Following my telephone call to you on Friday, I would be grateful for your consideration of the developmental health problems I am noticing in my work as a health researcher. For convenience I will dotpoint everything

Briefly, my personal background:

- shared ancestry Aboriginal and Irish convict
- registered nurse, I came to Cherbourg in 1993 looking for my family
- completed Master of Tropical Health at University of Queensland
- PhD research at Cherbourg looking at family violence
- at the same time another Indigenous colleague, Lorian Hayes, researching Foetal Alcohol Syndrome
- co-writer for Boni Robertson on the ATSI Women's Task Force on Violence Report
- Postdoctoral studies into Granny Burnout in Indigenous communities of south east Queensland
- Grannies have identified "we need to grow up our kids better"
- Postdoctoral study is now centred on early childhood development and Foetal Origins of Adult Disease
- I am a member of the Australian Research Alliance for Children and Youth and on the committee for the 15th International Congress on Child Abuse and Neglect.

I would like to make a submission with the following points:

exposure to teratogens is overlooked in Indigenous communities (and elsewhere in marginalised groups)

- common teratogens used in Indigenous communities include tobacco, alcohol, marijuana and inhalant sniffing
- there is possibly a large number of children with behavioural problems which can be linked to parents' use of addictive substances
- there are no cross disciplinary teams available to effectively assess infants and young children for neurodevelopment birth injuries with a view to early intervention
- Indigenous children in communities who display learning disabilities are labelled "bad kids", they are caught up in a profund cycle of victim blaming, and in turn, this commences their own cycle of using addictive substances that first begins with inhalant sniffing
- there are no considerations of adolescents and their behaviour problems until they come into contact with the criminal justice system
- children with neurodevelopment birth injuries probably account for the larger number of incarcerated children and adults
- although other countries such as Canada have protocols for children with alcohol related birth injuries, no such protocols are in place in Australia
- Australia has no data, identified by cross disciplinary teams, on neurodevelopment birth injuries, and
- in the event of a child being diagosed with a learning disability in rural Queensland, little or no recognition is given and even less assistance is available

I have attached an article, "Pandora how do we open the box?" that I wrote approximately 12 months ago in regard to children I see as invisible for disability services simply because they have not been diagnosed with a disability.

The second attachment is a letter from a developmental paediatrician regarding a boy, now 15 but 14 when examined, for whom I have been unable to access suitable services, disability or otherwise. In spite of him operating with an intellectual level of 7 years, I have been unable to access education or even a safe and appropriate place for him to reside.

I am here at Jundah Aboriginal Corporation at Cherbourg which is a facility run by women and includes a safety house, for mostly two out of every three weeks until the end of July:

telephone 0741 682 531, fax 0741 682 533, email jundah@bigpond.com.au.

The other week I am at the Queensland University of Technology's School of Public Health:

telephone 07 3864 5724, fax 07 3864 3369, email j.hammill@qut.edu.au.

I would be most grateful if I could contribute.

Jan Hammill

Pandora, how do we open the box?

During the recent observance of Child Protection Week, the Queensland Cancer Fund called on the Queensland Government to urgently embark upon a program of parent education aimed at reducing the effects of passive smoking on children. Supported by the Heart and Asthma Foundations and the Australian Medical Association of Queensland, the Queensland Cancer Fund estimated that up to forty Queensland infants die annually from exposure to tobacco smoke as well as multiple health problems being caused to children generally.

These expressions of concern, while long overdue for serious attention, represent only a small portion of the problems around exposure to teratogens, that is, substances known to cause harm during the most crucial development period of human life, the embryonic or foetal stage. Commonly known teratogens have included the drug, Thalidomide, and the herbicide, 2,4,D and 2,4,5,T**,** better known as Agent Orange. Meanwhile the insidious teratogenic effects of tobacco, alcohol, marijuana, amphetamine use and other habits including sniffing inhalants, have been ignored or considered too sensitive for intervention. There are also the issues around political sensitivity and one example is the absence of warnings on alcohol labels to alert women to the dangers of drinking when pregnant. Australian wine exports to most countries have to comply with legislation and attach a warning label. In Australia, there are no such requirements to protect women drinkers.

Research of the past decade has added considerably to the knowledge about brain development in the womb and paternal exposure to teratogens before conception. Surprisingly, few results from these findings have been passed on to the public to alert potential parents. The impact of substance use, and in particular, intergenerational substance abuse, on children's development is not attracting the attention it warrants given the worrying rates of illiteracy, behavioural disorders, low school achievement and early criminal offending, being reported. This is an area of much disquiet in specific socially disadvantaged groups where health is poor and the use of alcohol and other drugs is prevalent.

Foetal Alcohol Syndrome and Foetal Alcohol Effects (FAS/E), the most common cause of mental retardation in the United States, Canada and West Africa, has wide ranging implications for whole of life outcomes, yet receives very little attention in Australia. Health authorities have no data on prevalence rates and there are no cross disciplinary teams to perform basic screening and assessment for FAS/E. Likewise, there are no management strategies or structures across the various service agencies to ensure that children with FAS/E are positioned to reach their maximum potential.

A child with FAS/E entering school will display hyperactivity, attention and cognitive deficits, learning disabilities, language problems and poor impulse

control. Not always recognizable by physical features, the child's inadequate judgment and memory impairments, distraction and low frustration tolerance, compound into greater disabilities. Eventually their inability to focus and take responsibility for their behaviours, brings them into contact with the law. Only now as an adolescent are they provided with security, albeit through their incarceration in a detention centre. A tag of "young offender", complete with a police record, becomes their label for a lifelong sentence determined in the womb by factors outside their own choosing.

Whereas the USA and Canada provide best practice models and protocols across their health, education, welfare and correction systems for young people with FAS/E, similar policies do not exist in Queensland or indeed Australia. Society expects the parents to "take responsibility" perhaps without realizing that the parent too could have functioning deficits and the cycle of disability is being replicated.

The public needs to ask why prisons are getting bigger and early life course interventions thin on the ground? Are policy makers truly ignorant or are the problems related to children's developmental issues a Pandora's box of potentially mammoth proportions threatening over-stretched departmental budgets?

The existence and availability of pertinent protocols internationally clearly demonstrates that Australia's most disadvantaged children are the subject of institutional discrimination. This is rough justice for those unfairly consigned to survive with undiagnosed disabilities and little opportunity to access optimal life chances. The number of young people traveling a hapless life course indicates the urgency for services that genuinely address their needs. Better and earlier interventions are long overdue if we are serious in protecting the human rights of our children.

The Child Development Network

Developmental Paediatrician
Child Development and Behaviour
Provider 0421869J

09 May, 2002

Dear Dr

Re: **Date of Birth:**

Thank you for the referral. I was able to meet with …… and Jan Hammill (his carer) recently.

The purpose of this consultation was to examine ……'s predicament from a developmental point of view. From this perspective I have grave concerns about …., and in essence I would regard him as extremely disabled. I acknowledge, however, that I have little expertise in the area of indigenous health and related issues

The most obvious area of disability is academic. Regardless of the cause, ……'s academic capacity with reading, maths and writing are essentially at a late 1st, early 2nd grade level (age 6-7 years). With reading, for example, he had a word recognition of year 2, and this was essentially over-learned sight vocabulary. He had few strategies to decode words he could not immediately recognize.

With ……'s language more generally he was relatively uncommunicative, but his spoken conversation was characterized by limited vocabulary. Without formal testing evidence I suspect that his language is limited to an extent that would meet criteria for language disorder.

Another area of disability is within ……'s "executive control". This includes attention control, impulse control, short-term memory, ability to self-monitor, and ability to work in a goal–oriented manner. A large body of evidence for this conversation converges on the conclusion that .....'s executive control is not only poor, but represents a functional handicap in terms of his ability to meet anything like the developmental objectives of his age.

The practical consequence of this developmental picture is that I suspect ..... does not have the capacity for intentionality or the moral framework that is presupposed by the criminal justice system.

A contributing factor to this currently is his substance abuse. He is actively, regularly sniffing paint fumes amongst other substances. This can only serve to worsen his short term memory and executive function generally.

From the medical perspective there was concern that ..... may have Foetal Alcohol Syndrome given his past history. He does not, however, have the characteristic

physical features. He is a relatively small child, and this in combination with his cognitive problems, is consistent with Foetal Alcohol Effects even if he does not have the full physical phenotype.

..... himself appears to have little insight into his own predicament. His capacity for planning is limited and he lives in a perpetual present. His behaviour is often impulsive and as far as I could tell he had little sense of long-term future direction.

.....'s background has been highly prejudicial. There is a mixture of sniffing, alcohol, abuse, neglect, inconsistency and a variety of other factors all know to be causal for the problems he is currently experiencing.

In short, if ..... were a Caucasian child presenting with the same spectrum of problems we would classify him as extremely disabled. He is a 14-year-old boy with the academic skills of the average 7 year old. In functional terms this is equivalent to a mild to moderate intellectual disability. He essentially does not have the skills to manage the present, yet alone build towards any form of optimistic future. I feel this is an tragedy that his situation could have reached this state.

..... needs a comprehensive supporting environment to manage his daily living, as I do not believe he has the personal capacity to responsibly manage the freedoms that he currently enjoys within the city. Similarly, he needs an educational programme that is tailored individually to his needs if he ever is going to have a chance of future employability. If ..... were to be in such an environment where his daily life is structured and safe, and his educational needs are being met, then I would probably go further to explore the use of psychotropic medication to help him with his poor executive control.

Yours Sincerely

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