are present but no robust alcohol history can be ascertained and the child does not have sentinel facial features.
 - There is a need for clinicians to offer consultation and peer supervision, through initiatives such as the Clinical Forum on FASD.

- **Intervention:**

- Children may require unanticipated intervention during the process of assessment, particularly in relation to their mental health, risk and self-esteem.
- Interventions must be tailored to a child's profile of strengths and difficulties in order to be effective and should be considered in relation to the family context and their resources.
- Intervention in relation to FASD often comprises multiagency working in collaboration with those around the child to adapt their environment and the expectations placed upon them, rather than direct intervention with the child themselves.
- Professionals should consider intervention in terms of providing strategies and supporting carer's parenting. This must be with clinicians fully understanding of the child's unique profile and needs. Generic parenting input will likely be ineffective.



- Support:


- Families welcome having a single point of contact throughout the FASD assessment process, given that they see many different disciplines and professionals. This person could be their care coordinator.
- There is a need for support groups, both for carers of children affected by FASD, and those affected by FASD across the lifespan.
- There is a need for resources around FASD to inform multiagency professionals (particularly education), carers, and affected individuals themselves. At present there are only limited resources available from the 3rd Sector in regards to this.

- Training:

- There is an ongoing need for a coherent public health awareness message around FASD for the population, in order to aid prevention of FASD.
- There is an ongoing need for FASD awareness training for multiagency professionals.
- There is an ongoing need for training for all professionals on taking a comprehensive alcohol history – how to carry this out in a sensitive manner, how to document this, and the specificity required.
- There is an increasing need for FASD assessment and diagnosis training for health professionals, both in NHS Ayrshire and Arran and across Scotland. This applies to both established professionals and professionals in training.

- Research:

- There is a need to establish the true prevalence of FASD in Scotland (e.g. using active case ascertainment in multiple populations).
- We must establish an evidence base regarding the impact of prenatal alcohol exposure on bodily development and neurodevelopment in Scotland.
- There is a need to establish an evidence base for effective educational and parenting strategies for FASD.

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- Whilst some work contained within this document details carer and professional views of diagnosis, there is a need to establish affected individuals' views of their own diagnosis.
 - It is suggested that services evaluate their ongoing attempts to identify those affected by FASD, and to provide assessment, diagnosis, and support.

