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Australian Children's Rights News

Newsletter of the Australian Section of Defence for Children International
Issue Number 43, May 2007
ISSN 1320-7091

The Rights of Children in the Australian Juvenile Justice System Prenatally Affected by Alcohol

Sue Miers[1] and Anne Russell[2] - NOFASARD[3]

> ***"At a time in history when many people with disabilities are demanding the right to be fully participating members of their community, there is another group of people with disabilities who are crying out to be identified. At a time when people with disabilities are desperately trying to rise above their impairment and be recognised for their basic humanity, people with Fetal Alcohol Spectrum Disorder (FASD) are still struggling to be identified and understood. The disabilities associated with FASD are seldom recognised; seldom treated effectively and seldom connected to service dollars."***[4]

Alcohol is a teratogen, an agent that adversely effects normal fetal formation and in particular alcohol is known to have its greatest effect on the structure and function of the developing brain. Individuals with Fetal Alcohol Spectrum Disorder (FASD) have hidden brain damage that is permanent, long-lasting and has far reaching effects.

Unfortunately FASD has received very little attention by health authorities in Australia. There are no specially trained multidisciplinary teams to diagnose this disability and the Australian medical profession has received very little information about the disorder in their medical school training. In contrast, North America has over 70 specially trained FASD diagnostic teams and in Canada, FASD training is being implemented into their police service, corrections system and to lawyers and judges because they have realized that prevention and appropriate intervention and management is a far less costly alternative than serving them in jails.

So, in Australia, the disorder is poorly understood and affected children and adolescents are slipping through the system. Many affected children are not diagnosed with a disability because they either have IQs that

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This issue of Australian Children's Rights News is focussed on two important issues: the children and young people whose lives are blighted by pre-natal exposure to alcohol and the challenges that brings to the health and juvenile justice systems as well as education to respond to these young people in an appropriate and compassionate way. Like those incarcerated in the adult prison system, young people with a disability are heavily over-represented in the juvenile justice system, but their disability often goes undiagnosed, especially when this is a result of alcohol and substance abuse by their mothers.

Sue Miers and Anne Russell from NOFASARD (National Organisation for Fetal Alcohol Syndrome and Related Disorders) have clearly outlined the problems and challenges and pointed to some of the 'solutions', a result of their own extensive experience with the issues at first hand. Sue is a foster parent of a 26 year-old daughter who has partial fetal alcohol syndrome (pFAS). Sue has lobbied extensively on both a state and national level to raise awareness about FAS issues and is a founding member of NOFASARD. Elizabeth Russell describes herself as a recovering alcoholic who in 2001 found that her addiction had physically harmed her two sons. She has resolved to devote the rest of her life to the prevention, education and support of sufferers of fetal alcohol spectrum disorder and their carers ensuring a positive consequence of her sons' suffering and to this end has written two books on FASD. They are *Alcohol and Pregnancy – A Mother's Responsible Disturbance and Alcohol and Pregnancy – No Shame No Blame*. These are the first two books on FASD written from the Australian perspective.

This article comes out just as the Australian National Council on Drugs (ANCD), the principal advisory body to Government on drug policy, has released its report, "*Drug Use In The Family: Impacts And Implications For Children*", prepared by national and international leading clinicians and experts. This report found that more than 230,000 of the nation's children aged 12 and under were living in a household where they were at risk of exposure to a binge drinker. After reviewing the many data sources, the following figures represent the authors' best estimate at the numbers of children living in households with parental substance misuse:

- Over 230,000 children live in households where they are at risk of exposure to at least one adult binge drinker;
- Over 40,000 children live in a household where one adult is taking cannabis daily;
- Over 14,000 children live in a household where one adult uses methamphetamines monthly;
- Substance abuse occurred in families with complex circumstances, experiencing a host of problems.

This report did not, however, follow up on the numbers of children affected by Fetal Alcohol Syndrome and Related Disorders.

The Council Chairperson, Dr John Herron quite rightly pointed out that: " To improve child outcomes in substance misusing families we need more treatment programs that can go beyond just treating the individual and that can cater to the needs and demands faced by the whole family."

The second key article concerns the physical punishment of children – children's rights not to be hit in line with CROC. This article is an edited version of the speech given by the Honourable Alastair Nicholson AO RFD QC, Honorary Professorial Fellow, Department of Criminology, University of Melbourne and Former Chief Justice, Family Court of Australia, and Patron, Children's Rights International and Epoch Tasmania to mark International 'No Smacking' Day at Parliament House in Hobart on 30 April 2007. Professor Nicholson outlines the legal and social issues in Australia and elsewhere in a comprehensive review that takes in the research on the consequences of physical punishment and the perspectives of children. Since that speech, on May 16, the New Zealand Parliament has passed legislation (on a vote 113:7) that removes the defence of 'reasonable force', the first English-speaking common law country to do so. Once again, New Zealand 'punches above it weight' on children's rights and social justice issues and shows the lead to Australia.

Judy Cashmore
President, DCI Australia

fall within the 'normal' range; they are misdiagnosed with ADD, ADHD or one of the autism spectrum of disorders; or they are branded 'delinquent'.

> *"Delinquency is increasing in Australia……………..the presumed origin of certain delinquent and antisocial behaviour in Australia needs to be urgently revised because we are sending people with disabilities to prison for behaving in a manner that is consistent with every expert opinion on that disability. Would we punish a person with depression because they were sad?"* [55]

Children and adolescents with FASD are unable to learn from their mistakes; make changes in their behaviour or understand the consequences of their actions. They are impulsive; have poor personal boundaries; impaired judgment; easily manipulated; and often have far better expressive language skills than receptive language so they appear to understand more than they actually do.

Affected children have difficulty distinguishing between strangers and friends and have trouble structuring their own lives and their behaviours. They also require the consequences of their actions to be immediate and relevant. Without FASD competent therapists, psychologists and psychiatrists to help manage mental health, affected children experience problems with day to day life that they might otherwise avoid.

Children with FASD require external positive, consistent supervision and structure and unfortunately because of inadequate screening and diagnosis most find this through the legal system and juvenile detention facilities so in effect we are incarcerating these children/adolescents and punishing them for their disability.

Traditional interventions in juvenile detention facilities are usually based on principles of learning theory that expect individuals to learn from consequences either natural or imposed and take responsibility for their actions. There is an expectation that they can understand and process information, understand ideas and concepts, make links and form associations, interpret, store and remember information and take what is learnt in one situation and apply it in another. In actual fact this is exactly what is missing when a person has FASD.

> *"Psychological and social services have been put in place for people who are likely to respond to abstract concepts and who can independently work on their thoughts and behaviours keeping an ultimate goal in mind. Considering that FASD is a recognised diagnosis of prenatal alcohol exposure causing brain damage, imprisoning people with FASD seems counterproductive if the aim is to promote rehabilitation."*[6]

These interventions do not meet the needs of affected young people and their rights **will** be compromised unless their disability is diagnosed, understood and appropriately managed.

In financial terms, the cost of someone with FASD to society has been assessed as around $US5m. A good proportion of this figure belongs to the cost of incarceration of the individual; attempted rehabilitation, which because of the rationale cited above is unlikely to be effective; and then the highly probable recidivism. When we are looking at the cost of this condition, we must also look beyond the financial to the cost to the friends, family, employers, youth services, educational institutions and above all, to the individual whose human rights has been compromised in the worst possible way. Not only is that individual incarcerated because they are behaving in a way that is considered 'normal' for their disability, but it is compromised by the victimisation, wrongful sentencing, misunderstandings, discrimination and oppression of them **because** of their disability.

A young person with Down Syndrome would not be treated in the same way as a young person who has normal genetics; it would be unfair, definitely damaging and probably illegal, a contravention of his or her human rights and yet the human rights of people with FASD are being compromised daily. Amnesty International tells us that human rights are universal, they are inherent, they are inalienable and they are essential, but they **can be** violated, and in the instance of young people with FASD and the juvenile justice system in Australia – they are!

References

The FASD Canadian Guidelines for Diagnosis and Identifying Fetal Alcohol Spectrum Disorders in Primary Care http://www.cmaj.ca/cgi/content/full/172/5/628

Streissguth, A. (1997). The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. University of Washington Press.

Endnotes

[1] Sue Miers is the foster parent of a 26 year old daughter who has partial fetal alcohol syndrome. (pFAS) She has lobbied extensively on both a state and national level to raise awareness about FAS issues and is a founding member of NOFASARD (National Organisation for Fetal Alcohol Syndrome and Related Disorders) She has been invited to be a member of, and has reported to, various national and state government agencies in Australia, as a recognised parent authority in this area. In June 2006 she was awarded the Member of the General Division of the Order of Australia for service to the community through the establishment of the National Organisation for Foetal Alcohol Syndrome and Related Disorders, to community education and reconciliation.

[2] Elizabeth Russell is a recovering alcoholic who in 2001 found that her addiction had physically harmed her two sons. Her eldest son, who is 25 years old, was diagnosed with Neurodevelopmental Disorder – Alcohol Exposed and her youngest son who is 22 years of age has full Fetal Alcohol Syndrome. Elizabeth has resolved to devote the rest of her life to the prevention, education and support of sufferers of fetal alcohol spectrum disorder and their carers ensuring a positive consequence of her sons' suffering and to this end has written two books on FASD. They are Alcohol and Pregnancy – A Mother's Responsible Disturbance and Alcohol and Pregnancy – No Shame No Blame. These are the first two books on FASD written from the Australian perspective.

[3]The National Organisation for Foetal Alcohol Syndrome and Related Disorders Inc. (NOFASARD) was established and incorporated in Adelaide in 1998. It is Australia's peak body representing parents, carers and others interested in or affected by Fetal Alcohol Spectrum Disorder (FASD). NOFASARD is a registered charity and is staffed totally by volunteers. Through education and advocacy NOFASARD aims to improve the lives of children/adults with FASD and representatives from the organization present at seminars and workshops for both government and non-government agencies throughout Australia www.nofasard.org

[4] From: Attaining Human Rights, Civil Rights, and Criminal Justice for People with Fetal Alcohol Syndrome; by Ann Streissguth, and published in TASH Newsletter, Sept. 1998. For more information on the work of TASH, visit www.tash.org.

[6] Alcohol and Pregnancy: No blame No shame! Elizabeth Russell (2007)

Alcohol and Pregnancy: No Blame No Shame A Case Study

This case study about a young lad with Fetal Alcohol Spectrum Disorder (FASD) appears in the book "Alcohol and Pregnancy: No blame No shame!" and it is reprinted here with permission of the author Elizabeth Russell. Whilst this story is about a young Aboriginal youth, it is important to understand that Fetal Alcohol Spectrum Disorder does not just affect Aboriginal children and will be found wherever alcohol is part of the culture.

The narrator of this story 'adopted' Jack, a young Indigenous youth; or as Jack would tell it, he quite determinedly 'adopted' her. Regardless of who adopted whom, Dr Janet Hammill not only willingly took Jack in and stayed by his side throughout challenging times with the Queensland juvenile justice system, but also chose to advocate for him and the disability from which he suffers. Dr Hammill is an academic with a doctoral degree in Indigenous family violence and is a descendant of the Gamilaaray people of the NSW Pilliga forest. She hoped that by providing Jack with a stable home and 'mother' figure that it would give him a chance to turn his life around. Unfortunately both Dr Hammill and Jack were to find that very few interventions, even those of a loving, generous and knowledgeable 'mother' can stop a young person with FASD from spiraling down the path of petty crime into the waiting arms of the justice system.

Introduction

To describe Jack's story as tragic would create a depiction of a child born into only sadness and deny the happiness of early years being nurtured and secure within an extended family that chose to embrace him. Jack's awful misfortunes relate to his origins as an Aboriginal child with unrecognised neurodevelopment birth disabilities in a country not conversant with the teratogenic effects of alcohol or the complexities of intergenerational exposure to poverty, racism and discrimination. Jack's circumstances of birth were beyond his choosing and he was destined to follow a pubertal pathway through to adulthood bereft of valid interventions by those in authority. His experience as an adolescent is not related to the dedicated and generous 'grandmother' who adopted him and ensured security for his vital early years.

Given the miserly recognition of Indigenous social justice issues in Australia, including the crucial side effects of bleak deprivation, there are many destined for similar poor life outcomes especially in relation to dependence on alcohol and other substance use. The most critical and unrecognised of these is Foetal Alcohol Spectrum Disorders (FASD).

By tracing Jack's story as an Aboriginal teenager, invisible to identification by health and welfare professionals for early intervention yet highly visible to the juvenile and criminal justice systems, may trigger the appropriate reaction of shame and shock.

By explaining Jack's story, I will attempt to catalogue some of the neglect by those in authority and the long road, still with no apparent destination, that he, as a child, has had to navigate while burdened by a lifelong organic brain disorder. Where were the child advocates? Why was Jack's situation ignored; put in the too hard basket? How was Jack invisible to meaningful intervention? What about the others like Jack? What are the commonalities? How can our state, territory and federal governments maintain these cataclysmic circumstances?

Jack's story is just one of thousands that demonstrates the impact of historical racism and despair that Indigenous people are labouring under in Australia's contemporary, prosperous and envied society. It should be unnecessary to have to tell it.

Growing Up[1] Jack

Jack, born in 1987, was the second child to an Aboriginal teenager from an inland city. Exposed to heavy drinking during his time in the womb and throughout his mother's labour, Jack's arrival in an ambulance en route to hospital was earlier and quicker than expected. Today his prematurity status remains unknown as are his measurements at birth, that is, his Apgar assessment of heart rate, breathing, muscle tone, reflex response and colour, as well as his weight and length. These and the circumstances surrounding his first weeks remain unknown and will do so until Jack is of an age when he can personally seek the information should he feel the need is warranted. Given Jack's cognitive status, his birth data might always remain unexplored.

At three months of age, unable to cope with the demands of her second born, Jack's mother abandoned her baby in a community hospital. Alone in a crib in the children's ward, the plight of the little infant came to the attention of a member of the hospital domestic staff, Aboriginal grandmother, Clare. Beginning to take in the world around him and thriving with abundant attention from all who cared for him, baby Jack was irresistible. Clare acted swiftly to adopt him before other potential mothers made their bid.

Jack's world became that characteristic of many Aboriginal children. He was surrounded by an extended family of big sisters, lots of aunties, uncles, little cousins, nieces, nephews and doting Mum Clare. Jack's new big sisters remember him as "a beautiful, fat little fulla" who met every criterion for full membership of their family. Clare was especially protective of Jack and cared for him in the manner of her own strict upbringing. He was loved and taught to respect others and be mindful of his manners.

Jack remembers those early years as very special with Mum despite the crises she was going through in her own personal life with her partner, a younger man, who was drinking heavily and often violent towards her. Clare's last years were endured suffering from breast cancer and the treatment regime necessary in order to prolong her life. Her battle to survive was painful and lengthy until she finally succumbed when Jack was about ten years old. A year or two later, Jack's biological father, with whom he had little to do, hanged himself in a remote community.

Jack's world fell apart with the death of Mum Clare. He spent some time living in another state with an older 'sister' where he completed Grade 7 before returning to Queensland and a community high school for several months in 2001. It was while he was interstate that Jack first became involved with the juvenile justice system and this has since become a regular feature of his life.

The Department of Family Services placed him with another 'sister' who showed much patience with Jack and tried hard to assist him but he had developed a lifestyle of disappearing for days on end when he was not in the custody of the youth detention centre.

In hindsight and knowing now that he has the disability, Foetal Alcohol Spectrum Disorder (FASD), it can be seen that Jack has suffered considerably through the loss of stability and structures provided by Clare. His limited language and numeracy skills were the secondary disabilities that can be recognised now as compatible with his diagnosis of FASD.

Because his limitations prevented him from attending school, Jack was a sad and lonely figure. Unable to commit to routine and rules, he sought the company of like minded young people. He found them on city streets deliberately blurring their reality by sniffing paint, often mixed with toluene based thinners, huffing it through the mouth, from soft drink bottles barely concealed down the front of sweaters. Jack too became a sniffer, or more commonly known as "chromers". More recently, the preferred vessel for chroming has become a two litre milk bottle as Jack explained to me "because it can hold more paint, Man". There is no attempt at concealing these larger vessels which can be found discarded in city streets and parks.

Meeting Up With Jack

Jack came into my life through the front door in January 2002. He was in the company of boys from a rural community who had picked him up downtown. I thought he was from their community and made him welcome as such. However, when the boys returned home, Jack remained. Somewhat bemused, I found myself with a 14-year old boy, small of stature, happily ensconced in my spare bedroom with no apparent plans to leave. He was a congenial enough companion, willing to prepare us both a meal, take frequent half hour showers with lashings of shampoo, soap and whatever toiletries he could find in the bathroom, share his personally allocated bed with two little dogs and happily monopolise the television. He was delighted to give me a hand to do the grocery shopping, not just purchasing it but also unpacking it and putting it away. He also enjoyed being driven around in the car and appeared to enjoy my company and I own to being flattered by his respectful attitude towards me. On reflection, I had obviously replaced his beloved Mum Clare.

I was concerned about Jack's absence from his home wherever that might have been but he readily volunteered his homeless status. I had no idea that he was meant to be living with his 'sister' in an outer suburb and that there was no reason at all why he was not allowed to return home to her.

The attraction of being at my house, as I was to find out, was that I lived close to the city and he had easy access to his peer group of chromers. That, in conjunction with an abundance of food, a warm bed, shopping for new clothes and motoring magazines, cruisin' in the car, romping with four-legged playmates, netting for crabs in the nearby creek and being accepted into another family with little questioning, was indisputably a blissful life.

All that was missing were other young people. I tried to remedy this by enrolling him in the local high school where there was a higher than normal percentage of students from diverse backgrounds, some of whom were Aboriginal. Both Jack and I thought he would be better accommodated in this environment. But his patience ran out early, in the uniform shop in fact. Jack could not see that being fitted with the appropriate uniform was an essential function before fronting up to school. What's more it was taking longer than the requisite five minutes that he was prepared to allocate to any task.

That was the way Jack and I continued our lives together for much of 2002, that is, when he was not resident in the youth detention centre. Some nights he would not arrive home and I would drive and walk the city streets asking others who lived as he did, whether or not they knew where he was. I was always greeted amiably and offered friendly replies from people who professed to know him whether it was those waiting for Rosie's van to call at City Hall at 9pm to dispense hot drinks and sandwiches or whether it was from others rugged up on park benches, around fires in favourite parks, or huddled in church doorways .

Jack introduces me to the juvenile justice system

Jack's escapades introduced me to the justice system. Frequently, I would receive a call from the police to tell me he was either in the watch house after having been picked up for some criminal activity such as travelling in a stolen car, or from the legal service telling me he had to be appear in the Children's Court on the next working day. I always made a point of being there for him and I know this strengthened our relationship. Likewise he looked out for other Murri young people. On one occasion, he said to me "Jan, David's down there and no one came for him." With a wave of the hand he indicated the lower level of the courthouse. On other occasions he brought a young offender home to share his own luxuries, namely warmth, food, shelter, television and his personal chauffeur. Clearly Jack had the makings of a youth advocate, a trait that would manifest strongly in 2005.

For those who haven't had the experience of waiting at a children's court, it is both a trial for all involved and a tiring experience. One has to be on time for the first cases to be heard as it is difficult to find out which juvenile offenders will be seen first and how long the proceedings are going to be. If one arrived half an hour late, it could all be over due to the fewer than usual cases set down for that day. On other days one could sit, often with families whose acquaintance had been made at previous sessions, drinking water from the slot machine, buying sandwiches at minimal cost made by volunteers from the Salvation Army while sharing our frustrations and despair at the behaviour of those we were there to support. Mostly waiting supporters were grandmothers and always the discussion centred on "What is wrong with our kids? Why can't they stay out of trouble?"

Often too it was not hard to see what the immediate problems were. On a number of occasions, the young ones waiting to be called into the court would have their plastic containers of paint strategically placed in the landscaping of the court. There they could continue their chroming habit and, at the same time, comply with their summons to appear in court.
Firstly, their legal representative would brief them outside in the garden and then disappear again inside. The miscreants could resume their huffing before being called before the magistrate while clearly still under the influence.
When the court had decided their fate, the youngsters had agreed to the magistrate's requests and put their signatures on whatever documentation was proffered to them, they were free to go and resume their habit.
The courts recognised me as Jack's carer when he was not in the detention centre although I never applied for or received any financial remuneration. Each time he was released into my care, Jack would be required by the courts to fulfil certain obligations under the terms of his parole or bail orders and the Department of Family Services would be assigned the task of ensuring that Jack abided by the formal agreement.

Each court appearance would leave Jack and I drained. Often we would see another young person who had been discharged and had no transport home and between us check to see if they wanted a lift somewhere. On one occasion, to my dismay, after having convinced the magistrate that Jack had not been involved in a particular incident, he gave a running commentary to our passenger on how he and his mate carried out the offence for which he had just been proven innocent.

Too frequently, the magistrate's terms meant that Jack had to undertake community service and adhere to a curfew. This is where his capabilities failed him and I was later able to place this behaviour into the context of his disability as well as the guilelessness as demonstrated above. Jack was in fact unable to meet the requirements of his bail conditions because his poor executive functioning impacted on what was expected of him.

The Department of Family Services was also lax in their obligations and probably weighed down under the increasing burden of child care that was being dropped in their laps. Their duty was to collect Jack on the agreed days to take him to do either his community service work or other activities under their supervision.

On the days they were rostered to pick him up at and return him home, they could not be counted on and their hours were often quite flexible. Sometimes the department would call for Jack 3 hours late and bring him home an hour or two later.

Despite Jack phoning me immediately he arrived home, it always took me at least ten minutes to walk to my car and drive home. Jack's disability disallowed him any understanding of time and although I knew it was only ten minutes, to Jack it seemed hours or he would forget I was on my way. That was sufficient time for him to go seeking friends who were hanging out on city streets. This peer group was engaged in chroming, petty crime, car theft, break and enters, ram-raiding liquor stores with older boys, etc. To Jack it was exciting and a privilege to be included for these were "my family" as he often told me and sometimes used when he was pleading for me to allow him to bring girls home.

Jack's method of contacting me to go and collect him from somewhere was usually made via a reverse charge call from a public phone box. These calls were charged to my account at the rate of slightly less than $5 each as against 40c if he had the cash or a phone card.

Each time I drove Jack to a designated place where he could meet friends for a few hours, along with several dollars to buy food and drink, I would give him change for the phone. However, the few hours frequently became overnight or several days and in that time, the money for a phone call became an essential contribution to his survival. I then tried buying $10 phone cards but these lasted less time as they became a barter item and I suspect were promptly traded, at a discount, for cash. I would be told that a certain bully stole it from him.

Solving the mystery, getting a diagnosis

I knew instinctively that Jack was being truthful to me in his efforts to stay out of trouble. Moreover, I was able to observe his cognition and incapacity to make good choices, manage time in any form and especially to control his impulses. My ponderings became concerns about his neurodevelopment status as he had known alcohol exposure in utero. In collaboration with the psychiatrist at the detention centre, I was able to instigate his diagnosis and assessment by a developmental paediatric who verified my concerns that Jack appeared to have a form of Foetal Alcohol Spectrum Disorder and….

……. in essence I would regard him as extremely disabled.

The most obvious area of disability is academic. Regardless of the cause, [Jack'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 recognise.

…… he was relatively uncommunicative, but his spoken conversation was characterised by limited vocabulary. Without formal testing evidence I suspect his language was limited to an extent that would meet criteria for language disorder.

Another area of disability is within [Jack'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 on this conversation converges on the conclusion that [Jack'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 [Jack] does not have the capacity for intentionality or the moral framework that is presupposed by the criminal justice system…………

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

In short, if [Jack] was a light skinned 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 a tragedy that his situation could have reached this state.

Despite this pertinent and revealing diagnosis, and written appeals by me to the Premier, the Minister for Health, the Minister for Family Services and the Commissioner for Children and Young People, I was referred back to the Director General of Family Services who assured me that his staff was dealing appropriately with Jack.

Still, meaningful services for Jack's needs were not forthcoming. Indeed they did not exist and at the time of writing this chapter, Queensland does not have available a framework for action or strategic plan specifically for people having, or suspected of having, FASD. Increasingly though, a degree of awareness is stirring with initiatives based around training health educators and providers with the most concerted efforts originating from within Indigenous communities.

During one of his periods in the youth detention centre, I mentioned to a warder that Jack had been diagnosed with FASD. The Aboriginal warder replied "Yes, all the Murri kids are like that." While this was probably not true of all community children and young people it is more than likely true of those who become involved in the juvenile justice system. In Canada and the USA, having FASD equates with high incarceration rates and is a critical issue in the profile of those affected.

Around that time I was unable to continue as Jack's carer as his chroming habit was becoming a problem even when I was home with him. He had paint secreted in various places under and around my old house and my close proximity to the city was particularly detrimental to his wellbeing. His involvement with the juvenile justice system continued and it was only during the periods of detention that his health improved.

Inside he would regain weight, have hobbies, play sport and paradoxically benefit from structures in his life. Inside he had the company of other Indigenous young people many of whom Jack had grown up with and frequently among these was a smattering of relatives.

On his release the Department of Family Services attempted a reunion for Jack with his birth mother who resides in a northern coastal town. She and her partner continued to drink, have very stressed lives and another five children. The mother's partner regularly beat Jack and the situation proved too difficult for all to manage and before long Jack was in trouble with the law again. He spent some time in a northern detention centre and upon release returned to Brisbane.

Jack and his Peers

Raising a teenager again, and one with a disability that perpetually compromised his ability to function on a daily basis, was inevitably an interesting experience that brought daily challenges for both Jack and myself as we tried to work together as well as outwit each other.

I refused to supply money for cigarettes and this drove Jack to use every opportunity at shopping malls and elsewhere to scour the streets for bumpers or cigarette stubs. On the pretence of needing to go to the toilet, he would use the opportunity to check out the sand-topped receptacles outside doorways.

It was clear that various youth groups had spoken to Jack and his friends about the dangers of chroming in particular but they saw the habit purely as a social interaction as Jack explained to me.

> Jan, when you're happy, you go out for a feed and a drink with your friends. I like to go down to Hungry Jacks for a feed and a sniff afterwards.

This was similarly expressed by a 20 year old girl who spoke laughingly of joining her friends down in the riverside park for "a bit of a sniff". At the time she was waiting in the court minding a small girl in a stroller while the carer, the toddler's father, had to appear before the magistrate.

Later I volunteered to babysit in the waiting area while she went in to hear the verdict. She returned quite shocked "Shit. He's just been sent up for six months. What am I going to do with her?" She pointed to the child who was apparently not related to her.

I resumed my babysitting role for the young woman while she went to the public telephone to call her father who then drove in from an outer suburb to pick them up. I never found out what became of the child whose principal carer was now incarcerated.

Chroming was clearly an addictive habit that Jack was unable to beat. Homes abound in volatile substances no matter how vigilant one is and mine was no different. I became adept at locating and tossing everything I could think of that could be used by Jack in this way.

Often it would be a felt pen in his pocket or an aerosol innocently stored under the kitchen sink. But there were other telltale signs that Jack was sniffing in his behaviour such as sleeping with a knife, screw driver or other "weapon" under his pillow. Once, when I arrived home from work, he refused to let me enter the front door because he said there were people on the roof who would hurt me.

But if I thought Jack was having it tough, the young Murri girls he brought home were often in a more desperate situation and they resisted all my best intentions to find them help. Jack saw the solution as having them at our place but truthfully Jack was the limit of my emotional and financial capacity.

On one of many occasions, when we had one of Jack's "sisters" in the house, I insisted on driving her home with an apology for not being able to accommodate her. As we returned home in the car, Jack gave a most theatrical performance. With much exaggeration, he covered his face with his hands and rocked back and forth…..

> (Jack) *I'm shamed. I'm shamed. Jan you've shamed me. I told her you were a nice lady and now you've shamed me.*
> (Me) *I can't have underage girls staying. Their families must be worried.*
> (Jack) *Her mother told her to fuck off. She was drunk. She's always drunk. I told you that.*

And another time Jack wanted to share his bedroom with a 12-year old girl but of course I insisted on taking her home. Afterwards I was really made to feel the guilt …

> *Her mother's inside* (in jail). *She can't go home. You don't know what he does to her. And he makes her do everything – clean up after everyone. He talks bad to her – swears – tells her she's nothing – bashes her – and does worse. She told on him but no one listens. Her grandmother calls her a slut. No one believes what she says.*

When I was able, I would gently question the girls to see if their situation at home was okay. Mostly the girls would volunteer that their parents were either strict and/or punished them for chroming.

One very engaging girl, Karen, was a delight to have in the house and was especially caring of Jack particularly during a period when he was recovering from an attack with a broken beer bottle that cut a tendon in his hand.

I would drop them off at the hospital clinic and Karen would patiently sit with him until he was seen by the doctor. Had she not done this, Jack would have stayed only the obligatory five minutes.

On completion of the consultation she would phone me to collect them or catch the bus back to my place. When Karen felt the city sojourn was complete and she wanted to return home, she would phone her father and ask him to call for her. Clearly a daddy's girl, the diligent father would arrive, hug his daughter and thank me politely for letting her stay.

Police Profiling and Doing Time as an Adult

When Jack was first diagnosed with FASD I endeavoured to impart knowledge of the condition to police even providing them with resources on the condition.

For months we enjoyed an amiable relationship. If Jack was seen around city streets he was frequently brought home. For example, there would be a knock on the door around 3am and police would be on the doorstep with Jack in tow. I would ask Jack to apologise, shake the officer's hand and say "I'm sorry for being a pest." Grins would break out on faces, the police would depart with a stern reprimand and Jack would flop into bed.

However when Jack turned seventeen, things changed. He was no longer a juvenile and able to qualify for children's services but became eligible for the big house.

Queensland is the only state in Australia that jails seventeen year olds. Ironically, adulthood and the associated services are not available until the individual turns eighteen years of age. Thus the 17 year old youth of Queensland are placed in limbo where they are truly "neither fish nor fowl" but even so still highly visible in a negative context. When they offend, which inevitably they will do, simply because of the grim situation that is their reality, they become highly visible.

Indigenous young people with cognitive disabilities and the Australian juvenile justice system was the basis of a report by the Aboriginal and Torres Strait Islander Social Justice Unit of the Human Rights and Equal Opportunity Commission that was made public in December 2005.

It reported a high incidence across Australia of young people with disorders ranging from mild impairments to severe psychiatric disorders, and Indigenous young people were over-represented.

A crucial element in young people's involvement was poor educational achievement and this is well demonstrated in a community where Jack spent several years of his childhood.

That community has three primary schools within a five kilometre radius yet, in 2005, less than one in five young students graduated into high school. Regularly I see some of the community's young people living on the streets of Brisbane attracted by the excitement of activities lacking at home.

From time to time my house becomes a drop in centre for these young ones, some of whom I have known for the past decade. They are unable to read or write, engage in chroming and are heavily reliant on addictive substances especially cannabis. They are all good kids. I am treated respectfully and, despite their dire circumstances, no one has ever stolen from me.

Nevertheless, like Jack they are conspicuous to police. When apprehended, as may happen several times a day, they react with abuse and hostility which immediately triggers a response of power from the law. It is on these occasions that Jack and his friends come off second best.

As an example, I returned from overseas with gifts of new clothes for Jack which he immediately wanted to show off to his peers. A Murri kid in new clothes stands out like a beacon flashing "look at me - look at me." I should have been more vigilant because within two hours of donning his new gear, Jack was charged with possession of goods suspected of being stolen and, being Saturday of a long weekend, he was detained in the watch house until Tuesday.

My pleas to the watch house staff went unheeded. Once a charge was made the individual can only be released by the court. The lesson here that I learned for the future was to save the dockets and put them with a signed, written statement that they were the property of Jack, a gift bestowed on him by me and pop the evidence into his pocket.

Another time while waiting at a bus stop with friends, he and a mate were subjected to an on-the-spot search.

A stub of a joint was found in Jack's pocket and he and his friend were marched down to the nearby police beat through the midday market.

Inside Jack and his mate claim they were assaulted and thrown against a "steel cupboard". On direction from Jack's legal representative I filed a complaint with the Crime and Misconduct Commission (CMC) who handed the investigation back to the Queensland Police. In due course, and without making an appointment, I answered my front door to three police officers whom I invited in. Another emerged from down under my house where he was obviously checking out possible escape routes. They told me that Jack had an outstanding warrant which was not unusual. They also mentioned my letter to the CMC. Several weeks later I received a letter from the CMC informing me that the police had spoken with Jack and he did not validate my grievance against them. I quizzed Jack who said he "was down under the bridge sniffing and they come along." He explained that he was alone, was high on paint fumes at the time and scared when approached by the police. Not unexpectedly he told them he did not have a complaint about their behaviour.

While engaged with his peers and spending days on end down under the bridge, chroming and inebriated from stolen alcohol, Jack quickly ran up more charges, most of which are still to be heard. These range from unlawful use of motor vehicle (he was a passenger), robbery in company and with assault (his mate grabbed the victim's collar), two cases of burglary, enter premises and commit an indictable offence, assault and obstruct police as well as several breaches of bail conditions.

Issues of immediate concern

From Jack and my interactions over the past three years with youth service organisations there is no mistaking the groundswell of interest in neurodevelopment of young people who have been exposed in utero to alcohol, marijuana and tobacco. How do we then get the attention of the policy makers at higher levels and especially nationally?

Jack is now 18 and, despite being diagnosed with an organic brain disorder four years earlier, he has been invisible to help from government services. Jack's rights both as a child and as a young adult with a disability have been denied him and the violations against his liberty continue in breach of all international Human Rights Charters.

A medical practitioner who made an assessment of Jack when he was 17, while knowledgeable about Jack's condition, informed me that the state 'had' him, as at that time he was no longer a child and not yet an adult until he reached 18 years.

The doctor also advised that when Jack did legally become an adult, there are no existing services pertinent to people affected by FASD despite the obvious incidence of many cases.

Jack's place in society was determined by his exposure to alcohol when he was in his mother's womb. Likewise his mother's fate was undeniably predetermined for her too.

Jack's organic brain disability, although 100% preventable, will direct his entire life course and he will be unable to meet society's life expectations because his injury was not diagnosed until the crucial years of learning had passed. The suffering caused by the invisible disability that Jack has had to endure thus far has been shameful because he has been punished and blamed for not meeting the expected criteria for a healthy young person. In the absence of identification and appropriate treatment, Jack has developed secondary disabilities characterised by dropping out of school, chroming, addiction to alcohol and other substances, trouble with the law, repeatedly offending and being incarcerated.

Thus far he has been unable to extricate himself from being a negative statistic caught up in a cycle because services that may have helped his cause and enhanced his self-image were just not available.

Diane Malbin, Executive Director of FASCETS, Inc, an Oregon based non-profit organization aimed at reducing the incidence of FASD and promoting better outcomes for those already affected, advocates interventions that recognize individual strengths.

> *Many people with FASD are concrete, experiential, kinesthetic learners who learn by doing. Many are also friendly, verbal, creative, artistic, musical, mechanically inclined, and determined. People with FASD are willing and able to learn when techniques match learning styles and build on strengths rather than focusing on deficits. People with FASD can be and are successful in many professions. Some are accomplished musicians, computer technicians, athletes, electricians, artists, mechanics, carpenters, teachers, and are successful in other areas. Although some continue to need support, for example managing time and money, accommodations such as electronic organizers and networks of supportive people are effective in minimizing the disability's impact* (Malbin D, "Fetal Alcohol Spectrum Disorder (FASD) and the Role of the Family Court Judges in Improving Outcomes for Children and Families", *Juvenile and Family Court Journal*, Spring, 2004, 53-63.)

Jack's advantage for improved life prospects was shaped by his early years being raised by Mum Clare, a grandmother with old fashioned values and a lot of love for the small boy. Because of her early death, we can only surmise how he would have weathered the passage into puberty as a young person with FASD under her care.

For now though we need to concentrate on improving Jack's future prospects so they are not a continuation of those years without Clare's guidance. We need to ensure he retains his friendships with peers while finding a pathway that will maximize life chances for him.

As I close this chapter, Jack phoned from the prison where he will spend several more months. He said when he gets out he wants a job, a dog, maybe to do some surfing, a bit of cooking, some fishing and help me in the garden. I was touched by the simplicity of his needs and only hope we can make it together. He really is a wonderful young man.

Governments Need to Show Some Mettle

The Christmas holiday period of 2005 was marked by an inordinate number of alcohol-fuelled road accidents that resulted in more than 60 fatalities. The most popular suggestion to prevent this happening again has been teaching drivers to drive better and more defensively.

No one person has asked alcohol manufacturers to accept even partial blame. This is also the situation with FASD. The Minister for Fair Trading in Queensland issued warnings about giving unsafe toys to small children but still no mention of the dangers of drinking alcohol when pregnant.

Governments have to demonstrate leadership by legislating for alcohol manufacturers to show social responsibility and stewardship of their potentially dangerous products. Educating the public about the dangers of alcohol should not fall on taxpayers but be an essential role of those who produce any form of alcoholic beverage.

Given that FASD is a lifelong disability which critically impacts on life chances of individuals affected by the condition, Jack's situation cannot be addressed in isolation. Accordingly, in 2005, I made the following recommendations to Queensland's Minister for Disability Services.

Recommendations

1. Adopt a Human Rights approach and recognise Foetal Alcohol Spectrum Disorders as devastating lifelong organic brain disabilities.

2. Foetal Alcohol Spectrum Disorders are 100% preventable and therefore deserve an immediate state-wide multimedia strategy to raise awareness of the dangers of alcohol use in pregnancy. This can be done with or without, stewardship from alcohol manufacturers. Prevention does work (Astley, et al, 2004).

3. Appoint cross disciplinary teams to identify the incidence of Foetal Alcohol Spectrum Disorders. This should be a mandatory requirement for all youth who come into contact with the criminal justice system. The service should also be available on request by adults who repeatedly offend.

4. Do not re-invent the wheel. Collaborate with well-established international groups who have decades of highly reputable research knowledge and sound intervention practices behind them. As an example:

- Honourable Linda Reid, Minister of State for Early Child Development, Parliament of British Columbia.
- Canada Northwest FASD Partnership – Scientific Director and Paediatrician, Dr Sterling Clarren
- University of Washington Fetal Alcohol and Drug Unit – Director Professor Therese Grant
- University of Washington Child Health and Human Development – Professor Susan Astley
- FASCETS – Executive Director and FASD Educator, Diane Malbin.
- David Boulding, international legal advocate for people with FASD – dmboulding@shaw.ca

5. Set up an alliance of partners selected from key stakeholders from across disciplines; policy makers, health care providers, social services, justice, school personnel, law enforcement, parents, advocate groups, other relevant institutions and representatives from alcohol producers' associations.

Sponsor an international Foetal Alcohol Spectrum Disorders Conference to generate, promote and instigate collaborative awareness, research and initiatives.

Footnotes

[1] Aboriginal people refer to child rearing as "growing up" a child and sometimes by a carer other than a parent.

DCI-IS is pleased to announce the official launch of its new website!

Ther website can be accessed at the same address: www.dci-is.org For the moment, the text is only available in English; however,The sitewill be translated into French and Spanish as soon as possible.

NOFASARD: National Organisation for Foetal Alcohol Syndrome and Related Disorders - Australia

Since 1999 NOFASARD have been attempting to raise awareness at both a state and federal level of the lack of awareness and action relating to diagnosis intervention and management for individuals with Fetal Alcohol Spectrum Disorder.

Currently in Australia we have a situation where our medical and other health professionals have not received any training in diagnosing this disability so affected individuals are slipping through the system. These are individuals who are unable to learn from their mistakes and make changes in their behaviour or understand the consequences of their actions. They are impulsive, have impaired judgment are easily manipulated and often have far better expressive language skills than receptive language so they appear to understand more than they actually do. They also often have mental health and addiction concerns so these factors all amount to a recipe for disaster in terms of how easily they could come into contact with the law and become repeat offenders.

In Canada, FASD training is being implemented into their police service, corrections system and to lawyers and judges because hey have realized that prevention and appropriate intervention and management is a far less costly alternative than serving them in jails. In North America they have 70 specially trained diagnostic clinics for FASD - in South Australia and indeed Australia we have none.

FASD is a known root cause of many of the behaviour issues and societal problems that are currently being discussed in the media. Many of the children with FASD will be found in the foster care system and juvenile detention facilities. Many adults will be found amongst the unemployed, homeless, drug and alcohol treatment facilities and jails. Until affected individuals are recognized and managed appropriately there will be no solution.

People with FASD are not receiving the same level of care as those with other more familiar disabilities - this is a Human Rights Issue.

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