Queensland Government

Gold Coast Hospital
and Health Service

11th October 2020

Attention Sina Hutton – on behalf of Senator Stirling Griff
Principal Research Officer
Senate Standing Committees on Community Affairs
Department of the Senate
S1.59 Parliament House
Canberra ACT 2600
Community Affairs, Committee (SEN) Community.Affairs.Sen@aph.gov.au

RE: **Inquiry into Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD)**

As requested, below is the Gold Coast Child Development Service collective response to additional questions raised by Senator Stirling Griff.

Question 1

Regarding the 3-day training course you have provided to 270+ health practitioners to date: How do families find out who has taken the course and who can assist them with diagnosis? (There don't appear to be many practitioners listed on the FASD Hub which seems to be the only central point for this type of information?)

We agree, there is limited information out there to help families find someone who can assist with the FASD diagnostic process. We believe that the predominant issue remains the limited number of individuals / or services skilled in FASD diagnosis to meet the demand; but this is obviously exacerbated by those trained but then not promoting themselves as now 'FASD skilled'.

During our training course, whilst we strongly encourage practitioners (both public or private) to register on the FASDHub[1], only a small percentage have chosen to identify themselves as FASD 'experts'; ultimately it is up to the individual or the service. Whilst not readily available to families, as a service, we do retain limited information from all training participants, if a family subsequently contacts our service to enquire about their local area, we have in the past, contacted an individual clinician to see if they are willing to assist. Information is not however shared with the family unless agreed by the clinician.

The clinician reluctance to be identified on the FASDHub or other appropriate places is probably multifactorial;

- Both Private and Hospital Health Services e.g. local Child Development Services may be reluctant to advertise as their current waiting list are already breaching guidelines and therefore would struggle to incorporate the extra demand.
- For both private and public practitioners, whilst post course they identify as more clinically competent in FASD, they often report that they would like ongoing practical clinical supervision before they would consider themselves confident 'experts' in FASD diagnosis. Gold Coast CDS

---

[1] https://www.fasdhub.org.au/

offers some opportunities for clinical supervision, however this is not formalised, and limited by our own capacity without additional resources.

- In terms of clinicians subsequently committing to becoming a FASD diagnostic service post our education training, we have had greatest success with targeted training of a specific services i.e. Queensland Youth Justice, Newcastle and Rockhampton Child Development Services. In November this year we will provide targeted training to Cairns CYMHS and EVOLVE services. As a result of this success We have therefore brought this in as a training option for those and similar services.[2] It is important to recognise that we take our clinicians off-line to conduct this targeted training. The burden this adds to our waitlists and clinicians, and the fact that CDS Gold Coast does not receive remuneration for providing the training means that we are unable to offer this opportunity as widely as is needed.
- Children and families with FASD present as complex contexts that require more time to diagnose / support than is currently renumerated for. Including FASD in the 137 Medicare funding for 4 diagnostic sessions[3] and/or clearer guidelines on how to utilise part of NDIS funding for completion of diagnostic work, could assist some practitioners.

Our ideal future model would be that all public Child Development Services are competent in offering diagnostic assessment for FASD, following FASD training +/- subsequent clinical supervision programme if required. Whilst the Gold Coast CDS, has taken the approach of specifically advertising and identifying that we provide FASD assessments, as part of our routine work, we are aware that other Child Development Services are strongly opposed to indicating that they provide a specific diagnostic assessment, preferring to state only that they provide a diagnostic formulation for children with developmental concerns. This becomes an ideological debate, but in our experience, does limit the information available for families that are specifically looking for a FASD diagnostic assessment.

For families themselves, in addition to accessing the FASDHub, our impression is that they predominantly find information around FASD services either through word of mouth or local FASD support groups. However, the underlying issues remain, there are currently significantly fewer FASD diagnostic services than needed to service that segment of health care consumers.

Even if all Australian Child Development Services, were trained and confident in FASD diagnosis, and their ability to provide an FASD assessment was then common knowledge; many services have had minimal funding increase for decades (block funded with no adjustment to population growth). To manage the natural increase in service demand over time many services have been forced to implement age eligibility limitations[4]. On this basis they could argue that they have no in-built capacity to cater for the expected increase in referral numbers. This means that currently there are very few public health services for children > 8 years, and almost none for adults and there is likely to be little opportunity for growth in either area.

Question 2

Regarding the lack of diagnostic and support services in regional, remote and rural areas: Do you have a view on a solution for these areas, given your view that FIFO is unsustainable and inconsistent? For example, is telehealth an adequate substitute for face-to-face FASD diagnosis?

Regional and remote communities encounter many difficulties when it comes to accessing secondary and tertiary health care services. We firmly believe that a staged approach to assessment in conjunction with

---

[2] In November 2020 we are trialling our first online virtual group training with Cairns EVOLVE / youth justice and Child Development Service, this may open up scope to provide more team specific training.

[3] NBPSA submission May 2018 https://nbpsa.org/files/68.pdf/NBPSA%20joint%20response%20FASD%20MBS%20items%20(corrected)%2020180522.pdf

[4] Age eligibility is commonly either prior to school age or < 8 years of age.

revised and updated guidelines provides an avenue to diagnosis in this environment. Telehealth in turn would have an adjunct role to supporting this model.

As previous stated, we are working on a system of diagnosis for Primary Care specifically targeting rural and remote. It is being trialled at Mt Isa as we speak. We are hoping most diagnoses within remote or rural communities can be made by primary care, some with telehealth support and only a small number of the most complex needing to travel. The model has been co-designed with elders from the local community, but we think it will have wide portability[5].

Concurrently the COVID-19 Pandemic Health Response has allowed us to trial opportunities for FASD telehealth within our own service, and there is definitely scope for this to be extrapolated to provide telehealth support to regional, remote and rural areas. Our experience to date suggests that the early stages of the diagnostic process, along with some basic response to early intervention- support the family whilst they are progressing through the diagnostic process, and addressing immediate 'quick win' clinical issues, is both effective and successful through a telehealth model of care. Telehealth based diagnostic assessment will only function, if key requirements are met including (1) adequate infrastructure in place including computer and telephone/internet capability, and (2) a local health worker present to both collate available local information, bring local context awareness and proctor the telehealth interaction.

At this stage telehealth examination of the more complex cognitive functions (for example: higher level language, executive functioning, complex attention, motor function), still requires specialised equipment or face to face assessment delivery. There are solutions to this that our service is currently exploring, but these have start-up costs that in the current financial environment become inhibitive.

As a service, we would be eager to trial our proposed model of care for a telehealth delivery mode for rural / remote community referrals, either as a complete service or as part of the tiered approach currently being trialled, but this unfortunately would be limited until both remote community and state funding support becomes available. We have attached a basic costing in Appendix A as an example of what we believe it would cost to establish a full telehealth diagnostic service.

Question 3
What therapeutic/diagnostic/support options are available to children when they "fall short" of a diagnosis under the current guidelines, which other submitters also consider too rigid – can they only seek treatment/assistance for whatever other conditions you can diagnose?

The FASD Australian Guideline review[6] may potentially expand the criteria for FASD diagnosis to include those children with moderate-severe functional impairment of symptoms. Until changes are actualised, there is a cohort of children, who have moderate to severe functional impairments but do not meet the current FASD diagnostic guidelines. Not achieving diagnosis, even though there is clearly demonstrated functional impairment and need has a high potential for restricting their ability to access supports.

This is not as problematic for children under the age of 7 years who should still be able to be obtain appropriate early intervention support through the NDIS ECEI framework. In this case, request for access is based on their level of functional impairment regardless of an underlying diagnosis. Many of these children will be labelled as 'FASD at risk' awaiting further diagnostic review when older. This process, in our experience, has been very positive, both in ensuring early intervention and also reducing the number of children being inappropriately 'labelled' with an alternative diagnosis particularly ASD, purely to obtain disability supports.

---

[5] See link https://www.griffith.edu.au/menzies-health-institute-queensland/our-institute/epic-health-systems/yapatjarrathati-project

[6] Gold Coast CDS is a member of the consortium group revising the Australian FASD Guidelines being lead by Dr Natasha Reid at UQ.

However, once a child is > 7 years [7] current requirements state that they typically will require a specific diagnosis that falls within the NDIS Category List A or List B (which FASD falls under). Locally we have had some limited discretionary exemptions that have allowed continuation of the NDIS plan for a further 12 months after a child has turned 7 years of age, however this has required additional resources to both support and complete the reapplication process. We do not believe that similar discretionary exemptions occur in other districts or that they are applied equally across all children. We would advocate for this capacity to be universal, allowing for continued funding or access to funding based on an individual child's functional impairment, with extension of funding approved until it is clinically appropriate[8] to re-evaluate FASD diagnosis[9] and there is financial support or public health service availability to complete the subsequent assessment.

Our experience suggests that reassessment for possible FASD diagnosis can be more targeted, based on key functional challenges that an individual child has, and previous assessment information. This ultimately reduces the cost of the subsequent assessment. In view of the ongoing demand for FASD diagnostic services within the public system, we would advocate that this reassessment, if required, be built into NDIS funding completed by therapist that already have developed a relationship with the child and family. Individual clinicians can then reach out to services like our own, or the child's private paediatricians to provide clinical guidance on whether FASD diagnosis is now met.

Outside of NDIS, there are currently very limited other avenues for diagnostic / intervention FASD supports. The only options for families would be either through current Medicare Funding Schemes via GP, which has prohibitive gap payments or paying completely for private services. As highlighted above, we are not aware that a final decision has been made regarding utilisation of Medicare 135/137 sessions for children with FASD.

Our experience, suggests that children under Guardianship with the Department of Child Safety, are further disadvantaged, with significant reluctance, to subsidise these additional costs. Child Development Services, like our own, are not funded to be able to provide longer term intervention / therapy supports for this cohort of children.

As per previous submissions, even the current more restrictive FASD diagnostic criteria is not recognised for Education Supports, unless the child also meets other Education criteria i.e. Intellectual Impairment or Autism, creating a significant gap in service supports for these children.

The key to successfully supporting individuals with complex presentations like FASD is a person centred, holistic care approach. In the case of children this means integrated and consistent treatment and support across home, school and social contexts. Any approach to strategically planning treatment for children on the fetal alcohol "Spectrum" should seek to remove siloing within contexts and implement a comprehensive and cohesive approach to supporting growth of the child, ensuring that all areas of the ecological model[10]: child / family / community / society are supported i.e. including individual therapy for the child and family, additional education or group supports for the child and family within the community and reduction of legislations / policies that become unsurmountable barriers. Until all layers are addressed, there will always be individuals that continue to fall through the gap, and subsequently cost the economy significantly in secondary disabilities.

---

[7] Whilst ECEI cut off is < 7 years, local experience over the past 12 months, has been that as soon as a child is > 6 years NDIS >7 restrictions have been placed on their NDIS application requests.

[8] Current decision is arbitrarily based solely on a child's age.

[9] Clinical recommendations for repeat assessments typically occur at key transitional periods i.e. commencement of school, transition to high school, transition to young adult – where an individual child's functional impairment is more likely to be identified as significant.

[10] Uriel Bronfenbrenner – Ecological Systems Theory

Question 4

The Uni of Qld submission suggests that FASD assessment and diagnostic services should become part of routine practice across a wide range of settings (GP, psychology, OTs etc who could have this embedded in their uni training) and specialist services such as yours can then be reserved for the most complex cases. What are your views on this approach?

In principle, we are supportive of this approach, especially as the simple calculation of demand[11] vs resources clearly recognise insufficient public (child development equivalent) or private services available to meet the needs of all children and adults at risk of FASD.

As per our submissions and subsequent discussion, the best model would be a tiered approach;

- Level 1 - The more 'simple cases'[12] are diagnosed within primary care and immediately linked into disability support services for intervention.
- Level 2 - The moderately complex cases requiring a multidisciplinary approach could utilise a combination of GPs, school (guidance officers), allied health and paediatricians / mental health specialists (either individually or within the context of a Child Development or equivalent Multidisciplinary team)
- Level 3 - Tertiary services, such as our own, would then be available to provide enhanced clinical support of Tier 2 services i.e. in the form of joining case discussions to assist with any diagnostic uncertainty, and / or providing additional formal tertiary level assessment if clinically indicated; especially when local services are unavailable. Other roles for Tier 3 services would including advances in diagnostic processes, research, training and FASD advocacy.

Whilst in theory this approach has merit, implementation of this strategy, will require significant further logistical development.

For the model to be successful, it would require an increased awareness of FASD in both the community and individual clinicians. Raising awareness for FASD should be addressed as part of a population health strategy.

Individual clinicians then must be upskilled in FASD, particularly around what is achievable within primary care or single allied health services, and how to utilise your multidisciplinary colleagues when required.

Our understanding is that currently there is very limited specific information around FASD in most undergraduate programmes i.e. speech pathology, psychology, occupational therapy, physiotherapy, social work, nursing and medicine. Whilst the skills taught in the existing curricula are indeed the same skills needed to assess FASD, they are predominantly taught within the silo of each individual health profession. The diagnosis of FASD in the majority of cases requires a multidisciplinary collaborative approach between disciplines. If FASD were taught within university programmes it could be used as an exemplar of multidisciplinary real-world collaborative practice making it a significant value-add for each course and a win-win-win for the institution , the graduate and the patients.

Within the Gold Coast, both our allied health clinicians and Paediatricians have engaged with local university courses to provide some FASD training, whilst feedback has been positive, sessions still remain limited to individual disciplines and only one lecture.

Finally, the most significant hurdle will be the additional demand it would place on Primary Care, particularly our GP colleagues. In conversations, outside of FASD, we are aware there is an exponential trend of historically tertiary based services being pushed into primary care. FASD diagnosis, would

---

[11] Current estimated prevalence of FASD within Australia to be between 2-5%. 50-60% of pregnancies are unplanned - In 2016, of women who reported they were unaware of being pregnant for part of their pregnancy, with 1 in 2 (49%) drinking alcohol before they knew they were pregnant and 1 in 4 (25%) continued to drink, once pregnancy was confirmed.

[12] Further work would be required to define 'simple FASD cases' – likely to include child with confirmed high prenatal alcohol use, severe global developmental delay (in the absence of confounding factors) +/- FAS facial features / or microcephaly.

therefore need to compete with all other areas of health care; both in terms of GP's time for education / training as well as their day to day clinical activities.

Within the Gold Coast we have had some preliminary conversations around GP's with special interests in particular areas i.e. ADHD, Children in Care or Adolescent -Youth Friendly, however initial discussions indicates that this approach is not universally supported and raises a number of other practical concerns.

Finally, for Primary Care providers (medical and allied health) to embrace Level 1 FASD diagnostic assessments, the barriers around Medicare Reimbursement will need to be addressed. Even for a 'simple FASD cases', an individual clinician will need to allocate direct patient time to complete a developmental history and relevant examination which typically will exceed current consultation guidelines. There is also likely to be significant indirect time e.g. to collect and collate all available information, participate in multidisciplinary case conferencing, and complete referrals to necessary services, much of which is also currently not claimable under the Medicare Scheme.

Question 5

UQ suggested that, given the high rate of co-morbidity, that there should be routine screening for FASD in patients presenting with some of the frequently occurring comorbid conditions. And children undergoing assessment for FASD should also receive holistic assessment of their physical health. Are you supportive of that approach?

We are definitely supportive of this approach, and this is certainly something that we do within our own service, either specifically during a formal FASD diagnostic assessment or when a child is seen within any of our other clinical services i.e. for medical review with a Paediatrician.

Co-morbidities for children with FASD include both developmental / behavioural / mental health conditions e.g. ADHD, Developmental Co-ordination disorder, Anxiety or Autism, as well as more typical 'health' or 'physical' co-morbidities e.g. constipation / toileting, hearing and other ENT presentations, sleep disorders, or other muscle / joint presentations.

Co-morbidities may occur either as a direct result of pre-natal alcohol consumption or due to other co-founding factors i.e. genetic family history, poor antenatal care, prematurity, exposure to other adverse child experiences[13].

As previously alluded to, whilst co-morbidities definitely exist within this population, our experience is that some children may be labelled as having additional co-morbid diagnosis, where FASD may be the better explanation i.e. a child diagnosed with Oppositional Defiance Disorder (ODD), where symptoms are better explained by FASD related dysexecutive problems, which in turn requires an alternative approach to intervention management.

In view of the intertwining of FASD and cofounding risk factors, in addition to screening for co-morbidities, we also practice and would strongly advocate screening for all pre-natal and post-natal experiences that will interplay with a child's presentation and their subsequently their response to intervention.

Work completed by UQ, along with our current database, could be used to identify the key co-morbidities / co-founding factors and best options for screening including timing and screening tools particularly for children under the age of 16 years. Whilst, outside the scope of our clinical experience, there would also be additional co-morbidities that are only identified later in adults with FASD, this would indicate that screening for key co-morbid diagnoses would need to occur across the lifespan of the child-young person-adult.

It is also important to acknowledged that when looking at co-morbidities, that the reverse is also applicable i.e. any child presenting initially with concerns with a co-morbidity diagnosis e.g. Congenital Heart Disease, Learning Problems, Emotional Dysregulation or other mental health conditions should also be routinely

---

[13] Adverse Child Experiences – ACE

asked about alcohol use in pregnancy. This is addressed within the framework of increased community awareness.

Thank you again for this opportunity to continue to provide additional information, for us this clearly represents the commitment that both yourself and the Senate have made to ensure a significant depth of understanding to this complex situation.

As always, we would be more than happy to provide further clarification or additional information.

Authors:

Dr Haydn Till
B.Soc.Sci. (Psych), Hons 1st Class, M.Clin.Neuropsych., Ph.D., JP Qual. (Qld)
Registered Psychologist and Endorsed Clinical Neuropsychologist
Advanced Clinical Neuropsychologist | Child Development Service - Gold Coast Health
Clinical Lead | FASD Clinic – Child Development Service - Gold Coast Health
Adjunct Fellow | Macquarie University
Senior Lecturer | Griffith University

Dr Francoise Butel
BHB, MBChB, Cert Public Health, FRACP (General / Community Child Development)
Paediatrician
Team Leader | Child Development Service
Director | Community Child Health – Gold Coast Health

A/Prof Doug Shelton
MB BS, Dip Paed, FRACP
Churchill Fellow
Eminent Staff Specialist
Clinical Director | Women's & Children's Health Services - Gold Coast Health
Senior Lecturer | Griffith University
Honorary Adjunct Associate Professor | Bond University

Appendix - Preliminary costing for GCHHS Child Development Service Telehealth Clinic to Assess FASD

This preliminary budget is based on an expected number of 50 rural/referrals being completed in a calendar year using a tiered telehealth assessment. The assessment paradigm is based on the current brain domains that are or can readily be formally assessable remotely (i.e. motor domain will not be directly assessed).

The Multidisciplinary Team for this clinic will include the following disciplines and proportional employment. The approximate cost (including oncosts) for the positions are also offered. Please note, that these costs may vary slightly in a formal budget proposal:

Discipline	FTE	$
Developmental Paediatrician	0.4	120,000
Clinical Neuropsychologist	0.8	120,000
Speech and Language Pathologist	0.4	60,000
Social Worker	0.4	60,000
Administration Support	0.4	40,000
	Ongoing Wages Per Annum	**380,000**

GCHHS is currently well established for most IT related elements for delivering Telehealth services. The addition of this service would include the development of specific IT processes to facilitate some of the assessment process that is not currently available off the shelf (secure portal for test delivery and remote responding on computer tests).

The estimated cost of this development is **$45000**.

Elements of the assessment process not currently used by our service but for which equivalent online/Telehealth delivered formats are available will cost an additional **$30000**.

Formal model development and validation is a critical part of this initial clinic development. Validation will inform operational model and cost structure to a level that will allow it to be replicated nationally. Validation will be conducted in partnership with a university partner.

The estimated cost of this validation is **$60000** with in-kind contribution from the university partner.

The cost is $515,000 per year. We would look to complete a three-year block funded service in order to establish and validate the model of care across a substantial number of cases. Therefore, total funding over 3 years would be **$1,545,000**