Foundation for Alcohol Research & Education

Boom or bust:

what will FASD policy look like in five years?

FARE Chief Executive, Michael Thorn

[CHECK AGAINST DELIVERY]

Good afternoon and thank you for the introduction. Let me acknowledge the Noongar people on whose land we have met over the past three days. Thank you.

I have a great deal of affection for the FASD community - a community of carers, researchers, policy wonks, officials, doctors and health professionals, all with a shared interest in those with a Fetal Alcohol Spectrum Disorder. Lots of terrific people.

It's a family. It behaves like a family with occasional differences of opinion and regular squabbles, but blood is thicker than water and this family always comes together when it matters.

I don't know all of you, but I have come to know many of you extremely well and some of you I now count as very good friends.

My association with the FASD community dates from 2011 when Australian governments were once again engaged in another one of their periodic, but completely hopeless consultations with civil society about national alcohol policy.

At this meeting public health leaders, mostly academic-types, were advocating cogent arguments for World Health Organization-endorsed public policy interventions – policies on price, availability and promotion – but were largely dismissive of concern to balance these population-wide interventions with niche issues such as alcohol's effects on the unborn child. Their dismissal wasn't that they weren't concerned, just that they saw these as peripheral issues.

I saw it differently. I saw alcohol-exposed pregnancies as a policy opportunity. An issue where it would be difficult for the alcohol industry to advance their usual tropes about individual responsibility, personal choice and problem drinkers, to forestall change.

As someone who has spent most of their career in public policy-making, it is clear that policy change rarely happens quickly or rationally. Change largely occurs incrementally and haphazardly.

As the Australia Institute's Richard Dennis observed recently, we are often better advised to take the small offerings now, rather than holding out for the big prize.

To illustrate, he says, had The Greens accepted Kevin Rudd's 2009 carbon pollution reduction proposal, today Australia would be celebrating a decade of sensible climate change policy.

Instead Bob Brown rejected Labor's proposal as inadequate, and look where we are today – no price on carbon, no national energy policy, no Bob Brown and a decade of disputation and despair in an environment where the summers are hotter, the storms more violent and the existential threat to the planet grows.

The past decade of FASD policy proves my point. Services have been established, health promotion campaigns conducted and networks of carers and health professionals built. Governments' have appropriated money and, slowly but surely, put in place programs to respond to need; maybe not enough, but at least some.

We are certainly in a better place than a decade ago. Today FASD is on the political agenda, arguably the most important achievement of our collective efforts both in Australia and New Zealand.

How has this come about? Here are my thoughts.

In Australia, the House of Representatives Standing Committee on Social Policy inquiry report, *FASD: The Hidden Harm* was critical. This committee chaired by Graham Perrett and including Dr Sharman Stone set out a terrific plan for action, which is as relevant today as it was in 2012.

The work in WA's Fitzroy Valley was instrumental in our journey and I would like to acknowledge June Oscar and Maureen Carter for initiating the Lililwan project. Lililwan brought talented and dedicated people together, brought money, brought expertise, brought legal advice, bought energy and brought hope into the fight for justice.

Arising from this project was Tristan's story. I thank Tristan for being such a wonderful talent and also filmmaker Melanie Hogan for capturing the issues and his life so gently and clearly.

Research has continued apace. PhDs have been conferred, conferences held, papers published, reputations made and our knowledge and understanding expanded.

Telethon Kids has been at the centre of this action and the CRE is a testament to this good work. Liz Elliott, Carole Bower and many more researchers have been central to overall efforts.

There is now a formal network of carers and families supporting one another. Sue Miers has been tireless in bringing carer voices to the fore and for establishing NOFASD with Vicki Russell and Louise Gray. Anne Russell from the Russell Family Fetal Alcohol Disorders Association has been another key figure.

Important niche services have emerged like those in the juvenile justice system, led by the likes of Catherine Crawford here in WA and Tony Fitzgerald in New Zealand.

The Commonwealth, and a growing number of jurisdictions, are providing funding to support a broad range of programs, including clinical, diagnostic and prevention.

I give credit to Doug Shelton and James Fitzpatrick for their efforts in establishing and building a clinical network across Australasia. Diagnostic services are now available in every jurisdiction. The network of clinicians grows by the day and knowledge about FASD and how to respond continues to build.

The Australian Government announced its national FASD Strategic Action Plan 2018 – 2028 yesterday. It sets the right priorities, the enablers are good and it is pleasing to see serious attention given to evaluation. The funding is modest, but it is new money.

The concern will be about how these funds will be allocated and whose voices will be listened to. We certainly need to be listening to parents and carers.

These are some of the achievements and highlights of this progress we have made.

FARE has played a role too.

Our journey began in 2010, when FARE allocated a number of grants totalling a little over $500,000 to the likes of Telethon Kids and Westmead Hospital to seed a number of projects.

Then came our contributions to the FASD Inquiry and later the development and launch in 2012 of the 2013-16 Australian National FASD Action Plan. We were significantly aided in putting this together by Sue Miers, Liz Elliott, Carole Bower, Anne Russell (who we proceeded to poison – sorry Annie), Vicki Russell, June Oscar, Lorian Hayes and the Heathers: Heather Jones, Heather Douglas and Heather D'Antoine, and others too.

The development of the plan did two other things: it built a coalition of interests that has grown into this family assembled here today and it resulted in FARE becoming the Canberra end of this network and the policy leader and advocate.

We continue to heavily engage in government relations efforts, especially in the Australian Parliament, developing policy and writing submissions.

FARE also pioneered public awareness campaigns. First with Pregnant Pause, initially using our own funds, and then with the assistance of the ACT Government and later the Commonwealth. Pregnant Pause focuses on mums-to-be, their partners and families, with the aim of encouraging and supporting alcohol-free pregnancies. The Pregnant Pause brand is now recognised around the world.

The other important program is Women Want to Know. The campaign has now been in the field for more than four years and is slowly but surely raising awareness among GPs, midwives and obstetricians about the need to talk to patients about alcohol and pregnancy – because women *do* want to know.

Finally, FARE along with our colleagues at Alcohol Health Watch in New Zealand has kept alive the 20-year campaign for mandatory pregnancy warning labels to be placed on all alcohol containers. And believe it or not, we are nearly there!

I don't know what precisely FARE's role will be into the future. We undoubtedly will continue our focus on prevention and seeking big public policy change: reform of the way alcohol is taxed, availability controls, restrictions on marketing and promotion, and better treatment services to close the 20-year treatment gap.

It is likely we will escalate our health promotion and public awareness work and become more invested in campaigning for change.

But what now for the future of FASD? Will it be boom or bust?

I'm sure you all know the answer because we are on the road to making FASD history. But fair warning, there is still a hard road to hoe. There will be more than the odd pot-hole and wrong turn to negotiate.

These will be the challenges of those who are destined to continue on this important journey. There are many opportunities to continue to advance the cause, but it is more likely this will be by evolution rather than revolution.

Let me address what I think the future holds. I have six points.

First, there is obvious unfinished business. The need to fix the problems with access to the National Disability Insurance Scheme. A persistent problem that should not be so hard to rectify.

However, we can help, as Doug Shelton says, by better aligning FASD diagnosis with the NDIS's system of assessment for support.

The development of a national system of clinical diagnosis and its eventual integration into child development services is needed. This will require the training of many more health and allied health staff if there is to be equity of access.

Services will need to be tailored and made fit for purpose for urban, regional and remote parts of the country. Establishing prevalence, undertaking routine screening, training, data collection and program evaluation, are all on the 'to do' list.

Public awareness campaigns remain paltry. More than 75,000 alcohol-exposed births each year is simply not good enough.

While Australian and New Zealand Governments have given their imprimatur to mandating pregnancy warning labels there remains a way to go before we see these appearing on alcohol containers in the way we would wish.

And, of course, what is really needed is a comprehensive alcohol and health warning labelling regime. A system of rotating warning messages like we require for tobacco, because we know this is the most effective way to deploy health-warning labels.

Second, there are major implications in diagnosing more and more people affected by FASD.

This will place increasing pressure on a range of services, including justice, education, health and welfare. If the current prevalence estimates are reasonably accurate this will result in significant new burdens for all these services. It will require them to adapt, develop new programs and find new ways of responding to a young person once thought to be autistic to one who actually has FASD.

These services will need to be developed quickly if the obvious risk of creating secondary disabilities is to be averted. Then there are the support service needs of families and carers.

Who will fund this? Who will coordinate the needs of these individuals and assist them and their families navigate the system through education and employment. It is critical that families are supported in this difficult area.

Thirdly, there are the less tangible risks associated the good progress we have made over recent years. The problem of success!

I foresee a number of potential and troubling threats to the harmony and goodwill that the FASD community currently enjoys. There are lessons to be learnt from difficulties the mental health sector is experiencing as government and clinical responses have moved to the centre and become mainstream.

The squabbling over money, fallings-out between once close colleagues, strong differences of opinion between experts about the science, service delivery models and priorities. The competition for the limelight and tension over the allocation of resources between prevention and treatment, urban versus regional, and governments wanting to be 'seen to be doing something'.

There are opportunists and carpetbaggers to be found whenever new money is splashed around by governments, and no doubt in time we will see a few of these appear in this sector.

These are real and present dangers, which could derail the progress we are making. Beware the risk of victimhood. Remain a coherent group, stick together and maintain the strong connections between carers, clinicians, researchers and advocates.

Fourthly, there is the challenge of program scalability, taking niche to national. How do we take small-scale, well-funded research projects in different areas: justice, primary health and apply these to different areas and scale up across jurisdictions?

Population-wide programs can be notoriously difficult to establish and are frequently resisted by established program owners.

Fifthly, there are advocacy challenges. The most successful health policy issues are where there is consistency of message from consumers, researchers and clinicians and this requires everyone to become a policy advocate in some sense.

We must equip individuals and groups to advocate for policies that improve their lives and those of others – difficult to do when the demands of everyday life are great, with little relief. Sue Miers will attest to the frustrations of carer advocacy. As Jane Latimer said to me yesterday we need the voices of powerful men to be added to the debate, because as she said they are practically non-existent at present. And I don't mean voices of the condescending and platitudinous.

Finally, there are the threats posed by the alcohol industry. This is an industry, which at a collective level is utterly shameless in denying the evidence and merchandising doubt about the harm caused by alcohol.

Let me remind you of *Booze before babies*, FARE's 2012 analysis of the alcohol industry's submissions to the Parliamentary Inquiry into FASD. A report which showed 10 false claims made by various industry groups in their submissions to the 2012 Parliamentary Inquiry including 'talking down' the need for action and suggesting that current industry activities are sufficient in preventing FASD.

A report that led to legal action against FARE by the alcohol industry. The alcohol industry would, if they could, undo overnight all that we have achieved and we have to be vigilant and ready to counter their egregious activities at a moment's notice.

This is an industry, together with its public relations affiliates like DrinkWise that is not to be trusted. Their relentless commercial interests cannot and should not be allowed to go unchecked.

Prevention

I want to close by returning to the theme of prevention - FARE's core business. I have said that we will continue our health promotion work – Pregnant Pause and Women Want to Know – and with any luck begin new programs targeting alcohol's contribution longer-term health harms, such as cancer, cardiovascular disease and dementia.

Will FARE continue its close association with FASD? I think yes, because the truth is that FASD is one aspect of a much wider range of alcohol-caused problems.

It provides advocacy leverage because the stories resonate with decision-makers and the political class. It's an issue which cannot be ignored because the stories are always personal and powerful.

Let me explain. But first allow me to show you a video about the *End Alcohol Advertising in Sport* campaign.

[Video of End Alcohol Advertising in Sport campaign]

So why have I shown you this video? First, I want you to sign up to the campaign.

Second, I want to return to the big question of preventing alcohol harm, because the clear consensus here at this conference is that FASD is preventable.

However, the approach to prevention needs to be more than one simply targeted at women drinking during pregnancy. It needs to be about changing Australia's drinking culture, a culture that is a function of an alco-genic environment, where alcohol is a part of every-day life, from celebration to commiseration.

An environment saturated in alcohol advertising and marketing. Where we are repeatedly told drinking is the norm. We know policy change is hard and it takes time, but it is possible if people are motivated and mobilised.

There is a simple prescription for stopping alcohol harm – increase the price of alcohol through a reformed system of taxation, reduce its availability, particularly packaged liquor, and restrict its marketing and promotion, especially that which targets children and young people. These are the big policy interventions that will reduce the prevalence of FASD and other alcohol harm.

However, convincing people, including our political leaders, to act on this prescription is hard.

The *End Alcohol Advertising in Sport* campaign is a manifestation of FARE's thinking about how to achieve the essential policy change required to prevent harm, including alcohol exposed pregnancies.

Overwhelmingly, Australian's hate the association of alcohol brands with major sport, especially when children are exposed to this prolific marketing. Nine out of 10 want the exemption lifted that allows alcohol ads to be broadcast during children's viewing times. *End Alcohol Advertising in Sport* is designed to end this exemption.

While this is a modest policy objective it represents a means to an end. This is to build a supporter base that can be mobilised to bring about wider reform. FARE will continue our efforts to fix the way alcohol is taxed, and we will work with states and territories, where the opportunities emerge, to address the increasing availability of alcohol. But it is hard to engender community outrage for tax reform and likewise for supply-side availability controls.

On the other hand, people are moved to take action about alcohol advertising, as they are with gambling and junk food advertising, especially that which targets children. *End Alcohol Advertising in Sport* is a campaign we can win – and when we do we can move onto these other issues.

Our interest in FASD should not preclude us from concern about the wider determinants of alcohol harm: the cheap booze, its incredible availability and its prolific marketing and promotion.

There are clearly particular needs for the FASD community, but it is no more or less than the needs of those affected by alcohol-related family violence, child neglect, street violence or those affected by alcohol caused cancer, cardio-vascular disease or dementia.

The FASD community should play a role in tackling the bigger problem of alcohol harm by supporting the WHO's recommended population-wide interventions because in doing so the number of alcohol-exposed pregnancies will be reduced.

If we capitalise on the boom for FASD, the alcohol problem can be busted. Good afternoon and thank you.

Ends.