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DEVELOPING LOCAL FETAL ALCOHOL SPECTRUM DISORDER DIAGNOSTIC SERVICES AND MODELS OF CARE IN AUSTRALIA

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ABSTRACT

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder caused by prenatal alcohol exposure (PAE). Recognition of FASD within Australia has continued to grow, particularly with the development of the Australian Diagnostic Guide, yet the availability of FASD-specific services continues to be limited. This paper presents the views and experiences of the six sites across Australia involved in developing a FASD Model of Care (MoC) in their local area. Each site completed an online survey that included forced-choice questions (e.g., "What challenges did you face with creating your Model of Care?") and free-text options (e.g., "Describe the process of establishing an FASD clinic at your site"). In addition, follow-up interviews were completed with each site to ensure results were accurately captured. As a result, eight key themes were revealed: (1) importance of the FASD Coordinator position, (2) clinicians' attitudes impact clinic success, (3) MDT co-location as a contributor to success, (4) improved FASD awareness, (5) inadequate planning for local contexts, (6) developing local networks, (7) difficulty maintaining community engagement and (8) challenges with the Australian diagnostic guide. Finally, these themes are discussed within the Australian FASD context, advocating for the need to expand and improve these service offerings.

Keywords: fetal alcohol spectrum disorder; prenatal alcohol exposure; FASD

INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term describing the neurodevelopmental and physical impact of prenatal alcohol exposure (PAE).[1] Early detection and intervention of FASD can improve long-term outcomes, as FASD is linked to a range of comorbid conditions and secondary outcomes, such as contact with the justice system, mental illness, and unemployment.[2–5] A FASD diagnosis also provides an opportunity for individuals, families, and broader support networks to better understand and reframe behaviours associated with FASD.[6] Yet there continue to be barriers to early diagnosis,[7] including clinician level barriers[8] and diagnostic capacity.[9]

Clinicians in Australia and internationally continue to have difficulty diagnosing FASD, particularly

with the stigma associated with FASD.[8,10–12] As Bell et al., noted, stigma and FASD fall into three categories: personal responsibility and blame towards biological mothers, anticipated trajectories for individuals with FASD, and felt and enacted stigma experienced by the child and their family.[10]

Despite knowing about the potential harm that alcohol may cause unborn babies,[13] the Australian Diagnostic Guide was first released in 2016[i] modelled from the guidelines developed in Canada.[14] The development of this guide was a positive step toward improved recognition of FASD in Australia, although there continues to be limited referral pathways for diagnosis and therapy services and limited capacity for FASD diagnosis across the country.[15]

The Australian Diagnostic Guide advocates for using a multidisciplinary team for diagnosis as this allows the assessment of the range of outcomes that tends to be associated with PAE.[1,15] The ideal assessment process for an FASD diagnosis would include a paediatrician, psychologist, speech pathologist and an occupational therapist where clinically appropriate.[1,6] However, there are very few multidisciplinary FASD diagnostic clinics within Australia. For example, at the time of the release of the Australian FASD diagnostic guide, there were four specialist FASD diagnostic clinics across the country.[i]

To help improve diagnostic service capacity within Australia, this study aimed to develop a nationally consistent diagnostic approach, data collection, and referral process. Within Australia, we do have a national FASD action plan[16], though it is recognized that each state and territory prioritizes FASD activities differently. For example, the Northern Territory (NT) had developed their own FASD action plan,[17] and Western Australia (WA) launched a FASD MoC implementation framework,[18] whereas other states (e.g., South Australia (SA)[19] and Tasmania[20]) placed less focus on FASD within their drug and alcohol strategies.

This project engaged existing services that target high-risk populations (e.g., individuals in remote communities, individuals linked to child protection services, and individuals linked to the justice system). Due to the varied FASD focus across the Australian states, we expect there to be unique challenges associated with the roll-out at each site. This project had two broad aims: (1) to improve FASD diagnostic capacity and (2) to increase FASD awareness, knowledge, and advocacy. This paper examines the roll-out of five new FASD specialist MDT clinics and the development of local Models of Care (MoC). A separate paper (Panton, Fitzpatrick, Pestell et al., in preparation) will explore the success of the diagnostic clinics, training clinics, and community education sessions. The current paper utilizes qualitative techniques to explore the relative challenges and successes at each site, sustainability, and future clinic goals.

METHODS

Project design

This project had two broad aims: increasing diagnostic capacity and improving FASD awareness, knowledge, and advocacy through various activities (e.g., community education sessions). This paper evaluated the roll-out local FASD diagnostic services and MoCs across Australia.

Participants

Site Leads

There were six sites involved from across the country, including Patches Assessment Services (WA and NT), Central Australian Aboriginal Congress (CAAC; NT), Danila Dilba Health Service (DDHS; NT), Child Development Unit, Women's Children Hospital (CDU WCH; SA), FASD Tasmania (Tasmania), and

[i] Specialist FASD diagnostic clinics in 2016 included:
- Patches Assessment Services (previously PATCHES Paediatric Child Health & Education Services), Western Australia
- Sydney FASD Assessment and Diagnostic Clinic, Sydney Children's Hospitals Network (Westmead)
- FASD Clinic, Community Child Health, Southport Health Precinct Gold Coast Health, Queensland
- FASD C.A.R.E (previously FASTRACK Clinical Services), Perth, Western Australia

Goulburn Valley Health Service (GVHS; Victoria). The University of Western Australia Site Lead (CP) and Project Officer (KP) led the evaluation of the project.

The role of the site leads was to manage and lead the development and roll-out of the FASD diagnostic services at their site through line management of the coordinator (described below). The site leads remained constant at all sites, except for DDHS, which had a site lead replacement in the last quarter of the project. The new DDHS site lead did not have any previous knowledge or involvement in the project. The site leads from Patches, CAAC, DDHS, and CDU WCH were medical doctors (mostly paediatricians), while the site lead from FASD Tasmania had a PhD (Social Science).

Coordinators

Each site had a coordinator, with varied clinical backgrounds including, nurse/midwife (n = 3), social worker (n = 1) and occupational therapist (n = 1). The coordinator's primary role was to coordinate the Community Reference Groups (CRG) for the FASD Diagnostic Services and the development of the MoCs. The coordinators were critical for the smooth running of the FASD diagnostic clinics. Their role included gathering background clinical information and liaising with other agencies. The coordinator managed the MDT and case conferences during the clinic and compiled any further information from the family and/or other agencies.

The coordinator role in CDU WCH and GVHS both remained stable across the project. At CAAC and DDHS the coordinator positions were vacated for three and six months, respectively, in the middle of the project. FASD Tasmania did not have a coordinator for the last two quarters of the project, with clinic coordination managed remotely through Patches.

Consortium members

In addition, to the site leads and coordinators, there was community representation through a parent advocate and NOFASD, the peak National body representing the interests of individuals and families living with FASD. These consortium members were invited to quarterly committee meetings and were encouraged to share their valuable insights.

Evaluation survey participants

Site leads and coordinators were invited to complete the evaluation survey, though only one survey was submitted for each site. Both the site lead and coordinator contributed to the survey at some sites. In total, there were nine participants in the survey (n = 6 coordinators). Across the six respondents there was an average of 18 years clinical experience.[ii] All participants provided informed consent to be involved in the evaluation.

Survey

The online survey contained reflective questions for the coordinators and/or site leads regarding their site's experience in the project. Topics included demographic information, setting up the project and FASD clinic, CRGs, MoCs, community engagement, sustainability, future goals, and overall successes. This had open-ended questions (qualitative, e.g., "How is your MoC currently being utilised?") and questions that selected multiple options (quantitative, e.g., "What difficulties did you encounter with your CRG? [select all that apply]").

Procedure

Establishing clinics, CRG and MoC

Each site was trained on the Patches multidisciplinary FASD assessment model – a sustainable fee-for-service diagnostic clinic approach – and then adapted to fit their local needs. Each site formed its own CRG, which included various stakeholders (see Figure 1). The key purpose of the CRG was to help coordinate existing mainstream and local service capacity to increase FASD-related service activity, identify systemic gaps in the service processes, and advise on the development of the MoCs.

[ii] n = 1 participant did not respond with their profession or clinical experience.

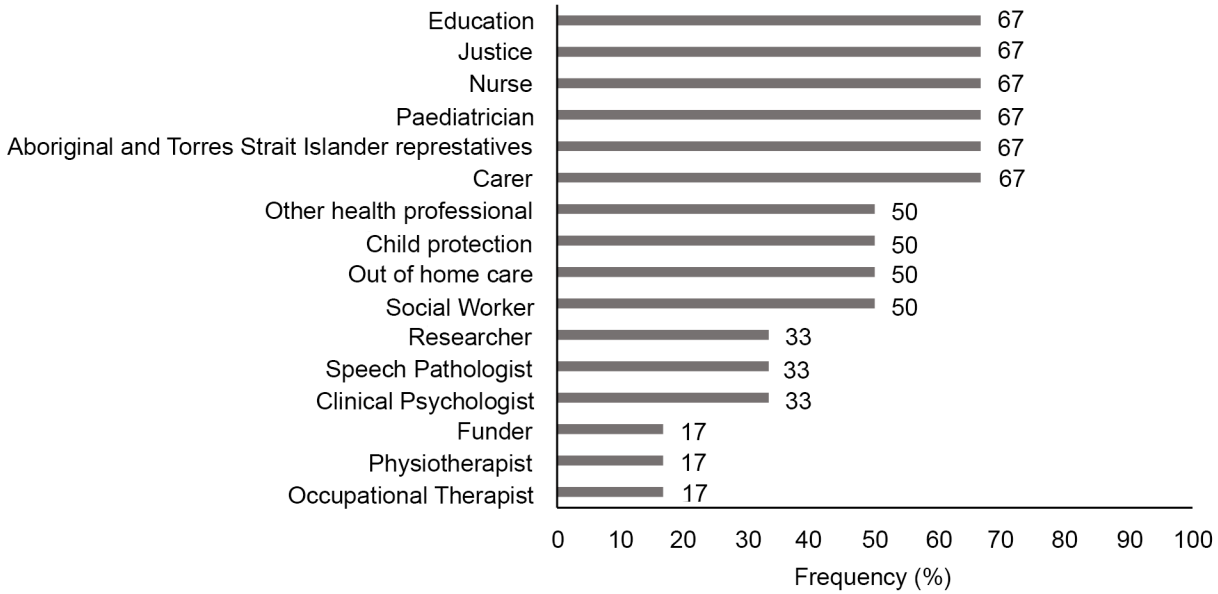

FIGURE 1 Stakeholder representation in the Community Reference Groups.

MoC development within Australian Aboriginal communities and for families in areas of social disadvantage, including in the child protection and justice systems, was a focus of this project, by replicating processes undertaken in the WA Kimberley and Pilbara regions.[21] This stakeholder engagement process, service mapping, and MoC development, utilized existing coordinated mainstream local service capacity to increase FASD-related service activity and identified systemic gaps in the service processes. By developing locally tailored MoCs and using nationally endorsed referral and diagnostic guidelines, appropriate referral services were provided to those diagnosed with FASD and their families living in participant sites.

Coordinators from the other National Consortium sites were provided examples of the MoCs created for the Pilbara region[21] to use as a guide for developing their own local MoC. Each site was encouraged to meet the following criteria for MoC development: (1) reasons for referral, (2) screening (workforce, resources, instruments and tools), (3) who can refer and/or support, (4) diagnostic assessment teams and service providers, and (5) services and funding for those diagnosed with significant impairment.

Evaluating the service

Ethics approval for this project was obtained through The University of Western Australia (RA/4/20/5792), and this project follows the principles outlined in the Declaration of Helsinki. Partway through the second last quarter of the project (November 2019), an email was sent to site leads and coordinators with information about the study and a link to a Qualtrics survey to complete Part 1 of the study. For Part 2 of the study, sites were contacted to complete a follow-up interview. This interview aimed to ensure that responses were accurately interpreted and address any ambiguities in the Qualtrics questionnaire responses.

Data analysis

Data from the interviews were transcribed and imported into qualitative data management software

NVivo and analysed inductively to develop themes. In addition, quantitative data from the survey was imported into Microsoft Excel to develop frequency tables.

RESULTS

Service overview

Patches

Patches already had an established FASD clinic before the commencement of this project. However, initially, these clinics had minimal administrative support and clinical input (coordinator, paediatrician, speech pathologist, neuropsychologist and cultural consultant when possible). Through this process, Patches had identified that a key aspect of clinic sustainability was coordination and administrative support, without which viable FASD clinic models could not succeed. As a result, Patches maintained fee-for-service funding arrangements with the justice system in WA and the Territory Families (Youth justice and child protection) in the NT to sustain services to populations at high risk of FASD.

Central Australian Aboriginal Congress

CAAC initiated the Child and Youth Assessment and Treatment Service (CYATS) through the project. CYATS provides two streams of care: multidisciplinary diagnostic assessment and discipline specific (speech or occupational therapy) assessment and therapeutic support. CYATS assesses a range of neurodevelopmental disorders (e.g., ADHD, Autism Spectrum Disorder), including FASD.

By the end of the project, the CAAC clinic model was sustainably funded for a team of eight, though this was through various mechanisms. Before this service roll-out, individuals had to travel (sometimes interstate) to receive a FASD diagnostic assessment. This service started with a waiting list of over 200 (including a range of neurodevelopmental disorders) and worked to develop service delivery efficiencies (as of October 2020, they had a waitlist of 160).

The CAAC coordinator noted:

> "There was not as much openness to FASD previously… cognitive distress was assumed to be due to trauma and other social determinants. This project and prevention project has made Alice Spring a National leader of FASD diagnostic and therapy activity."

Danila Dilba Health Service

DDHS formed the ABCD clinic, which provided an integrated assessment of behaviour and cognitive development. Through the ABCD clinic, children with confirmed PAE were identified. However, limited FASD diagnoses were made. Despite the difficulty in gaining traction for an FASD-specific diagnostic service throughout the project, DDHS utilized this opportunity to review and improve the identification of children with FASD within the service.

Child Development Unit, Women's Children Hospital

The CDU at WCH is a multidisciplinary team-based assessment clinic, delivered on-site at the hospital. CDU at WCH planned to undertake FASD assessments in response to referrals as part of their regular child development service model. CDU at WCH planned to seek ongoing core funding for ongoing coordination time and a neuropsychologist to be spread across the metropolitan area in Adelaide. Other Child Development Units and child protection services had also commenced independently undertaking FASD assessments by the end of the project. The project has been significant in advancing clinicians' clinical understanding, capabilities, and confidence in diagnosing FASD, increasing the awareness of FASD amongst education, youth justice, and community members across metro Adelaide. The SA Site Leads reported that:

> "From an overall perspective, participation in the National FASD Consortium project has been incredibly significant and beneficial for clinicians, education, youth justice and community members across metropolitan Adelaide and to a lesser extent South Australia more broadly. The project has fast-tracked the Key relationships and linkages have been established with stakeholders caring for, supporting and working with children and young people suspected of living with FASD. A MoC has been penned and work will continue to ensure that it is embedded in the developmental and referral pathway and lead to access to diagnostic services and intervention pathways. A FASD special interest group has been established for clinicians."

FASD Tasmania

The training and diagnostic clinics started in Royal Hobart Hospital; however, not all clinicians required for the diagnostic assessments were based in Hobart (i.e., not all clinicians were co-located at the hospital). This created challenges when trying to plan diagnostic clinics with appropriately trained clinicians.

After the project, there remained local interest in FASD across multiple sectors, and some degree of FASD diagnostic activity continued, primarily through private avenues. However, site leads indicated that further training across the state would be highly valuable, as Tasmania needs more clinicians equipped with the baseline diagnostic skills.

Goulburn Valley Health Service

GVHS educated and sourced appropriate clinicians from within GV Health who were interested in joining the team, which was based within the hospital in Shepparton. At the end of the project, local staff from the FASD clinic at GVHS had committed to building capacity in terms of the number of children seen per year (currently limited to 12 children per year) and the assistance provided to families (e.g., therapy services).

Community Reference Group development

The CRGs had broad stakeholder representation to reflect the varied services often involved with an individual on the referral pathway for an FASD diagnosis. For example, most sites included representatives from education and justice and developed specific MoCs for these systems. Additionally, most sites had an Aboriginal and Torres Strait Islander representative to ensure the MoCs were culturally appropriate.

Site leads and coordinators noted that the CRG were able to identify the benefits of MoC development, including providing avenues to get answers for their clients, providing screening, referral, assessment, diagnosis, management plan development, and clearly outlining the existing services and pathways. Staff at GVHS also indicated that the main benefit of the CRG was establishing a network of professionals. Additional benefits of the CRG (as identified by each site) are listed in Figure 2.

MoC development

Patches

Patches had previously developed MoCs for the region,[21] though additional MoCs were created for Leonora, East Kalgoorlie, and NT Justice throughout the project. Patches continue to use the MoCs and sustain service activity through a fee-for-service model incorporated into policies and procedures for diagnosis in the justice, metropolitan, and outreach settings.

Patches indicated that one of the key components in achieving a financially sustainable clinic is integrating a fee-for-service multidisciplinary clinic model. The fee-for-service model requires efficiencies in process and economy of scale, which helps achieve sustainable service delivery in complex environments.

It was important for Patches to maintain links with partner agencies, including disability services, justice, and child protection. These continued links helped individuals who were diagnosed to continue to access the support of these well-established government agencies

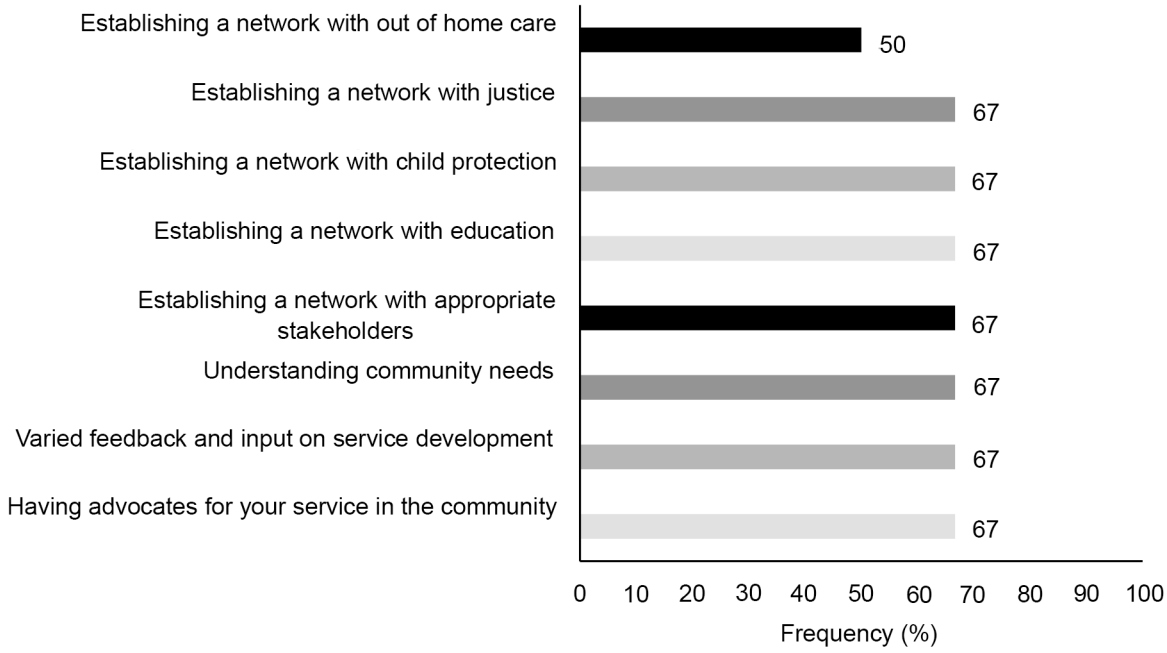

FIGURE 2 Identified benefits of engaging with a CRG during the project, as reported in a post-project evaluation survey of coordinators and site leads ($N = 9$ respondents).

post-diagnosis, and it also helped to ensure that funding was not tied to a single source.

Central Australian Aboriginal Congress

CAAC developed MoCs for Antenatal, Postnatal, Early Childhood, School-Aged Children, and Youth justice. CAAC indicated that the MoCs developed described their working partnerships and referral pathways adequately. CAAC reflected that gaining buy-in for the MoCs was not too difficult, as it was noted that being a primary health care service meant that they had access to the required allied health services and GP gateway access. Service-level agreements already existed, and partnerships with relevant services had been formed.

Child Development Unit, Women's Children Hospital

CDU WCH created 3 MoCs covering women's education, Ages 0–6, Ages 7–18. CDU WCH noted that it was a priority of the local team and CRG to focus on women's health and prevention through the MoCs. Justice representatives on the CRG indicated that they would prefer for children and adolescents within the justice system to be considered no differently than those within the community, and as such, no justice-specific MoC was developed. Justice representatives did not want these young people to feel further marginalized or differentiated from their peers by being considered "other."

The CDU WCH coordinator indicated that these MoCs will continue to be developed and refined in response to feedback, though indicated that further buy-in was needed to help with distribution. The coordinator had (anecdotal) evidence that there was considerable practice variation in discussing alcohol use in pregnancy across antenatal services in SA. Additionally, it was identified that other services in SA could undertake FASD diagnostic assessments.

FASD Tasmania

FASD Tasmania drafted three MoCs to cover three different age ranges: Infants (0–4 years), Children (4–12 years), Young people (12 years and

over). However, it was impossible to implement the limited FASD diagnostic activity at Royal Hobart Hospital and staff turnover at FASD Tasmania. The CRG engagement also reduced toward the end of the project, which may be partly attributed to local staffing instability and difficulty maintaining the alignment of views of all CRG members.

Goulburn Valley Health Service

GVHS created three MoCs covering early childhood (0–5 years), education (5–16 years), and justice (10–16 years). This MoC helped identify referral pathways that organisations could follow step by step. It was used to encourage local service providers to consider FASD as a possibility for their paediatric clients who were experiencing challenges not otherwise explained. It also gave those working in education, early childhood, and justice systems some direction for determining which clients may be appropriate to refer and how they could better support them.

Overall challenges with MoC development

Even though most sites were able to develop finalised, workable MoCs, some challenges were identified with the development of the MoCs (Figure 3). Predominantly, sites were concerned about ensuring that the developed MoCs would be clinically useful for the region and the target services. A continued challenge for many sites was gaining buy-in and traction for the MoC through local stakeholders and clinicians. As a result, DDHS did not produce an MoC.

Overall successes and challenges

Patches already had an established FASD clinic before this project, though it had expanded outreach diagnostic services and improved therapy services. Three of the remaining five sites successfully launched FASD diagnostic services (GVHS, CDU WCH, and CAAC). The three sustainable sites noted more successes (M = 15.33, SD = 4.93) compared to the remaining two clinics (M = 6.00,

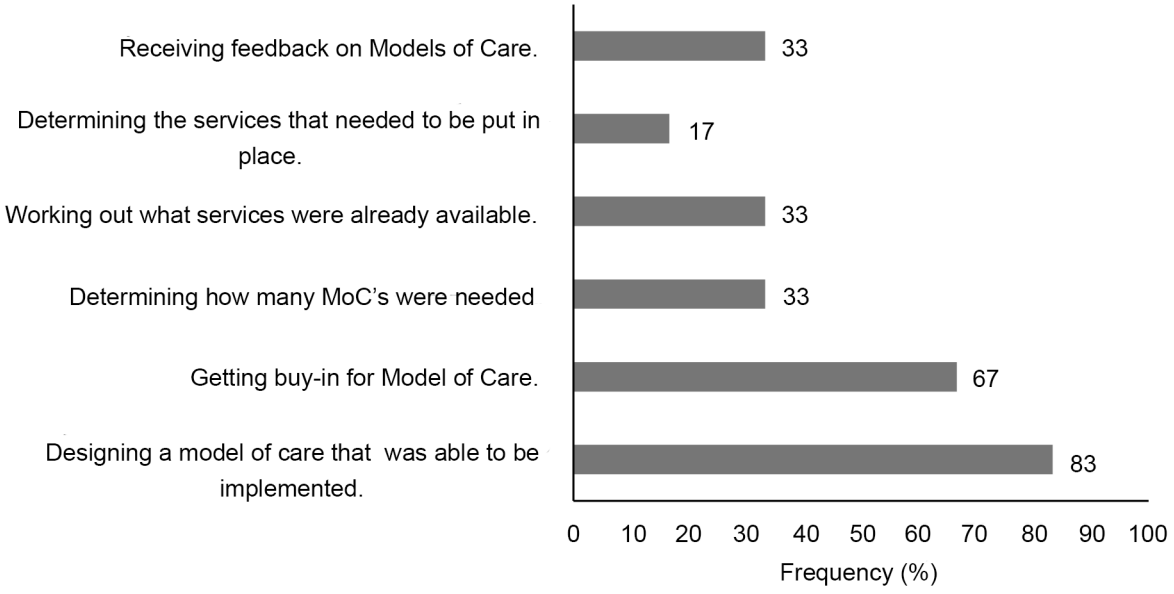

FIGURE 3 Challenges in establishing MoCs, as reported in a post-project evaluation survey of Coordinators and Site Leads (N = 9 respondents).

SD = 1.41). Conversely, the two non-sustainable clinics highlighted more challenges (*M* = 21.50, *SD* = 10.61) compared to the three sustainable clinics (*M* = 8.33, *SD* = 2.31). The overall successes and challenges are captured through the themes below.

Theme 1: The importance of the FASD coordinator position

The coordinators' role was essential for developing effective and sustainable FASD diagnostic services. DDHS and FASD Tasmania had unique difficulties establishing diagnostic clinics at their sites. Both sites suffered from staff turnover in the coordinator position during the project. A challenge for both sites was attempting to embed a specialist FASD diagnostic service within a large metropolitan primary health care setting. Patches site lead noted:

> "[A] key aspect of clinic sustainability is administration support without which viable FASD clinic models cannot succeed."

Theme 2: Clinicians' attitudes impact clinic success

Turnover in key roles (coordinator, paediatrician and psychologist) was identified as a barrier to success. Paediatrician and local clinician support were also essential for the clinics' success. The sustainably funded clinics noted that local clinician and executive support was crucial for success. FASD Tasmania indicated that differences in levels of support for FASD diagnosis among some clinicians could prevent constructive work within the CRGs, creating a barrier to developing an agreed MoC.

The three sustainable sites noted strong executive support as potential contributors to success. This included "enthusiasm" and "proactive" response, "active" involvement, "good team leadership" and "lobby[ing] hard" for funding.

Theme 3: MDT co-location as a contributor to success

The sites that had ready access to an MDT (e.g., hospital-based) had greater success with clinic roll-out. However, FASD Tasmania noted the difficulty in coordinating clinicians for the FASD clinics, as it was often geographically challenging for clinicians to attend. For example, in Tasmania, not all clinicians required for the diagnostic assessments were based in Hobart (i.e., not all clinicians were co-located at the hospital). Additionally, within the diagnostic team in Hobart, there were concerns about assigning a diagnosis of FASD without consent from a child's birth mother when the child was a ward of the state or had a legal guardian that was not the biological mother. These concerns were unique to this site due to differences in privacy legislation within Tasmania. This issue, coupled with difficulties coordinating geographically diverse clinicians, hampered diagnostic activity at this site.

Theme 4: Improved FASD awareness

A key success at all sites was the increased FASD awareness. This has included more public conversations about FASD, more recognition of FASD, providing avenues to get answers, and increased local interest. In addition, all sites notified newly diagnosed cases of FASD to the Australian Registry to improve national data on FASD prevalence.[iii]

Theme 5: Inadequate planning for local contexts

One overarching key challenge at the sites without sustainable clinics (i.e., DDHS and FASD Tasmania) was the lack of appropriate planning for the local areas. DDHS noted that it "has taken some time to work out what the community needs." It was observed that there needed to be further planning to better meet the needs of the local regions, rather than attempting to apply a national model in areas where it may not be appropriate. FASD Tasmania indicated that the consortium demonstrated a limited understanding of Tasmania, including the inherent differences across the 4 regions.

Theme 6: Developing local networks

The sustainable clinics indicated that one of the key successes of the project was increased local

[iii] https://fasdregistry.org.au/

networks, which were developed through the CRG, community engagement sessions, and local clinical training. Additionally, the consortium Coordinators formed their own network, regularly meeting to share resources, discuss challenges, and celebrate clinic successes. It was noted that the coordinators network was a "useful forum of conversation."

Theme 7: Difficulty maintaining community engagement

One of the key successes of the project was the local networks created through the CRGs and community engagement sessions. However, all sites noted difficulty maintaining community engagement, particularly with some agencies resisting FASD diagnosis. Each site listed some specific challenges with community engagement and a summary of the overall community reception (see Table 1).

Theme 8: Challenges with the diagnostic guide

Concerning the diagnostic guide, one of the challenges was involving occupational therapy efficiently in the diagnostic process, and as such, motor processing, sensory processing, and visual-motor integration were often not adequately assessed. Other challenges with the diagnostic guide included the Affect Regulation domain. GVHS noted that this domain was "frequently up for discussion in clinics." The Coordinator indicated that with some of the social situations that children presented with, it was often difficult to get a prior diagnosis. Finally,

TABLE 1 Community Engagement Challenges and Community Reception of the Project.

Site	Challenges with Community Engagement	Community Reception of the Project
Patches	• Concerns about stigma relating to FASD • Local clinical stakeholders not supporting FASD diagnosis • Issues of competition and lack of cooperation across different services	• Overall positive reception for the project • New models in Leonora and East Kalgoorlie, and built up NT justice
CAAC	• Cultural and language barriers • Time needed to engage families and build rapport	• Positive. Improved understanding of FASD, particularly with justice and legal services
DDHS	• Support from management	• Limited community involvement
CDU WCH	• Other metro CDUs ability to undertake FASD assessments was limited due to the complexity of the diagnosis and lack of resourcing, though information was still distributed to these sites	• The community has been very receptive to hearing about FASD and initiatives being undertaken in SA
FASD Tasmania	• Slower than anticipated to engage CRG • Difficult to organise meetings and follow-up and availability when state-wide	• Community interest in FASD was strong, with high attendance at community education sessions
GVHS	• More difficult to engage with justice but later on were able to develop a connection with youth justice and Legal Aid • Maintaining interest in the project was more challenging, particularly managing attendance at CRG meetings	• Community reception has been overwhelmingly positive that there is something available now for these families • Excitement for the project lowered when people learned of the clinic's small capacity (12 client's year) and the limitations of the clinic (i.e., diagnosis only)

Note: *Adapted from Panton, K. R., Fitzpatrick, J. P., & Pestell, C. P. (2020), on behalf of the Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Services and Model of Care Steering Committee.* Report to the Australian Government Department of Health: FASD Diagnostic Services and Models of Care Project *(ISBN: 978-1-74052-967-9).*

an ongoing issue was accurately obtaining information about PAE from the biological mother.

DISCUSSION

This study aimed to evaluate the roll-out of five new FASD diagnostic clinics and local MoCs. Qualitative methods were used to identify key challenges and successes at each site. It was clear that a flexible diagnostic approach was required to fit the local context. Three out of the five clinics will continue to be sustainably funded, though all six clinics (including Patches) have plans to expand their services to improve sustainability.

Overall success with the clinical model

The national FASD diagnostic service model was grounded in robust clinical processes, modelled from the Patches MoC.[21] Across the project, we developed effective funding models, including blended block funded and fee-for-service funding models that contributed to the service efficiency and a high number of assessments completed per unit time.

A key positive outcome of this project was that FASD diagnostic assessments were integrated into all services. This project has improved the ability to conduct FASD diagnostic assessments within each site and has increased diagnostic capacity in other regions. However, some sites still have limited capacity to complete FASD diagnostic assessments due to the high level of clinical and administrative time needed. Running MDT FASD clinics take approximately 20 hours of clinician time and 10 hours of administration and coordination time. Apparently, not having adequate funding in place puts a significant burden on clinical and administrative teams.

Clinicians and coordinators as keys to success

The gold standard for FASD diagnostic assessments is an MDT,[1,15] although it was recognised that a co-located MDT produced more successful outcomes during this project. Additionally, and perhaps unsurprisingly, clinical teams that did not have strong support and enthusiasm for FASD were less successful overall. Specifically, two clinics noted reluctance in the paediatrician's willingness to diagnose FASD due to concerns around ethical issues, maternal consent, and stigma. Nevertheless, paediatricians have a significant role in leading FASD prevention, assessment and diagnostic efforts,[22] making clinical success difficult without paediatrician support.

FASD is a complex condition that requires consideration of various viewpoints and ethical issues.[23,24] Within Tasmania, there were specific challenges around consent and privacy legislation, which impacted the success of the diagnostic clinics. More broadly, clinicians continue to have difficulty diagnosing FASD, with shared concerns including stigma,[10] the validity of FASD as a diagnosis, and determining the avenues for support if a diagnosis is received.[8] Therefore, it is important that FASD training and education address ethical, social and political issues that continue to be barriers toward improved FASD screening, diagnosis, and management.[9]

Local contexts

All sites noted increased FASD awareness within their clinical services and the local community. Conversely, lack of FASD awareness is a key barrier to improving FASD diagnostic and management services.[22,25] Building local awareness of FASD is important to building local capacity and local FASD advocacy.

In some sites, further work is needed to better understand the local needs, as it was identified that this national approach did not fit each local area. With the diversity across the four main regions in Tasmania, it is recommended that time is spent trying to better understand how the MoC would need to be adapted for local areas and how these areas can stay connected.

Challenges with the diagnostic guide

Some of the issues identified with implementing the diagnostic guide have also been described elsewhere.[25] Work is currently being undertaken to

improve the Australian FASD diagnostic guide, and it will be essential to continue to consider the perspectives of clinicians that have actively used the guide in this updating process.[26]

Future sustainability

The demand for FASD diagnosis in Australia far outweighs the diagnostic service availability. Therefore, it is important that funding is afforded to efficient clinical models, such as the private or blended public-private models presented in this project. University FASD clinic models have traditionally been used to train clinicians in FASD diagnosis. However, it does not offer the most efficient and sustainable model for success. Within Australia, the combined fee-for-service (private or NGO) and government-funded (e.g., state child development services) models require financial and logistical support to sustainably meet the diagnostic demand.

Further areas of focus

We have seen a marked increase in FASD education through formal training clinics, and the FASD Graduate Certificate is now offered internationally at the University of Western Australia. Each consortium site developed a model of service delivery that best suited local needs, though at some sites (e.g., Tasmania), the Patches model was not adopted locally, and no sustainable clinic model has been achieved at this stage. In the case of Tasmania, the value of training clinicians (e.g., school psychologists) outside the traditional multidisciplinary team (i.e., paediatrician/physician, speech pathologist, psychologist, occupational therapist) was clear. Utilising the knowledge gained in the FASD training clinics in Tasmania, school psychologists upskilled other school psychologists and local clinicians. School Psychologists have the potential to complete parts of the FASD diagnostic assessment, and provide a referral pathway toward FASD diagnosis.[27] The recent coroner's inquest[28] into 13 young people that died by suicide in the Kimberley region highlighted the importance of the school psychology service for supporting students with behavioural difficulties and complex needs. Future work could develop training for school psychologists to become more FASD-informed. Additionally, the coroner's inquest recommended that individuals within justice and child protection be routinely screened, as FASD is over-represented in these settings, where individuals are more vulnerable to developing further secondary difficulties, including mental health concerns and substance abuse misuse.[29]

All sites expressed interest in improving FASD therapy services in their local area. Receiving a FASD diagnosis is an important first step for a child, adolescent, or adult to better understand themselves and be better understood and supported by others.[6,24] As with diagnostic services, therapy services for FASD are also limited and not well-researched.[30] With the increased diagnostic activity, as evidenced through this project, it will be important for individuals with FASD and their families to access appropriate support.

Further support for therapy services

A future area of focus for most sites also included expanding therapy services. Within Australia, NDIS is a vital source of sustainable funding for appropriate therapy and support for FASD. Individuals with FASD can meet the eligibility criteria for significant functional impairment associated with disability. We recommend that the NDIS provide further training and disseminate evidence-based information about FASD, particularly within their assessment and eligibility guidelines.

A significant obstacle for children with FASD receiving additional support in the classroom (e.g., educational aide time, learning and behaviour support) is the Australian state departments not accepting FASD as a disability eligible for school-based funding.[15] Children with FASD often need support with regulating their behaviour in the classroom, as they can be quite disruptive.[31] Disengagement from school is also a risk factor for engagement with the justice system.[2,32] To help provide children with

FASD with better opportunities, the criteria for disability support funding in schools should include FASD as an eligible diagnosis.

The prevalence of FASD in child protective services and the justice system is well recognised.[32] To help support individuals in these systems, it is recommended to target funding for therapy services. Early intervention within the child protection system can help to enhance the stability of care placements and potentially reduce the trauma of multiple placements. This, in turn, may help to reduce the likelihood that children will progress from the child protection system to the justice system. State and territory departments of child protection, education, and justice systems should be integrated with the Australian FASD Strategic Action Plan,[33] to provide a mechanism for accountability and therapy funding within each agency when supporting individuals with FASD.

Limitations

This study utilised a qualitative approach to better understand the factors contributing to developing successful local MoCs. However, a small sample was used, focusing on an Australian context, limiting the generalisability of our findings. In addition, there were no standardised measures used in this study, and "success" was arbitrarily attributed to sustainably funded clinics.

CONCLUSION

This paper has highlighted the successes, challenges, and lessons learned from rolling out local FASD MoCs across Australia. Although some sites required a more strategic and nuanced approach to better match the local needs, successful clinical models were produced. Although local diagnostic capacity has increased, clinical and community education efforts must continue to help with ongoing recognition and understanding of FASD. With three new sustainably funded FASD diagnostic clinics, the next step will be to improve the availability of local therapy services.

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