National FASD Clinic and Clinical Network Plan

Purpose

The purpose of this proposal is to establish a National Fetal Alcohol Spectrum Disorders (FASD) Clinic and Clinical Network across Australia.

Overview of FASD activities

Government policy in responding to FASD is at a critical junction in Australia. Researchers and passionate individuals have worked tirelessly to raise awareness of FASD at local and national levels. The success of these efforts resulted in an Inquiry by the House of Representatives Social Policy and Legal Affairs into FASD in 2012.

The Foundation for Alcohol Research and Education (FARE) played a pivotal role during the Inquiry, and in responding to FASD, by coordinating the development of *The Australian FASD Action Plan 2013-2016* (Action Plan) which was released in September 2012. The Action Plan describes the actions required to reduce the number of people born with FASD and support those affected. FARE worked with 33 key researchers, clinicians and parent and carers groups to develop the plan which is a fully costed roadmap for action.

In 2013, the Labor Government released the *Commonwealth Action Plan to reduce the Impact of FASD*. This was re-released by the incoming Liberal Government in August 2014. As part of this plan, five priority areas have been identified and a Technical Network was established to oversee its implementation.

There have also been a number of research projects taking place across Australia over the last few years. One of the most comprehensive has been the Lililwan project in the Fitzroy Valley in Western Australia. As part of the Lililwan project, all children born in 2002 and 2003 were assessed by a specialist multidisciplinary team that travelled to the community. This project found high rates of alcohol consumption among pregnant women and high rates of FASD. The Telethon Kids Institute and Sydney University, funded by the Australian Government, are currently coordinating a national pilot of the Australian FASD Diagnostic tool and this work is expected to be completed by the end of the year.

Nevertheless, across Australia the prevalence of FASD remains unknown. This is due in part to the lack of diagnostic opportunities, lack of standardised diagnostic screening and collection of data, as well as a lack of awareness about the issue. Fundamental to improving outcomes for FASD is improving diagnostic capacity, including funding clinics and training health professionals in how to diagnose FASD. This proposal addresses these issues.

Proposal

1. Creation of National FASD Clinical Network

Currently in Australia there are limited opportunities for a child to receive a diagnostic assessment for a Fetal Alcohol Spectrum Disorder (FASD). There are three operational diagnostic clinic models, one located at The Children's Hospital at Westmead in Sydney, New South Wales, one at the Community Child Health Service in the Gold Coast, Queensland, and the PATCHES Paediatrics rural and remote FASD clinic model in the Kimberley and Pilbara regions of Western Australia.

However, across Australia there are a growing number of clinicians who undertaking FASD diagnosis or trying to establish diagnostic services in their area. Funding for these clinicians is extremely limited and there is no national coordination of the services, the diagnostic tool used, or training on FASD diagnosis. This has resulted in a situation where different clinicians are using different diagnostic systems and criteria.

The creation of a National FASD Clinical Network will ensure standardisation of approaches to FASD assessment, diagnosis, data collection and management, and post-diagnosis interventions across Australia, as well as use of the Australian Diagnostic instrument. It will also allow information sharing between clinical teams to ensure consistency.

To this end, the Telethon Kids Institute has taken initial steps to establish a network and have called the first meeting of clinical representatives in October 2015. It is envisaged that a senior representative from each clinical team/service would attend clinical network meetings (held by teleconference). The Network would aim to achieve the following:

- Provide collegiate support in establishing and expanding FASD diagnostic services.
- Create and maintain a database of all clinicians undertaking FASD diagnosis.
- Develop a standardised, defined set of protocols for FASD screening, referral, assessment, diagnosis, data management, therapy and reporting.
- Maintain a database of FASD diagnosis and outcomes, and make this information available for use by researchers and those working on service delivery improvement.
- Work towards the development of an accredited FASD diagnostic training program.

It has been identified that there are currently over 30 specialists who could join the network initially and once established, this number would increase over time.

It is planned that the National Coordinator and administrative officer for the network would:

- Establish the processes and databases for the network.
- Provide the secretariat role for the network and coordination of teleconference meetings and minutes.
- Maintain databases and ensure the completeness of data entered.
- Prepare reports and briefs for the Network based on the data obtained.

It is also proposed that the FASD Clinical Network hold clinical forums once each year (starting in year two) to engage a wider audience of clinicians and allied health professionals to update on professional standards for FASD in Australia.

2. Establishment of FASD Diagnostic clinics in different settings across Australia

As proposed in *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016* improving the diagnostic rates and diagnostic capacity for FASD would result in those affected receiving greater support and assistance. Obtaining a diagnosis for FASD early in one's life is crucial to improving that individual's life. A diagnosis allows for an understanding of the specific deficits that an individual has and identification of the appropriate healthcare, education, and service needs of the individual and families/carers.

When the primary disabilities of FASD are undiagnosed or misunderstood, this can result in the person with FASD developing secondary disabilities such as mental health issues, alcohol and drug problems, disrupted school experiences and inappropriate sexual behaviours. Early diagnosis and intervention can help to minimise these secondary disabilities. Therefore, building Australia's capacity to diagnose FASD is essential.

FASD diagnosis is determined through a multidisciplinary approach undertaken by a range of health professionals including: paediatricians, clinical or neuro psychologists, occupational therapists, speech and language therapists, physiotherapists, and social workers.

There are different models of how a clinic can operate, and FARE's FASD Plan present four options. Two models are currently being used by the existing services and Australia needs to test a range of diagnostic clinic models to deliver services in metropolitan cities; rural centres and in remote regions. There are different issues in access to health services in metropolitan, rural and regional areas.

The two existing metropolitan clinics receive some support from state governments. The clinic at The Children's Hospital at Westmead has been awarded $300,000 per year for four years from the New South Wales Government. The Gold Coast clinic is funded through existing resources within the Community Child Health Service. Neither of these clinics operate on a full-time basis. A third metropolitan clinic at the University of Western Australia has received $200,000 per year for two years and will respond mainly to justice system referrals.

Dr James Fitzpatrick from PATCHES Paediatrics (Paediatric Child Health and Education Services) has established FASD clinics in remote communities in Western Australia including Broome, Derby, Fitzroy Valley, Port Hedland and Karratha, and in metropolitan Perth. PATCHES is based on a mainstream funding model, through the Rural Health Outreach Funding (RHOF), Medicare Benefits Scheme and Disability Services funding for therapy follow-up. These clinics operate on a fly-in-fly-out model that is supported by local care coordinators and Aboriginal Therapists. This model has the potential to be scaled to additional remote, regional and metropolitan sites across Australia, and the bulk of funding for this model can be accessed through mainstream funding mechanisms.

Alongside these clinics, it is proposed that a rural diagnostic clinic be established in Shepparton, Victoria. There are currently no services for FASD diagnosis in Victoria and this would be the first rural FASD diagnostic clinic in Australia. The clinic would be based at Goulburn Valley Health in Shepparton and take children from across the Goulbourn Valley region.

It is proposed that the clinic will link with existing obstetric and paediatric services (including pre-conception, pregnancy, postnatal and infancy clinical areas), existing child development services, and provide training opportunities through the Rural Health Academic School, Melbourne Medical School, Melbourne University.

Different clinical models for FASD diagnosis are required in Australia and the diagnostic capacity needs to be urgently increased. Australian Government funding to these four clinics would see the testing of clinic models in metropolitan, rural, regional and remote areas of Australia. These models could be then replicated across Australia.

Project budget

Funding: $3.1 million over three years would allow for the creation of the National FASD Clinical Network and the establishment and continuation of FASD diagnostic clinics across Australia. Commitments of Australian Government funding are needed to ensure that the existing clinics continue to operate and are able to expand their coverage.

3. Indicative budget

Item	Year 1	Year 2	Year 3	Commonwealth Funds (total)
Creation of National FASD Clinical Network				
Clinical Network coordinator (FTE 0.6)	$69,308	$73,467	$73,467	$216,242
Administrative officer (FTE 0.4)	$31,906	$33,830	$33,830	$99,566
Salary on costs	$20,243	$21,460	$21,460	$63,163
Development of databases and maintenance	$10,000	$10,000	$10,000	$30,000
Clinical forum to exchange information and expertise	-	$70,000	$70,000	$140,000
Total	**$131,457**	**$208,757**	**$208,757**	**$548,971**
Establishment of FASD Diagnostic clinic Goulburn				
Personnel Salaries include:	$139,436	$141,360	$141,360	$422,156
General paediatrician (0.1FTE)	*$32,530*	*$32,530*	*$32,530*	*$97,590*
Developmental paediatrician (0.125 FTE)	*$41,000*	*$41,000*	*$41,000*	*$123,000*
Clinical Psychologist (0.1FTE)	*$12,000*	*$12,000*	*$12,000*	*$36,000*
Speech Pathologist (0.1FTE)	*$11,000*	*$11,000*	*$11,000*	*$33,000*
Social Worker (0.1 FTE)	*$11,000*	*$11,000*	*$11,000*	*$33,000*
Administrative officer (FTE 0.4)	*$31,906*	*$33,830*	*$33,830*	*$99,566*
Support for Rural Clinical Student placements	$27,767	$46,600	$49,458	$123,825
Assets: Equipment / Capital (Psychological and developmental assessment tools, 3D FASD facial camera and photographic analysis software)	$20,000			$20,000
Administration / Overheads	$40,000	$50,000	$50,000	$140,000
Evaluation		$11,688	$12,039	$23,727
Total	**$227,203**	**$249,648**	**$252,857**	**$729,708**
Funding for existing FASD diagnostic clinics				
Supplementary funding for Westmead clinic	$125,000	$125,000	$125,000	$375,000
Supplementary funding for Gold Coast clinic	$180,000	$180,000	$180,000	$540,000
Funding for PATCHES remote clinics in Western Australia (Kimberley and Pilbara)	$350,000	$300,000	$300,000	$950,000
Total	**$655,000**	**$605,000**	**$605,000**	**$1,865,000**
Overall total (excluding GST)	**$1,013,660**	**$1,063,405**	**$1,066,614**	**$3,143,679**