Northern Territory Government

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To the House Standing Committee for Social Policy and Legal Affairs

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Re: Inquiry into Foetal Alcohol Spectrum Disorder

The Paediatricians at Royal Darwin Hospital wish to make a submission to this important Enquiry.

We believe we are best placed to comment on the Intervention needs and Management Issues of Foetal Alcohol Spectrum Disorders (FASDs) in the Top End of the Northern Territory as outlined in the Terms of Reference.

Summary

We believe that FASDs are difficult to diagnose, under-recognized and poorly managed in the top end of the NT. Therefore affected individuals and families are not receiving the necessary support and intervention that may limit the lifelong consequences of their impairments and the opportunity to prevent FASDs in future children is being missed

Rates of FASD in the NT are not know but we believe the rates in the NT may very high, perhaps the highest in the Australia, given high rates of alcohol consumption and the poor performance of Northern Territory Children on measures of developmental status and school performance.

We support the development of National measures to enhance the diagnosis of FASD, document rates, monitor outcomes and improve access to therapeutic intervention for affected families. However the unique setting of health care services in the Northern Territory and the particular needs of remote dwelling Australian's must be given due attention.

There is evidence of Foetal Alcohol Syndrome rates in the Top End of the NT which includes a 3-4 times higher rate of FAS in the indigenous community. (1) Therefore the specific needs of remote dwelling Indigenous children must be considered in the further development of services for families affected by FASD in the NT.

We support measures that have been shown to reduce alcohol consumption generally such as reducing availability and increasing price.

We support the further development of therapeutic services for individual's burdened by alcohol and other substance abuse and particularly the development of services for young women.

Background

It is well known that alcohol consumption in the NT, as measured by sales data, has been substantially higher, generally of the order of 50% higher, than the national rate for decades. (2,3) As measured by self-reported consumption in the National Drug Strategy Household surveys (NDSHS), the proportions of Territorians who drink at risky levels is substantially higher than the national rate and all other jurisdictions (4,5,6). The 2010 NDSHS reports NT women being 1.5-2.0 more likely to drink at risky levels for short and long term harm and abstaining at significantly lower rates than the national average. (6) Of national significance the recent NDSHS reports alcohol consumption at risky or high risk levels in Indigenous Australians at twice the national rate and 1.5 times the national rate for Remote and very remote dwelling Australians. (6) Further evidence of the burden of alcohol related harm in the NT is that it has the Nation's highest rate of hospitalization and death attributed to alcohol. (7,8)

In the most recent Australian Early Developmental Index (AEDI) report NT children were found to have the highest rates of developmental vulnerability. Thirty eighty percent of NT children assessed were found to be developmentally vulnerable on one or more of the domains tested, compared 23.6% of children nationally. (9) The AEDI community data highlights the huge disparity in developmental status between the children of extremely remote communities in the NT and Australian children generally. eg. 80.9% of children in the Daly region where found to be developmentally vulnerable in 2 or more domains compared with 11.8% nationally. (10). Similarly the NAPLAN report from 2011 documents a large disparity in measures of school achievement with over 80% of Indigenous and extremely remote dwelling children in the NT not meeting national minimum standards on a number of measures. (11) Clearly there are many factors contributing to this large gulf in developmental status and school achievement but in the jurisdiction that has countries highest levels of alcohol consumption it is not unreasonable to assume that FASD may be a significant contributor.

Intervention Needs and Management Issues

The Paediatricians employed by the Royal Darwin Hospital play a pivotal role in the screening and diagnosis of FASDs in the Top End of the Northern Territory. The majority of Paediatricians in the NT are General Paediatricians supported by intermittent visiting sub specialists. Currently there are no resident and or visiting Behavioural or Developmental Paediatricians, Paediatric Neurologists or Geneticists who at times may assist in the assessment of children in regard to FASDs. General Paediatric clinics are conducted at remote and urban Indigenous Health Clinics in addition to Royal Darwin Hospital and Darwin Private Hospital. A large percentage of referrals to these clinics involve a request for further assessment of growth, behaviour and or cognitive problems. (30% of referrals to RDH Paediatric clinic in 2011 cited a behavioural and or learning problem – personal communication). Therefore FASD is a consideration in a large number of the children seen. The exact rates of FASD are not known but given the high rates of alcohol consumption, teenage pregnancy and social deprivation in the NT it is likely the rates of FASD are particularly high in our community. Harris and Bucens in a 10 year retrospective study in the

top end of the Northern Territory documented Foetal Alcohol Syndrome (FAS) rates of 0.68-1.87 per 1000 overall live births and 1.7-4.7 per 1000 indigenous live births. (1) Much higher rates have been documented in communities with very poor social determinants of health such as the Western Cape Province in South Africa, i.e. 39 per 1000 live births. It is likely this is an underestimate of FAS and rates FASD rates are significantly higher again. (12)

The diagnosis of FASD in the Top End of the NT is made by individual Paediatricians with the assistance of further assessments by Psychologists, Speech therapists, educational specialists and Occupational therapists. Therefore diagnosis relies on a number of factors, in particular Specialist Paediatric and Allied health capacity and individual expertise. There have been no screening programs to date. The diagnosis of a FASD is not an easy task given the range of presentations ,the variation in professional knowledge, the absence of facial anomalies, the requirement to confirm in utero alcohol consumption and the need to consider many other contributing factors.(13) Specific FASD diagnostic tools are not routinely used and if recommended there would need to be a significant investment in training and increased Paediatric, Speech therapy, Psychology and Occupational health capacity across all areas of the Top End of the Northern Territory. There are often significant delays in the assessment and diagnosis of children with neurodevelopmental problems. The Darwin Children's Development Team, the main provider of publicly funded Community Allied Health Services in the Darwin Urban region, currently has the following waiting times. Children aged 0-4 years wait 16 months for assessment by a Speech Pathologist and 14 months for assessment by an Occupational Therapist whilst children aged 4-6 years wait 20 months for a Speech Therapy assessment and 24 months for an Occupational Therapy assessment. (personal communication Janice Diamond acting Manager Children's Development Team Darwin, June 2012). Most families are not able to fund assessments with the small number of private practitioners. Access to multidisciplinary assessments in the remote community setting is believed to be significantly poorer. The recent the development of an outreach multidisciplinary team is positively acknowledged.

Once children have been assessed and diagnosed as in need of developmental and or behavioural therapeutic intervention there is also significantly limited capacity. In the Darwin Urban area the Carpentaria Disability Service is the primary provider of publicly funded multidisciplinary early intervention services and currently provide therapeutic intervention to children up to school age in whom developmental delays are detected in 3 or more domains, i.e. a high level of developmental delay and therapeutic need. Children with FASD therefore may not qualify for their service so join the long waiting lists at the Children's Development team or see private therapists if able. (Personal communication John Callanan, Psychologist, Carpentaria Disability Service – June 2012) Once children reach school age, the Department of Education and Training in conjunction with Darwin Children's Development Team, are the main publicly funded provider of therapeutic services for children with learning, developmental, behavioural and or physical disability. The experience of Paediatricians, Carpentaria Disability services Staff and Darwin Children's Development Team staff involved in the care of children with these difficulties is that their therapeutic needs are not being meet due to limited therapist capacity and infrastructure across the Top End of the NT. The amount of unmet therapeutic need in school age children and remote communities is thought to be significantly greater. Any efforts to increase the diagnostic capacity for FASDs in the NT must be matched by a significant increase in capacity to provide corresponding therapeutic intervention across the whole of the NT.

There are many children in the Top End of the Northern Territory waiting unacceptably long periods of time for assessment and diagnosis of developmental, learning and or behavioural problems. There is a widespread believe that their subsequent therapeutic needs are not being met particularly the school age and remote dwelling children of the NT. We do not

know how many of these children may have been harmed by alcohol exposure in utero but it is likely to be a substantial proportion. We do not know the details of their developmental, educational and adult outcomes but based on international literature the individuals affected by FASDs in the Top End of the NT are likely to be greatly overrepresented amongst the children performing poorly on the AEDI and NAPLAN assessments and the individuals involved in the child protection system, the justice system and the unemployed.

Therefore we welcome evidence based measures that will help us with the timely diagnosis, targeted intervention and preventative measures for families affected by FASD. At a population level there is evidence that increasing price (i.e. taxation) and reducing availability (i.e. Outlet regulation) will reduce alcohol consumption and related harms. We believe if implemented these measures will have an impact on all population groups including young women and reduce rates of FASDs (14) Finally the difficulties associated with delivering services to families from some of the most remote and challenged communities in Australia must be a priority in the NT.

Thank you for considering our submission

Yours Faithfully

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Dr Paul Bauert, Director of Paediatrics, Royal Darwin Hospital

Dr Peter Morris, Paediatrician, Royal Darwin Hospital

Dr Keith Edwards,Paediatrician, Royal Darwin Hospital

Dr Ruth Lennox, Paediatrician, Royal Darwin Hospital

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Dr Kathryn Roberts, Paediatrician, Royal Darwin Hospital

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For Correspondence, Dr Louise Martin, [redacted], [redacted]

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