



**House Standing Committee on Indigenous Affairs
Australian Parliament House
Canberra ACT 2600
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**Submission to the Australian Government Inquiry into the harmful use
of alcohol in Aboriginal and Torres Strait Islander Communities.**

Dear Standing Committee members,

We welcome the Australian Government's interest in developing considered policy responses to alcohol use in Aboriginal and Torres Strait Islander communities, and to Fetal Alcohol Spectrum Disorder (FASD).

I submit this document on behalf of the Alcohol and Pregnancy & FASD Research Team at Telethon Kids Institute, Perth Western Australia. Our team has collaborated on National FASD-related research into screening, prevention, diagnosis and therapeutic interventions. Recently our group was approached by the National Disability Insurance Agency to provide advice on the implications of FASD for the NDIS. We believe that the current Inquiry provides an excellent opportunity to share the collective experience of consumers, clinicians and researchers in this field.

We present the following focused information on alcohol use patterns in Aboriginal communities, including during pregnancy. Our focus for this submission is on the remote Kimberley communities of the Fitzroy Valley with whom we have strong research partnerships. We also summarise FASD prevalence in Australia and relate this to the economic and health service implications of FASD in the field of disability.

We would welcome the opportunity to provide further information to the Inquiry either through supplementary written submissions, or by appearing before the Inquiry Committee, should this be requested of us.

Dr James Fitzpatrick

On behalf of the Telethon Kids Institute Alcohol and Pregnancy
and Fetal Alcohol Spectrum Disorder Research Team
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Alcohol and the Kimberley:

Ethanol (here termed alcohol) is the organic compound used in alcoholic beverages. It is a mood altering substance that, consumed in moderation, has an established and generally positive role in Australian society. However, when used in excess, in early life or during pregnancy, alcohol has significant health impacts including increased cancer risk, impairment of judgement and memory, organ system damage (e.g. liver, brain), interruption of brain development, and fetal alcohol spectrum disorder (FASD).(5, 6)

Australia has among the highest alcohol consumption in the world, at 10 litres of pure alcohol per annum per person aged 15 years or over.⁵ Localised data is available for certain geographical areas. For instance, prior to alcohol restrictions being introduced in Fitzroy Crossing, the annual per capita consumption of pure alcohol was estimated to be 27 litres, which equated to 35 cans of beer per week for every person in Fitzroy Crossing.(9)

Alcohol use in pregnancy is common in Australia, with up to 51-60% of Australian women consuming some amount of alcohol during pregnancy.^{6,7} Research suggests that Indigenous Australian women are less likely than non-Indigenous women to drink in pregnancy,⁸ but are more likely to drink at hazardous levels.⁶ The authors of this submission have partnered with Aboriginal organisations Nindilingarri Cultural Health Service, Marninwarntikura Women's Resource Centre, and research partners The George Institute and Sydney University, to conduct a landmark study in the Fitzroy Valley, The Lililwan Project. This study will document, for the first time, alcohol use in pregnancy and FASD prevalence in an entire population cohort.(11) It is expected that high rates of drinking in pregnancy, particularly at high-risk levels, will be reported.(12, 13)

Overcoming alcohol in the Kimberley region, a case study: The Fitzroy Valley Alcohol Restrictions

The Fitzroy Valley, 40km East of Broome, is home to 4,500 people (~60% Aboriginal), and comprises some 45 discrete communities with Fitzroy Crossing as main the service centre.(1) In 2006 these communities were in a crisis with unprecedented high rates of alcohol abuse and related harms, violence and death. In response to 55 deaths (13 suicides) in their community in the space of 12 months, community members called for a coronial inquiry into deaths in region. This inquiry found that alcohol was a contributing factor in each of 22 deaths investigated.(3, 4) These findings prompted local community leaders to call for alcohol restrictions that were legislated by the Director of Liquor Licensing in September 2007 such that 'the sale of packaged liquor, exceeding a concentration of ethanol in liquor of 2.7%... is prohibited to any person, other than a lodger'.(7)

The social and health benefits of these community-led, targeted restrictions demonstrate their immediate and enduring positive impact, with an 88% reduction in sales of pure alcohol at a local outlet (from 104 to 23 litres/day), a reduction in alcohol-related police tasks (28%) and alcohol-related hospital admissions (36%), and an increase in school attendance (14%).(4, 8) In addition to demonstrated local success, national research indicates that alcohol restrictions are effective if locally supported and universally applied.(10)

Fetal Alcohol Spectrum Disorder (FASD):

FASD includes a group of clinical diagnoses relating to permanent damage to brain structure and/or function in the context of alcohol exposure during pregnancy. FASD can be diagnosed with or without a recognisable pattern of facial features, growth impairment and birth defects (Fetal Alcohol Syndrome). The consistent feature of FASD is severe lifelong learning and behavioural impairment.(14) Lifelong effects are significant, with 90% of adults with Fetal Alcohol Syndrome having mental health problems, 60% having trouble with the law and disrupted education, 40% having substance abuse issues, and fewer than 10% living or working independently by 21 years of age.(15) FASD most often occurs in the context of early life trauma and disadvantage in the early years, including low socioeconomic status and welfare dependency; and exposure to household stressors including food insecurity, single parenthood, domestic violence, and mental health issues in a carer.(16) For these reasons, it is important to address the causal pathways to drinking in pregnancy, as well as the family and community-level supports and interventions required to prevent FASD, and to support those affected.

Prevalence of FASD varies internationally. International data suggest that 1-2% of the population in the US are affected by FASD.(17) Higher prevalence is observed in communities with high-risk drinking patterns, including Indigenous communities in Canada, the US and Australia.(17) In Australia it is likely that FASD prevalence (0.68 per 1000 births) has been underestimated.(18) The highest rates of FASD reported worldwide to date were documented in school-based studies of Cape Coloured populations in South Africa, where FASD prevalence rates of 210 per 1000 (21%) were found.(19)

The power of data in influencing policy, The Lililwan Project:

In 2009 community leaders commissioned The Lililwan Project FASD prevalence study, in partnership with The George Institute for Global Health and Sydney University. Data from this study are not available at the time of writing, however the process of community-led research generating high quality prevalence data has had significant impact on policy and practice. The Lililwan Project has provided FASD prevention locally, and at a regional level in the Kimberley. The research methodology has informed models for multidisciplinary FASD assessment and diagnosis. Significantly, the high profile use of film in advocacy and leveraging relationships at the Australian Human Rights Commission, Australian Government and United Nations has placed the issue of FASD on the national agenda. The processes and findings of the Lililwan Project have informed policy and practice through an Australian Government Inquiry into FASD (2012), the United Nations Forum on First Peoples (2010, 2012), and a World Health Organisation Global FASD prevalence study methodology (2013). High quality research, when coupled with innovative advocacy, has the potential to influence policy nationally and globally.

The economic and social impact of FASD:

FASD is the leading causes of preventable intellectual disability and cost up to \$5.4 billion per year in the US.(20) The lifetime cost in terms of service use and loss of productivity for an individual with Fetal Alcohol Syndrome (FAS) is estimated to be US\$2.5 million.(21) For those with any diagnosis on the FASD spectrum the cost is up to US\$22,000 per year over their lifetime.(21) These estimates exclude welfare and justice costs, which add dramatically to the economic burden. Significantly, it is estimated that 25% of juveniles in detention have a diagnosis on the FASD spectrum.(17, 22)

Diagnosis of FASD requires a multidisciplinary team, ideally comprising a paediatrician, psychologist, occupational therapist, speech pathologist, physiotherapist and social worker. A Canadian study has been estimated that the cost of a diagnostic assessment is \$3,110-\$4,570 CAD per person.(20) A diagnosis of FASD requires that significant impairment of 3 or more neurocognitive domains, or two domains plus structural central nervous system abnormality are present. Therefore those with FASD represent a population with a disability as defined for other neurodevelopmental disorders.

Early diagnosis and intervention is crucial in reducing secondary disability in FASD. Currently supported programs such as Better Start provide funding for a range of neurodevelopmental conditions, and we argue that FASD should be included on the list of Better Start eligible diagnoses. As Australia moves away from a diagnosis-based disability funding, the NDIS operational guidelines for therapy support estimate that \$12,000-\$16,000 in therapy per annum would be required to provide early intervention support (0-6 years). In FASD diagnosis is often delayed, and it is important that any disability support funding should acknowledge this by extending eligibility age to 8-10 years.

Overcoming Alcohol in the Kimberley, Strategies for Implementation:

Preventative and other interventions are required to reduce future incidence and impact of alcohol-related harm and FASD. An appropriate theoretical framework for Kimberley-wide action on alcohol and FASD is the social ecological model.(23) This model is cross-sectoral and integrates policy, environmental, organisational, community and individual strategies to address a specific public health issue.(23) Social ecological theory has been demonstrated as an effective and appropriate framework when delivering social initiatives in remote Northern Territory communities.(24) Importantly, policy and environmental interventions that are community-led, including alcohol restrictions, have been reported to be the most effective and sustainable.(10) Effective advocacy on public health issues such as smoking that use combine research, marketing and high-level advocacy can raise awareness of and result in policy change for important health issues.(25, 26)

The impact of alcohol on Kimberley communities can be reduced by implementing strategies that reduce alcohol demand, restrict alcohol supply, gather high quality data, provide public health messaging and targeted messaging for high risk groups, build capacity in local organisations, and support those families and individuals most impacted by alcohol and FASD. Successful local models may be scaled into state wide and national impact by raising the awareness through high quality research of the effectiveness of interventions, lobbying Government and shaping policy that addresses causal pathways, system-wide and targeted interventions.

The art of the possible: FASD prevention in the Fitzroy Valley

In 2008, the Fitzroy Valley communities in partnership with local clinicians, educators, and national research institutes, initiated a multifaceted strategy to overcome FASD, termed The Marulu Strategy.(2) The initial stages involved documenting FASD prevalence through diagnosis, building local awareness and advocating for community resources. From 2013, a comprehensive FASD Prevention Strategy will be led by local Aboriginal organisations and research partners. If the FASD Prevention Strategy in the Fitzroy Valley can achieve the goal of reducing the percentage of women drinking during pregnancy to less than 10% by 2018, this will represent a saving of at least \$450,000 per year in service use and loss of productivity and in the Fitzroy Valley alone. If these figures are extended to the wider Kimberley, the preventing FASD has the potential to save the WA Government almost \$2 million per year.

Strategic policy that addresses both the supply and demand aspects of alcohol use in Aboriginal and Torres Strait Islander communities are recommended. A strategic framework proposed for the Kimberley region is presented as Figure 1.

In addition to broad policy approaches, meso- and micro- level strategies are required to support regional systems change and community-led interventions. The successful model developed in the Fitzroy Valley is presented as Figure 2.

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OVERCOMING ALCOHOL AND FASD – KIMBERLEY INVESTMENT BLUEPRINT

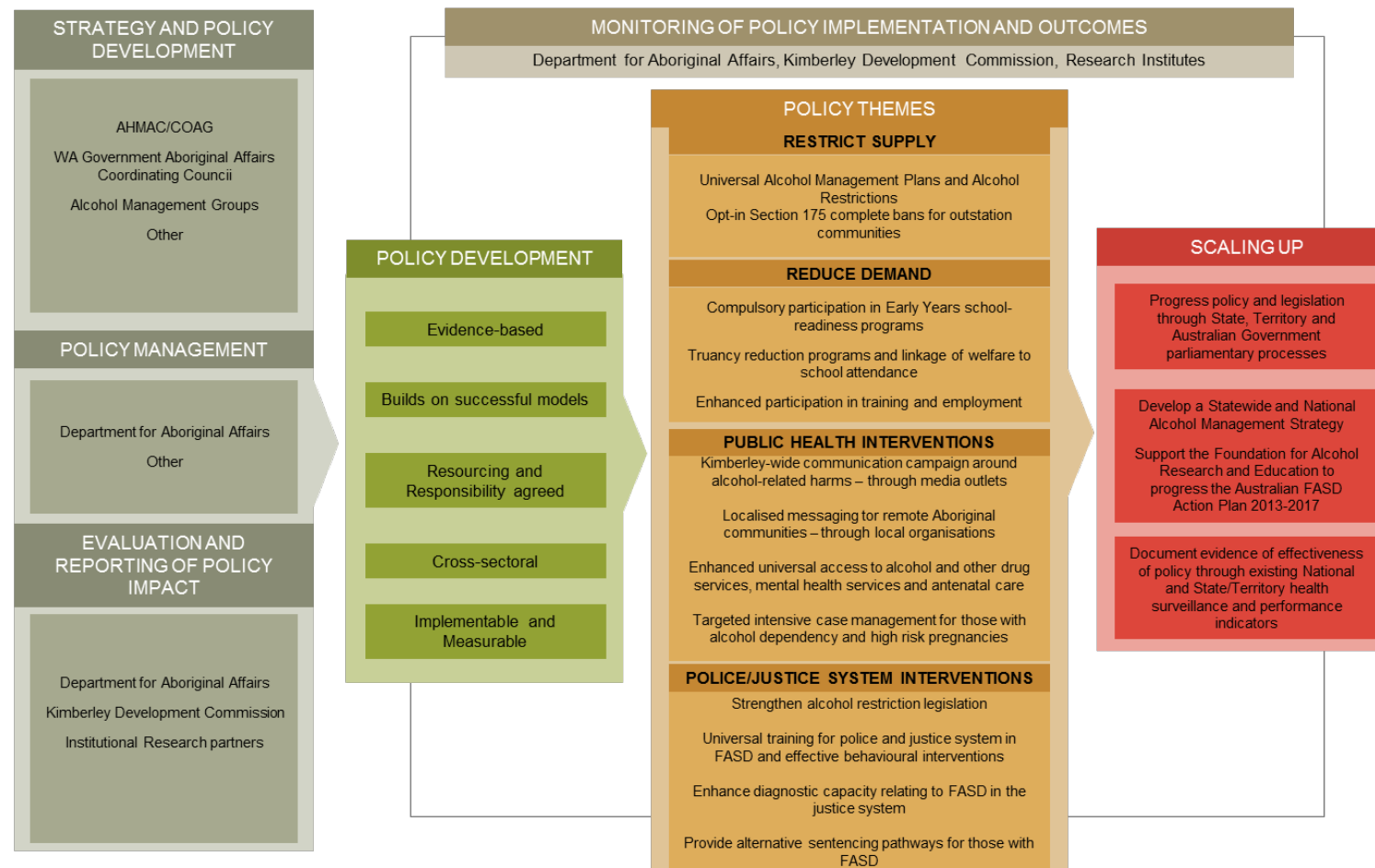


Figure 1. Regional policy recommendation for addressing alcohol abuse in the Kimberley.

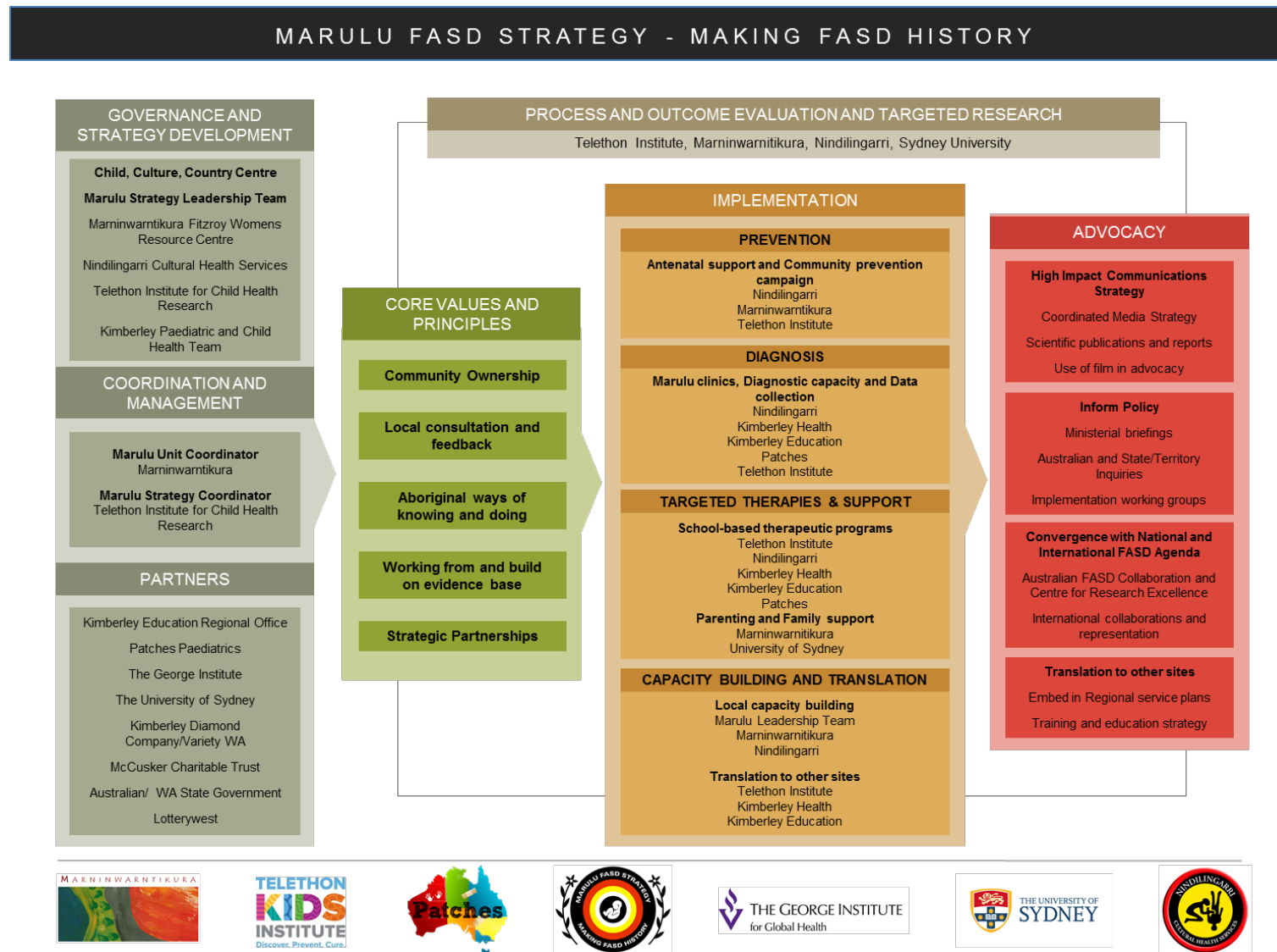


Figure 2a. Marulu FASD Strategy – Making FASD history in the Fitzroy Valley.

MARULU FASD STRATEGY 2013 - 2017

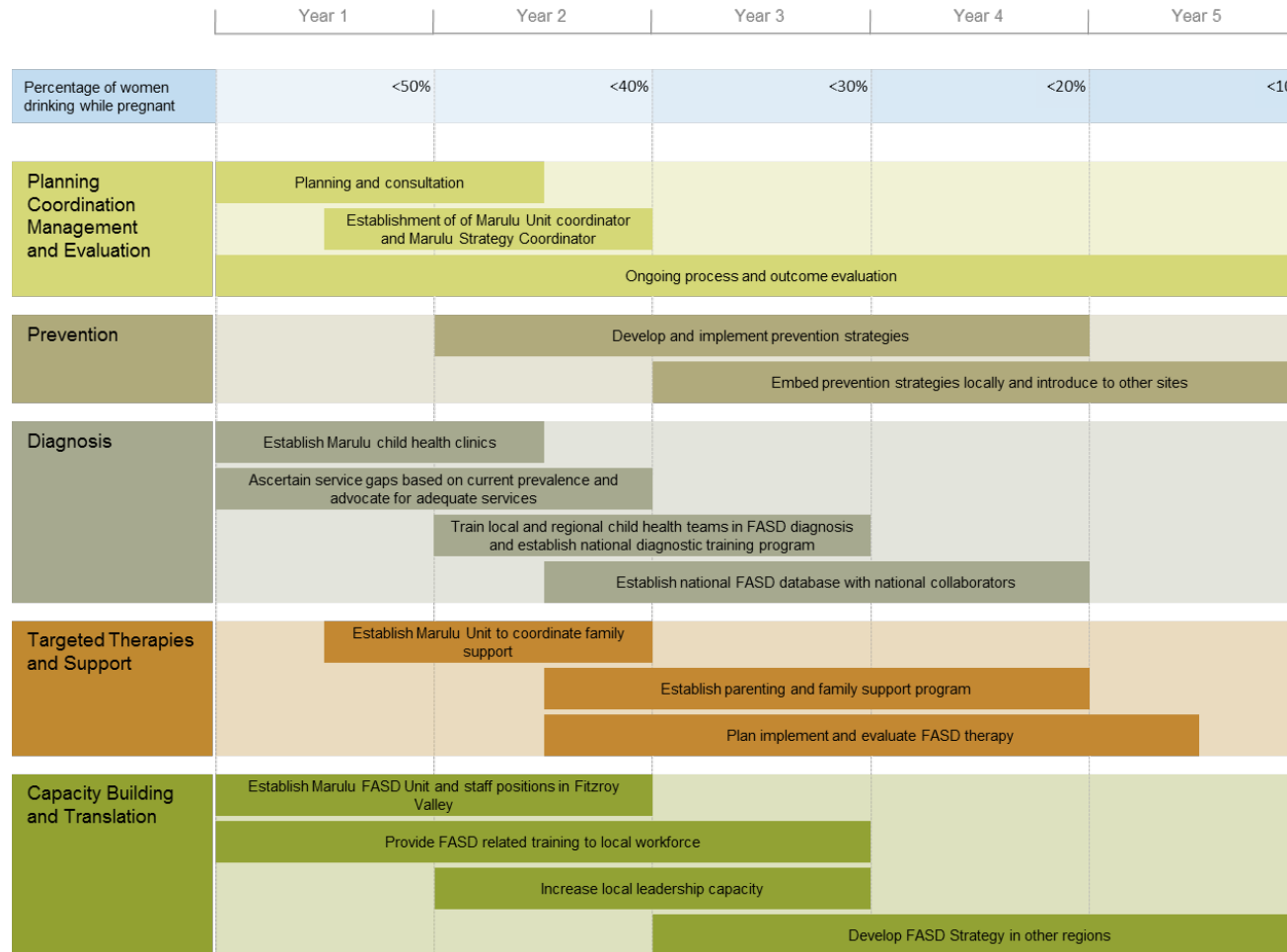


Figure 2b. Marulu Strategy Implementation targets and timeline.