Submission to the Royal Commission into the Protection and Detention of Children in the Northern Territory

Developmental Trauma of Children of Central Australia

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PREFACE

Developmental Trauma is trauma of physical, physiological and emotional nature which impact on the developmental outcomes for children. It is endured by a disproportionately high number of those under the auspices of the Child Protection and/or Correctional Services.

The attached submissions are brought together due to the widely acknowledged need to develop a Multi-Disciplinary Developmental Trauma team that not only can respond to the immediate needs of children and youth within the justice system but more importantly to identify, diagnose and develop management plans that can consistently support primary preventative interventions. The longer term goal is ultimately being to divert their paths away from the justice system towards a more inclusive, and fulfilling life within their communities.

The development of a 'healthcare front door' where specialized services are coordinated and dedicated to the complex healthcare needs of our young people who are at risk due to the collective trauma they have experienced are recommended. This is an entry point to support an integrated system where our young people are identified within the areas of education, welfare, disability and justice. This entry point will robustly assist with the difficulties of overcoming the scarcity of services in this highly specialized area.

Purposeful, centralized coordination is key to not only enabling the 'healthcare front door' model but also optimizing current resources and developing systems and processes to ensure individual needs are identified and appropriate interventions implemented. The initiating assessment commence within the auspice of health starting within the paediatric specialty and followed with collaboration from other specialist Medical and Allied Health teams, while case management continues to be delivered in the community with collaboration of primary care services with other departments such as education, welfare and justice as relevant.

Despite the is growing evidence of the contribution of exposure to and experience of developmental trauma and the valued insights and of the combined experience of the authors, there is little the raw data of the regional incidence and prevalence of children affected by developmental trauma. At best one can only extrapolate global data which would suggest a significant proportion of affected children regionally. To this end it is difficult to define accurately the level of investment required. Further resources will be required but to a greater extent structural re-alignment will enhance resource utilization and allow a basis to build upon and capture the data to define the service into the future.

Each of the attachments discusses the role of recurrent and sustained stressors and trauma that have a significant impact on the neuro-cognitive development of young people. Although multiple and common sources of trauma are identified they include but are not limited to substance misuse, domestic violence, sexual assault, poverty, neglect and unrecognized disability. These circumstances are compounding and typically experienced throughout life's stages in-utero, infancy, childhood and adolescence. Without timely and sustained intervention through the provision of accurate information via a coordinated diagnostic methodology and an implementable management plan, these prevailing conditions manifest themselves through adolescence as 'anti-social' behaviours, eventually result in the attention of the justice system.

CONTRIBUTORS

Drs Megan Chambers and Sally Cleworth are the two half-time child and adolescent psychiatrists working in Alice Springs. They are offering this on the basis of their professional expertise and experience in New South Wales and in the Northern Territory while not experts on forensic child and youth within detention services, they have experience working in those settings. They have collectively worked in Alice Springs for last 4 years.

Dr Jennifer Delima, has been delivering clinical care to youth since 2005. This has been initially as Custodial medical officer, called to acutely review youth in detention in Alice Springs whilst awaiting transfer to Darwin correctional facility. Additionally, she continues to provide care to youth interfacing the Justice system whilst engaging with Addiction medicine as well as Sexual Assault medical services.

Ms Christa Bartjen-Westermann and Ms Susan Cooper are managers of the Sexual Assault Referral Centers (SARC) in Alice Springs and the Barkly. Both Christa and Susan have extensive experience as social workers in government and non-government organisations.

Dr Keshan Satharasinghe is a Consultant General Paediatrician who is committed to the development of a clinical service for children suffering the effects of Foetal Alcohol Spectrum Disorders. He has been based at the Alice Springs Hospital since 2011.

Whilst this dedicated groups of clinicians are not of aboriginal background, they are all acutely aware of the contextual limitations this presents. They would also like to acknowledge and thank the Indigenous Custodians of the land past, present and future and for allowing the authors ongoing practice upon their lands.

SUMMARY OF RECOMMENDATIONS

Recommendations from the Royal Commission are inclusive of a rigorous, long –term implementation and monitoring process.

A Multidisciplinary Developmental Trauma Team (MDTT) with capacity which can provide comprehensive physical health, developmental and cognitive assessments, and mental health assessment. This needs to be:-

a) Readily available to children of all ages, as they are identified as of concern.

b) It needs to be available for remote children and young people, with capacity for outreach so that they can be assessed in their own context, on their own land.

c) Comprehensive, so that specific issues can be identified (e.g. Foetal Alcohol Spectrum Disorder) and vulnerabilities likely to impact on their development are identified early e.g. poor frustration capacity and poor emotion regulation (identified as a major prognostic factor relating to future violence).

d) A range of specialized health services coordinated via a 'front door' and led by paediatricians so that a comprehensive management plan can be developed and continuously supported.

e) Strong case management for their healthcare needs in the community that is owned by primary health and supported by specialist medical and allied health services.

f) Provide clear and consistent healthcare support for an all-of-system approach to caring for our young people.

The MDTT would undertake:-

a) Assessment of cognitive (intellectual) capacity in addition to the considerations of charges / sentencing of the youth's chronological age. (Sect 30(14))

b) Early screening in the youth's contact with Justice / corrections should be that of intellectual capacity.

c) Appropriate training of police, corrections officers, judicial practitioners in identifying youth at risk of possible intellectual impairment. Also provide advice/support to community-based initiatives that are engaged in Prevention programs of Developmental Trauma; such as education programs for the prevention of FASD.

d) Training and support of those looking after 'at risk' children and young people - including but not exclusively foster carers, relative carers, and residential care workers. Training and

education in the effects of developmental trauma, and assistance in managing the problematic behaviours of the children.

e) Develop an early holistic medical assessment for those screening positive 'at risk' for intellectual impairment, so that the justice system is able to facilitate appropriate legal proceedings acknowledging the language /concept/ etc challenges.

f) A 'Youth Diversion' process that will also require tailoring to the intellectual impairment and cognitive capacity of the youth. Even simply written or verbal warnings may not be attended with insightful comprehension. (Part 3, 37)

g) Participate in the Youth Justice Advisory Committee (Part 13, 203) to ensure a Medical officer with either Custodial medicine or Adolescent mental health with knowledge also of health practice so that appropriate health care is provided as a basic consideration for every youth detainee.

h) The capacity for forms of intensive case management allowing for early intervention when plans are not working and persistent follow up to ensure that momentum is not lost when changes begin.

i) Coordinate intensive support for periods some families and carers need because of their own needs. This intensive support also needs to be effective for young people with no obvious connections strong enough to hold them in one programme or accommodation. This intensive support looks different at different times e.g. via a primary health setting, or via welfare settings.

j) To have capacity to be very available for periods to the young person, and to form strong links with the young person's own family context.

k) It is recommended that a well-resourced sexual assault prevention framework and action plan for an integrated whole-of system-approach to prevent sexual assault be developed including data collection, early intervention and treatment for children and young people displaying harmful sexualised behaviour.

SUBMISSION FOR THE ROYAL COMMISSION INTO PROTECTION AND DETENTION OF CHILDREN IN THE NORTHERN TERRITORY

October 2016

Contribution by Dr Megan Chambers and Dr Sally Cleworth

Introduction

This submission is authored by the two half-time child and adolescent psychiatrists working in Alice Springs, in the Central Australia mental health Service. We are making this submission because

- Many of our referred clients are of direct relevance to the scope of the Royal Commission, being either children in detention, in care, or at risk of both.

- We strongly feel that there are interventions which are possible to make which could alter the trajectory into and out of care and detention, but which are difficult to provide currently in Central Australia.

- These interventions require some additional resources, but even more some structural coherence in the approach to these young people.

- As is common in all jurisdictions, many of the children in detention are the same children who are in care, and who present to community mental health services, and are in trouble in education services. In the NT this group includes a much higher number of Indigenous children than other states and territories. There are a range of common factors impacting on these children - developmental trauma, including FASD and other biological challenges, transgenerational trauma, parenting gaps, exposure to domestic violence and substance use, accrual of a range of deficits in learning and prosocial competences which make it harder to remain in education and occupational settings, substance use and early criminal behaviour. Health interventions are one aspect of assisting these children, as part of an integrated approach with welfare, education, justice, family and community support in a multisystemic model.

In addition, we are not experts on forensic child and youth within detention services, although we have experience working in those settings. Our focus here is on the children and young people in Central Australia, and ways to approach service provision for those at risk of entering and those already in detention in the Alice Springs Correction Centre.

Recommendations

The following are our particular recommendations for service and resource changes which, the evidence suggests, can alter the trajectory into detention of 'at risk' youth.

1. A multidisciplinary health assessment capacity which can provide comprehensive physical health, developmental and cognitive assessments, and mental health assessment. This needs to be

- Readily available to children of all ages, as they are identified as of concern.

- It needs to be available for remote children and young people, preferably via a mobile component so that they can be assessed in their own context.

- Comprehensive, so that specific issues can be identified (e.g. Foetal Alcohol Spectrum Disorder) and vulnerabilities likely to impact on their development are identified early e.g. poor frustration capacity and poor emotion regulation (identified as a major prognostic factor relating to future violence).

- Centralised and linked to a range of services in Central Australia, so that a comprehensive management plan can be developed and reviewed and owned by primary health and specialist services, education and welfare services.

2. Capacity for multidisciplinary treatment approaches that flow from these assessments and which are well coordinated, made practical for remote contexts (e.g. with use of telehealth), trauma-informed, and sensitive to the age of the young person and their cultural needs. Treatment is sometimes necessarily delayed by the need to manage acute or high-risk situations such as suicidality, violent behaviour, threatened placement breakdown. Plans need to be reviewed regularly because circumstances and priorities of treatment often change, even as positive shifts start to occur.

3. Training and support of those looking after 'at risk' children and young people. Training and education in the effects of developmental trauma, and assistance in managing the problematic behaviours of the children. This needs to be comprehensive and ongoing, and available for education and detention staff, Territory families staff, and residential care workers and foster carers.

In particular, it is important to have a systematic training and support available for foster carers, relative carers, and residential care workers. This can take different forms for different people, but there are available programmes such as 'The Reparative Parenting Program' with which the authors are familiar.

4. The capacity for forms of intensive case management. This allows for early intervention when plans are not working, and persistent follow up to ensure that momentum is not lost when changes begin. In addition, some families and carers need intensive support for periods because of their own needs. This intensive support also appears effective for young people with no obvious connections strong enough to hold them in one programme or accommodation. This intensive support looks different at different times e.g. via a primary health setting, or via Territory Families.

The major issue is the capacity to be very available for periods to the young person, and to form strong links with the young persons own family context.

Case studies

The capacity to provide these interventions would apply to a range of cases, as in the following examples (amalgamated real cases):

1. CII [redacted]

2. CII [redacted]

3. CII [redacted]

4. CII [redacted]

CII [redacted]

Developmental Trauma

In all of these cases and with the majority of young people in detention in the NT, the phenomenon of Developmental Trauma is vital to understand.

Throughout the world, there has been an increased awareness of, and research into the group of children who appear in an overlapping group of services - mental health, special education, disability, juvenile justice, and welfare (van der Kolk 2005, Perry 2009, Cook et al 2005, Boivin et al 2012). These children have multiple things in common - early neglect, poverty, exposure to a range of developmental traumas, including domestic violence, family and care instability and disruptions and losses, a range of physical health issues, and early contact with the justice system.

Over the last 20 years especially there has been an increasing focus on this group of children and young people, partly fuelled by

- Recognition of poor outcomes in most jurisdictions, with poor educational and employment outcomes, high levels of substance use and early pregnancy, high levels of detention, difficulty in stabilising care placements. Outcomes for indigenous youth are consistent with these.

- Recognition that these children and young people are difficult to help, with most services struggling to meet their needs with any consistency, due to the complexity, chronicity and multiplicity of concerns.

The research has focused on a range of areas of need, including

- Awareness of biological components to the children's problems (notably an awareness of Foetal Alcohol Spectrum Disorders, the impact on the developing brain of chronic stress and arousal, and chronic neglect). In addition, the range of genetic influences and epigenetic effects is much larger than previously acknowledged.

- Awareness of the consequences of disrupted and abusive attachments. These are consequences to the children's development, sense of self and capacity to self regulate, to form satisfying mutual trusting relationships and their capacity for caring and empathy with other people.

- Awareness of the frequency of Chronic Post Traumatic Stress Disorder, on children and young people exposed to abuse, neglect, domestic violence and multiple losses. This results in chronic hypervigilance and states of hyperarousal, which adds to self-regulation difficulties. In addition it often results in the avoidance of situations that might trigger fear responses, including situations that are frightening, shameful or humiliating (e.g. school), or threatening (e.g. intimacy with adults, control by adults).

- Awareness of the impact of these stressors on learning, social functioning and capacity to be in employment. Executive functioning difficulties, similar to those with children with ADHD,

combined with chronic anxiety and hypervigilance decrease learning even for children attending school regularly.

The frequency of past trauma among youths in detention in the US is extremely high (over 90%) (Soulier and McBride 2016). In the NT it is likely to be similar, and with high numbers of Indigenous youth in detention the issue of trans-generational trauma is often an additional component cause of developmental trauma in this group. Much has been written about trans-generational trauma due to colonisation of Indigenous groups, where historical trauma such as forced removal of children from their families, is embedded in collective memory and passed from adults to children within a community or cultural group (Atkinson 2002, 2013). This kind of secondary trauma is a reality for many Indigenous children.

These and other findings have meant that when considering how to improve the outcomes for these children and young people, all service settings need to

- Be aware of the above factors (biological, psychological, social, cultural, historical)

- Have a holistic approach to the children and young people which takes into account their specific needs and vulnerabilities (bio-psych-social-cultural)

- Have a long-term recovery of function approach, so that the aim of intervention is to enable the child's best functioning in school and in family and relationships, and in development of an integrated and competent sense of themselves.

- Sustain involvement over time - recovery is not quick or simple, and is different at different ages. Continuity of care, and sustaining long-term relationships is essential for better outcomes.

For service systems, this means

1. Incorporating biological, psychological, social and cultural components. This is a multisystem approach, found to be effective now in a range of jurisdictions where other single system approaches are not effective.

2. Assessment needs to be biological, psychological, social and cultural. This means that the children's health needs and developmental needs are clarified including speech, hearing and OT assessments, nutrition and growth, cognitive functioning and academics, mental health, relationship and cultural connections and family ties, current and past losses, current social and peer functioning. These are all areas that need awareness and will impact on the child's outcome if not addressed.

3. Planning for recovery needs to include provision of sustainable care and relationships, strong family knowledge and connections and identity, a focus on educational recovery and opportunities for peer prosocial functioning. Physical recovery and the use of medication and behavioural strategies and therapy may be needed for the specific problems identified e.g. post traumatic stress disorder, executive functioning difficulties, self regulation difficulties, substance use.

4. Planning for recovery should include treating problems as well as making up deficits, and developing competences and strengths (providing opportunities to excel and develop skills)

5. The service system around these children and young people must be conceptualised as having multiple components that are integrated. The components will vary in specifics with the age of the child but essentially the components are the same:

Assessment components - paediatric, mental health, speech therapy, occupational therapy, psychology

Treatment components for the individual child, including speech therapy, occupational therapy, therapy for PTSD

Informed carers who are able to parent in a way that helps recovery. Foster carers, residential care staff, and relatives often need assistance to parent children who may be more disruptive and dysregulated, with decreased capacity to trust others and used to losses and change.

Educational support with a focus on recovery and opportunities. This often means individual or small group programmes, and opportunities for alternative programmes with a focus on activity and practical skill acquisition to increase confidence.

Intensive case management that allows for individualised services and monitoring, and the capacity to repair after failure. Sustainability requires intensive case management, and also for older children this may need to be supported by a legal framework of monitoring and supervision and capacity to work in an ongoing way with children as the structures around them changes.

Implications of trauma for children and young people in detention

Young people with histories of abuse, neglect, multiple losses and attachment disruptions, learning difficulties, FASD and Post traumatic Stress Disorder are over-represented in youth detention populations, in western parts of the world (Soulier and McBride 2016, Popova et al 2011, Shufelt 2006, Abram et al 2004, Teplin et al 2002).

In Central Australia, the vast majority of young people in detention are Indigenous, have suffered developmental trauma and their families have suffered transgenerational trauma. This has a range of implications for the young person's management in detention:

- Severe distress will be triggered easily for many young people, which may present as acute "at risk" periods. This will occur when the young person feels threatened, overwhelmed, coerced and alone. Distress will only settle as the young person feels safe, and connected to relatives and trusted other adults within the staff of the detention centre. Acute 'at risk' assessment needs to be able to differentiate distress from major illness, so that the appropriate safety-focused responses can be implemented. Too often the young person is deemed 'not mentally ill' while the distress is not recognised and arousal is not reduced by appropriate interventions.

- Many young people in detention will be easily aroused and overstimulated, with poor executive functioning and problem solving skills, and deficits in language ability and learning that can make it hard for the young person to understand and be understood, and manage the experiences of detention. Peer relationship difficulties, a tendency to distrust others and low frustration tolerance are associated problems.

- Many young people in detention have a poor capacity to interact with adults in authority and will react to them with challenge and distrust. This creates a confrontational interaction, difficult for either youth workers or young people to avoid. Both of these issues are improved by education of the adults in the nature of trauma.

- Many young people in detention will have problematic relationships with their families - these relationships may be lost, stressed, coercive or impacted by a range of parental health or substance use problems. This increases the arousal and sense of lack of connection of many of the young people.

Detention centres can function in a way that recognises these issues, and reduces distress for the young person, while still functioning for the purpose of detention, by:

- Respecting the young person's need for safety, by clarity and predictability and fairness of processes, making sure that family connections are enhanced, facilitating every young person having an advocate/ case manager/ communicator, creating opportunities for communication.

- Enhance capacities for recovery, of educational opportunities, social skills and peer interactions

- Offer therapeutic assessment and treatment of traumatic disorders, depression and anxiety and substance use disorders, psychotic disorders.

Current mental health service gaps

Current resources within the Child and Youth Mental Health Service are limited. To enable mental health services to properly contribute to the multidisciplinary comprehensive assessment and treatment of children and young people at risk, including providing assertive follow up, responding to acute and high-risk situations as they occur, delivering therapies and coordinating mental health remote outreach to young people and families, there would need to be

- Additional child psychiatry hours

- An increase in the number of mental health clinicians on the team

- including clinicians to specifically coordinate remote outreach

As for the young people in detention in Alice Springs, they almost all come from Central Australia, and need connection to families and communities, to education, employment and leisure activities in their own communities. While a territory-wide youth forensic service may be important for long periods in detention, for those going in and out more quickly, local case management that is connected and able to provide knowledge and coherence is essential.

The CYMHS team in Central Australia has historically seen young people in detention who are existing clients when they can be brought into the CYMHS offices. However proper case management is required with the aim of liaising with families and outside services, providing therapeutic interventions and education to corrections staff and families, and providing coherence before and after periods of detention. For the last few years, extra resources have been requested by CYMHS to enable assessment of a wider range of young people in detention, and to provide mental health intervention and case management as needed. These extra resources include

- Additional child psychiatry hours (approximately one day per week)
- A child and youth forensic case manager

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A SUBMISSION FOR THE ROYAL COMMISSION INTO PROTECTION AND DETENTION OF CHILDREN IN THE NORTHERN TERRITORY

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October 2016

Dr Jennifer Delima

This submission seeks to provide a brief summary of some of the issues pertinent to the Commissions review of Children in Detention and further information is available if additional clarification is required.

The following opinion is based upon clinical care delivered to youth since 2005. This has been initially as Custodial medical officer, called to acutely review youth in detention in Alice Springs whilst awaiting transfer to Darwin correctional facility. Additionally, I continue to provide care to youth interfacing the Justice system whilst engaging with Addiction medicine as well as Sexual Assault medical services.

The triad of substance abuse, sexual abuse and youth detention, speaks highly of the probable impact of childhood / in-utero developmental trauma background on these individuals.

Introduction

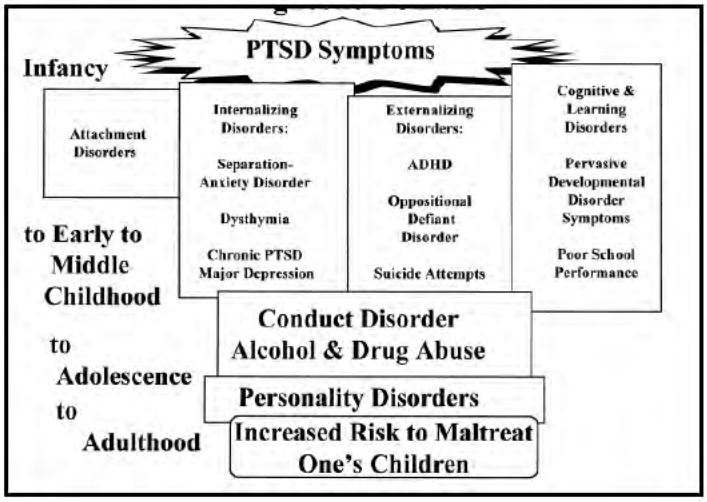
Delivery of youth justice should not be undertaken without provision of concurrent and timely assessment of the health (physical and mental) as well as the developmental background of the individual.

Involvement of the Department of Justice with requirement for detention in children and youth typically occurs at the culminating point of an increasingly and severely distressed individual.

Until early adulthood (approximately 24 years age), development of the brain and its functional capacity continues to significantly occur. Research on the impact of chronic and sustained stressors or trauma encountered during the in-utero, childhood and adolescent periods provides a growing body of evidence of resultant cognitive and learning disabilities with lifelong consequences for which the majority of affected individuals do not achieve full, independent living.[2, 4,10,12,16]

Un-remediated, these disabilities typically result in expressions of frustration, anger aggression, irritability, etc. seen as 'anti –social' behaviours that result in difficulties for family care, community engagement and eventual address through the Justice system.[2, 4, 7]

Importantly, the behavioural expression of developmental disability becomes more noticeably expressed as the child ages and becomes difficult for the family and community to contain as they enter adolescence when they typically come to the attention of the justice system.



M De Bellis 2001

FASD

FASD (fetal alcohol spectrum disorder) is the disability resultant from in utero exposure to alcohol. Although the estimated incidence of FASD among the general population is 2-5 %, the incidence is quoted to be significantly higher within the justice system. Data from countries that have long been considering the impacts of FASD e.g. USA, Canada, South Africa estimate FASD incidence in the Juvenile justice offender population as high as 60%.[15, 3]

FASD is now considered a worldwide leading cause of intellectual disability and requires to be specifically screened for in this population.

The worldwide trend of increasing uptake of alcohol in women of child bearing age and within social (often unplanned pregnancy) context, continues the risk of increasing numbers of youth eventuating in detention with the underlying disability of FASD and its consequent high recidivist rates and management /treatment difficulties.

Additionally, it is also unclear how many FASD affected young people in Central Australia are in 'Out of Home' care following their identification through child protection services

Data for Australia remains scant at present as it is only recently that Australia has come to recognise FASD. In the Northern Territory, the level of alcohol consumption, remains significantly higher than the rest of Australia, placing the region within the first 10 of highest alcohol consuming countries, with mainstream Australia only recently falling back around the 30th position.

Early childhood trauma

It is well recognised that communities in remote and rural areas suffer the impacts of poverty, and poor social determinants of health and well-being more than their city counterparts. This is further compounded by a general lack of and limited access to remedial services and supports.

In the Northern Territory, our remote areas are highly populated by our Indigenous peoples living in impoverished circumstances with limited health and educational resources and supports.

This level of poverty (especially psycho-social), is often associated with sequelae of lacking home environment stability, child neglect, exposure to violence, etc which places young children at further risk of neurological developmental disability.

Adolescent brain development

In addition to the above described insults to the young person's developing brain, must be added the consideration of the specific brain maturation that occurs in adolescence.

During this time the brain undergoes changes to achieve higher order cognitive function i.e. more efficient problem solving, decision making, memory recall, consequencing, language comprehension etc. [5]

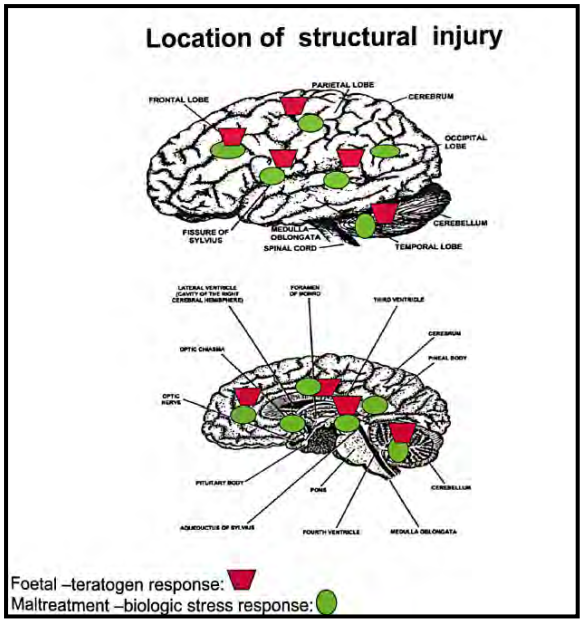
This period of brain maturation, is also associated with impulsive and risk taking activities which if undertaken on an already present underlying intellectual impairment, will increase the likely expression of 'anti-social' behavioural responses.

Further, alcohol has a direct inhibitory impact on brain maturation, especially executive function during the adolescent period, which of itself may result in functional brain disability.

Expression of brain disability

Research on the impacts of early childhood trauma and fetal alcohol exposure on the individual map in similar areas of the brain (see diagram below) with a resultant effect of similar but not necessarily equivalent learning and cognitive disability.[2,10, 11, 12, 13]

The areas of impairment are not equally expressed across all individuals, and hence no clear and single criteria can be described for ease of diagnosis.

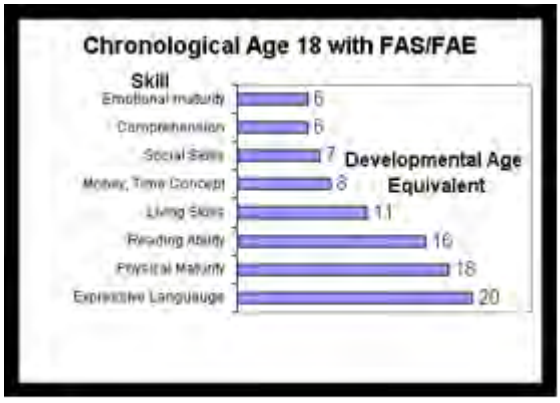


J Delima 2011

A composite of several assessments is required to define the extent of the individual's learning disability – this may include a paediatrician, child psychiatrist, adolescent physician, addiction medicine physician, neuropsychologist, clinical psychologist, speech therapist, occupational therapist etc.

There is little current Australian data available on the incidence of intellectual disability in the Juvenile justice population, however, extrapolation from countries (Canada, USA, South Africa etc) with similar per capita mainstream alcohol consumption as mainstream Australia would suggest that the incidence of intellectual impairment in the Northern Territory would be at least similar, at 60% if not higher.

Whilst these intellectually affected youth, often appear visually normal and have an apparent good expressive language, their functional intellectual capacity is significantly lower than their chronological age.



per D Malbin, MSW 2002

Issues pertinent to interface with Youth Justice

In youth who are neuro-cognitively well, it is assumed that they have achieved developmental capacity to know right from wrong as well as comprehend consequences of action. Hence their ability to engage with the Justice system has a higher propensity for positive outcome and change of behaviour especially if engaged with restorative justice and rehabilitation programs.

Unlike those described above, children and youth affected by early childhood trauma exposure or FASD suffer a spectrum of behavioural responses to their underlying impaired brain processing despite typically demonstrating an apparent excellent expressive language.

Their functional brain disabilities include many of the following:[16,17,15,7]

- poor executive function, (consequencing actions, abstract thought, decision making)

- poor self-regulation,

- impulsive behaviour,

- high levels of anxiety and aggression,

- high levels of suicidal ideation,

- learned 'helplessness' from inability to plan, choose, comprehend

- persistent hyper-arousal and hyper vigilance state

- dissociation and hence lack of memory for the event in question- may be perceived as 'lying'

- impaired cognition – learning, attention, capacity

- vulnerability for substance misuse disorder

Cognisance of this spectrum of learning disability requires youth involved with the justice system to have specific considerations made to ensure no adverse effect from unaddressed disability needs.

1. Fitness to interview:-
   a. Capacity to comprehend the process and implications.
   b. May be easily led to acquiesce to statements made without comprehension of the task required.
2. Comprehension by the youth of their 'Child rights' and ability to access assistance of legal counsel- may not have comprehension of ability to request assistance. YJA Sect 30(14)
3. Comprehension of 'request' for forensic procedure and ability to refuse in writing and consequences of this – may not comprehend implication. YJA Sect 32
4. Language comprehension capacity and literacy– expressed words versus meaning of phrases used. –will require specific measures to ensure that the youth does understand the legal process and its outcomes or otherwise have appropriate legal counsel and support provided.
5. Requirement for instructions to be non- complex and simple to enable single task completion without triggering hyper- arousal / vigilance states.
6. All staff involved with youth should be specifically trained to recognise or be aware of the risks of intellectual impairment upon an individual interfacing the justice system and adapt their interactions accordingly.
7. Early assessment requires to be undertaken by those specifically trained to do so.

Although the above list is not exhaustive, it is these components that do require attention to ensure a fair and equitable response to the intellectually impaired youth encountering the Justice system.

Additionally, differences in language and culture may further compound adverse and unintended outcomes for this population.

It is therefore imperative that clinical assessments be made within the context of appropriately trained cultural and language brokers to facilitate correct specialist interpretation of assessments is made.

Youth Justice Act 20161

Whilst the Youth Justice Act, clearly seeks to achieve community safety, victim reparation with just and fair remedial outcomes for the offender, modifications to the current act and its administration require to be made with awareness of the high incidence of intellectual impairment in this population.

Recommendations:

1. Assessment of cognitive (intellectual) capacity requires to be undertaken, in addition to the considerations of charges / sentencing of the youth's chronological age. (Sect 30(14))

2. Early screening in the youth's contact with Justice / corrections should be that of intellectual capacity

3. Appropriate training of Police, corrections officers, judicial practitioners in identifying youth at risk of possible intellectual impairment.

4. Develop an early holistic medical assessment for those screening positive 'at risk' for intellectual impairment, so that Courts may be advised as well as correctional services to facilitate appropriate legal proceedings acknowledging the language /concept/ etc challenges.

5. The 'Youth Diversion' process will also require tailoring to the intellectual impairment and cognitive capacity of the youth. Even simply written or verbal warnings may not be attended with insightful comprehension. (Part 3, 37)

6. The current Youth Justice Act, advises assessment by a medical officer primarily only for medical treatment if required. (Part 10, 173-174)

Youth typically do not identify their ill health until very late and then primarily through behavioural methods. It is recommended that all youth be clinically assessed by a medical officer with specific knowledge / training in assessment of fitness to interview and forensic medical assessment.

7. Youth Justice Advisory Committee (Part 13, 203)

This group should also include a Medical officer with either Custodial medicine or Adolescent mental health with knowledge also of health practice to ensure that appropriate health care is provided as a basic consideration for every youth detainee.

Recommendations for a Health support model for Youth detention:

All youth who come to the attention of Justice, should at the outset have a holistic assessment of their health (physical, mental and developmental) which may be undertaken initially by a Forensic medical officer with specific view to also screen for intellectual difficulty and referral to further specialist assessment as required.

Currently there is no formal diagnostic facility to enable comprehensive assessment of children /youth with intellectual disability.

A multidisciplinary facility (for children and youth , aged less than 18 years) to enable assessment of developmental trauma (in-utero as well as early childhood) is required to assess and commence early remediation through family support, school education, community engagement.

This intervention will assist to decrease the vulnerability of the youth to anti-social behaviour responses related to their distressed state of intellectual impairment.

Funding and support for such a unit, with its interface across justice, health, and education should be considered as an ongoing budget expenditure line independent of changes in policy or prevailing government ethos as the intellectual disabilities that these vulnerable youth experience can only be mitigated through appropriate diagnosis and ongoing consistent remedial support programs.

The unit will require to collaboratively interface with community organisations – education, child protection, primary health, residential rehabilitation to further support the affected youth.

Importantly, remedial supports / programs require to be of behavioural support methodology to cater to the learning disability of developmental trauma rather than CBT (cognitive based therapy) etc. based programs which cannot be comprehended by the sufferer.

Such programs require to be based in a therapeutic, positive nurturing environment, and with consistent support rather than 'boot camp' models.

It should be acknowledged that this support will require to be ongoing for the lifetime of the individual and further adjusted to their changing needs.

Illustrative cases from Addiction medicine:

1. Child with likely FASD +/- childhood neglect neurodevelopmental disability. CII [redacted]

2. Non- indigenous youth with a likely FASD impairment and issues of schooling difficulties, substance misuse, aggression and youth diversion needs.

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CII

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SUBMISSION FOR THE ROYAL COMMISSION INTO PROTECTION AND DETENTION OF CHILDREN IN THE NORTHERN TERRITORY

Sexual Assault Resource Centre, Alice Springs

October 2016

Dr. Jennifer Delima, Ms Susan Cooper, Ms Christa Bartjen-Westermann

Sexual Assault Referral Centre

1. Sexual Assault Referral Centre (SARC)

SARC is a specialist service providing crisis response in Alice Springs and the Barkly and provides long term support and treatment for children and adults affected by sexual violence. SARC's services are client centred and include a 24 hr forensic medical assessment crisis response as well as medical care for victims of sexual violence, which includes screening for injuries, treatment for sexually transmitted infections and drugs, and pregnancy prevention. Psycho- social support is provided during the assessments. Counselling is available to children 3-10 years of age, adolescents and adults who have experienced recent or historical sexual violence. SARC also provides support and counselling for partners, family members and non-offending significant others. SARC assists through the police, legal and court process as requested by the client. Furthermore, SARC is involved in primary prevention activities, although only as an informal extension of already limited resources and staff duties, as no identified position and funding exists for this activity.

2. Introduction

Sexual violence has and still is causing substantial social, justice, health and economic costs to individuals, families and communities. Sexual Violence is a very serious issue in our society, which is still silenced and underreported as compared to the recent changes in Domestic and Family Violence. Breaking the silence around Sexual assault appears to be a major challenge due to a myriad of reasons especially in Central Australia and the Barkly. Currently sexual assault service provision exist in Alice Springs and Tennant Creek but not in remote areas; hence people living in remote areas find it harder to access the services. This limited distribution of services is resulting in geographical gaps in services to communities, who are already very disadvantaged. Knowledge based on research suggests that specialist first crisis response services to sexual assault are very important. If these services are not available or not provided harm can worsen and in cases of child sexual abuse has been linked with a wide variety of psychiatric disorders in adulthood (Charlie Brooker, Karen Tocque 2016).

For a number of children placed in care via the statutory body, exposure to other prolonged trauma has been part of their lives apart from experiencing poverty, food insecurity, Volatile Substance Abuse and AOD exposure, lack of adequate health responses and overcrowding. These issues and their impact on children and their brain development have been explored by a number of authors (Sara McLean 2016). In order to respond adequately and comprehensively and to reduce young people at risk moving on a trajectory from Child Protection to Youth Detention and ultimately adult detention an investment in primary, secondary and tertiary service provision across a number of support areas is required.

3. Lack of consistent intervention models

During the last 10 years the Northern Territory has had two major inquiries. The "Little children are sacred" report which specifically looked at the protection of Aboriginal children from sexual abuse (2007) and the Report on the Inquiry into the Child Protection system in the Northern Territory (2010) provided a number of recommendations to address the situation of children and their families in the Northern Territory. A few recommendations were implemented but a majority have

not been addressed and are still very pertinent to the context of this current Royal Commission. Number 10 of the "Growing them strong" report refers to the investment in the development of secondary and tertiary prevention, and therapeutic and reunification services for vulnerable and at risk children, families and communities (Board of Inquiry 2010). Further recommendations relevant from the Board of Inquiry report would be number 23, 24, 31, 32, 33, 66, 146 to name a few.

The above mentioned reports were based on extensive consultation and research pertaining to the protection of children. The knowledge gained throughout these consultations has relevance to this current Royal Commission and provides background information related to the underlying causes as to why young people, mainly Aboriginal children, are over-represented in child protection youth detention in the Northern Territory. Further recommendations were provided by the NT Children's Commissioner in her report, which examines the services provided to Youth at the Don Dale Youth Detention Centre (2015). These recommendations appear to have not been acknowledged or have been lost. It appears there is no continuity in service provision models, as models and approaches change when the political and bureaucratic context changes. How can a safe and stable environment for children and their families be achieved if service models and policies, ideas and implementation processes keep changing within a short time frame?

The "Little Children are Sacred Report" (2007) identified a number of implementation recommendations in their report (no 93, 94, 95,96), which might be able to assist with the development of ideas for the implementation of recommendations in this current Royal Commission.

Recommendation

That recommendations from the Royal Commission are inclusive of a rigorous, long –term implementation and monitoring process.

3.1 Lack of critical assessment and therapeutic support models

As mentioned above Alice Springs SARC provides a specialised forensic-medical and therapeutic response for children and adults only in the main centres. The Mobile Outreach Services PLUS (MOS PLUS), which initially operated as part of SARC but later operated via the Child Protection agency, provided therapeutic counselling, information and education to children in remote communities. The target group consisted of children who experienced trauma from a range of child abuse and neglect issues, not only sexual abuse. This service was defunded in 2016 and left a gap in service delivery for children, especially in the Barkly region as SARC is the only trauma specialist service. It might be worthwhile mentioning that there is no specialised therapeutic support for children, teenagers or adults eaffected by sexual assault in remote communities.

SARC has provided extensive therapeutic support to adults and children and can draw on this long-standing experience and how the lack of early support services can have long standing impact on quality of life in general. Our counsellors have for example provided counselling to male clients in custody, who were sexually assaulted as children but did not receive any support at the time. These experiences manifest themselves in individuals in different forms, some of which will lead to anti-social behaviours, suicides, AOD addictions, mental health issues and criminal behaviour in young

people and adults (NZ Inquiry2015). It is argued that a consistent, multidisciplinary and collaborative assessment and therapeutic service system is required to provide a whole of community approach in urban as well as remote areas.

An area of concern, which has come to the attention of SARC via Central Intake meetings with Territory Families and the local Child Abuse Taskforce team, is the provision of Implanon (depo contraception) particularly in remote communities by clinic staff to girls as young as 11 and 12 years age. It is unclear as to how comprehensive the health and safety assessment process is, prior to administration. Implanon's function is to avoid pregnancy following intimate sexual activity and has little other protective factor with specific regard to sexual abuse and exploitation and more long term health (recurrent pelvic infection, and consequent infertility as well as PTSD etc) complications of these . Administering Implanon to young girls 12/13 could be seen as being complicit in the sexual exploitation of young girls, not to mention the potential health implications on a young maturing female body. The accountability around the treatment with Implanon is not clear and could almost be interpreted as enabling behaviour and systemic collusion of health professionals with perpetrators, even though the intent of the health professional is very different.

The above highlights the difficult situation of ensuring child safety in a rapidly changing environment where social media (goading young people into significantly risky sexual and other behaviours) has a tremendous influence and impact on the behaviour of young people and subsequently child safety assessments. It appears there is a clear gap in the provision of educative and supportive work for all, especially in remote areas. The "Little Children are Sacred Report" (2007) has identified this as important, specifically in relation to responding to sexually transmitted infections in young people. To provide school-based and community-based information and education programs about sexual safety, respectful relationships, consent, sexual health and STIs, sexual abuse and its long term impact are seen as important. The above and recent anecdotal information inform SARC that this needs to start in late primary school in order to have a preventative impact. Investment in education programs aligned with safety strategies might assist in building the required trust and safety so that children and adults can disclose if abuse is occurring (Little Children are Sacred 2007).

Recommendation

Investment in a consistent, multidisciplinary and collaborative assessment and therapeutic service system is required for Central Australia and the Barkly region. Long term, integrated approaches to preventing sexual violence should be given some emphasis. The National Association of Services Against Sexual Violence (NASASV) has developed a prevention framework which provides some key standards. These standards aim to provide guidance to program providers and to also assist policy makers to make decisions about practice and funding (Carmody, M., Evans, S. Krogh, et all (2009). In the Northern Territory there has been no Sexual Assault framework or strategic investment in sexual assault prevention programs. Limited Sexual Assault prevention education programs are currently provided in the urban area of Alice Springs and sporadically elsewhere and the Barkly region. These vary in style, extent and content and would benefit from a central collaborative coordination platform based on local and changing issues. This would also apply to the Barkly Region as education and prevention programs are Tennant Creek focussed with minimal capacity to expand into larger communities like Elliott and Ali Curung.

The Australian Centre for the Study of Sexual Assault refers to three forms of prevention primary, secondary and tertiary. The authors strongly argue that primary prevention must strengthen protective factors and overcome risk factors that facilitate sexual assault, which includes changing behaviour before it becomes established and hence lead to lower levels of sexual violence (Quadara, A. & Wall, L. (2012). Prevention programs are crucial especially in light of the recent technological changes which impact greatly on young people. Young people are using social media and the internet extensively and need to become educated about strategies being used and how best to protect themselves. Emphasis needs to be placed on how to avoid being vulnerable to sexual exploitation and what to do if this is occurring. The ever- changing environment requires flexible, place-based, fluid, culturally safe and innovative responses to deal with the presenting challenges. Programs and interventions need to reflect this and need to be based on local context and be able to be adapted depending on the presenting issues.

As mentioned above, SARC has learned through its counselling work about the devastating and life debilitating long term effects of sexual abuse in childhood. The NSW Rape Crisis Centre (2009) states " ...when the trauma takes place in early childhood, but presentation for diagnosis and treatment does not occur until adulthood, the impact of trauma on brain functioning and emotion regulation may have given rise to depression or Bipolar Mood Disorder, masking the initial cause of symptom presentation". As a civil society we do have a responsibility to reduce these long term effects such as mental health issues, PTSD, AOD, depression, anxiety, aggression, Borderline personality disorder and suicidal ideation. While a comprehensive trauma treatment support program is required a holistic prevention approach is equally important to avoid trauma in the first place.

Recommendation

It is recommended that a well-resourced sexual assault prevention framework and action plan for an integrated whole-of system-approach to prevent sexual assault be developed.

3.3 Lack of services for children and young people displaying harmful sexual behaviour

Through its collaborative work with other stakeholders like the protection system and police, SARC is well aware about the presenting group of young people allegedly displaying harmful sexualised behaviours towards other young people, especially in remote community areas. The terminology concerning this behaviour varies in different states and countries and has been an issue of extensive debate over the years. Victoria refers to problem sexual behaviour in relation to children under 10 years and sexually abusive behaviour for children and young people from 10years to 17 years. The National Society for the Prevention of Cruelty to Children in the UK uses the term harmful sexual behaviour and defines it in their report "Turn the page" (2014) as "one or more children engaging in sexual discussions or acts that are inappropriate for their age or stage of development. This can range from using sexually explicit words and phrases to full penetrative sex with other children or adults".

This group of young people is not receiving any supports in the Northern Territory and more than likely will end up in the criminal justice system. It is recommended that this group of children and young people should receive specialised support as soon as possible and be treated as

children/young people and so avoid criminalisation. However, it is recognised that some young people will have to be dealt with via a criminal justice response. The support system needs to be on a continuum of responses to children and young people displaying harmful sexual behaviour, ranging from early community-based identification and support for low-risk cases, to assessment, intervention and intensive work with the higher risk and needs cases (Hackett, S., Holmes, D. Branigan, P. 2016). None of these services exist in Central Australia or the Barkly region. The real danger is that high risk young people will continue on a steady path to become incarcerated and adult sexual assault offenders- not to mention the number of victims at the receiving end of this behaviour.

Recommendation

Data collection and early intervention and treatment for children and young people displaying harmful sexualised behaviour

4. Context of Out of Home Care

SARC has provided therapeutic support to children placed in Out-of Home Care over the years. While NT Territory Families does have its own therapeutic services team, who provide therapeutic interventions with children and young people traumatised due to abuse and neglect, the team has not always been operational and has not been able to consistently cover therapeutic support in relation to sexual abuse. The importance of therapeutic interventions should not be minimised and "just" providing alternative care and a place to live is not sufficient. The suggestions for therapeutic interventions range from providing a community-based service, which is delivered by a specialist team of practitioners to therapeutic residential care (Morton 1999). Therapeutic residential care is defined as

"intensive and time-limited care for a child or young person in statutory care that responds to the complex impacts of abuse, neglect, and separation from family. This is achieved through the creation of positive, safe, healing relationships and experiences informed by a sound understanding of trauma, damaged attachment, and developmental needs" (McLean 2011)

Where children, for various reasons, need to be placed in out of home care, the aim is to provide a safer and more secure living environment. The development of the National Framework for Protecting Australia's Children (2009-2020) and the subsequent development of the National Standards for Out of Home Care are seen as an attempt to introduce best practice in out of home care in Australia. The National Standards seek to drive improvements in the quality of care so that children and young people in Out of Home Care have the same opportunities as other children to reach their full potential in life wherever they live in Australia. The national standards are designed to improve the outcomes and experiences for children and young people by focusing on the key areas that directly influence positive outcomes. SARC staff members have learned from their contact with clients that they have been re-traumatised in Out of Home Care settings after having been removed due to sexual abuse. The Royal Commission into Institutionalised Sexual Abuse in care has provided numerous documents and recommendations, which are also very relevant for this context.

Children and Young people in Out of Home Care deserve that their needs are being met and that their upbringing is geared towards them becoming a healthy mature person who can function in the community. This means the service delivery should follow a comprehensive holistic individual needs assessment to enable best possible long term functioning and quality of life.

Recommendation

It is recommended that children in Out of Home Care be provided with a well- resourced holistic needs assessment process followed by a targeted intervention and support program.

Illustrative examples:

Case 1. Child neglect and possible FASD expression as sexualised behaviours

CII [redacted]

[redacted]

[redacted]

Case 2. Lack of holistic approach to child assessment as well lack of counselling services in remote context.

CII [redacted]

Amongst the issues raised by this case are: -

- Lack of capacity of practitioners in remote communities to undertake appropriate child safety and sexual abuse vulnerability assessments
- No availability for counselling therapy for children 'at risk'

Current approaches of care are primarily aimed at acute response (STI and pregnancy prevention) with little management of the underlying behavioural risks as well as longer term mental and physical health implications

Recommendations Summary

1. That recommendations from the Royal Commission are inclusive of a rigorous, long –term implementation and monitoring process.

2. Investment in a consistent, multidisciplinary and collaborative assessment and therapeutic service system is required for Central Australia and the Barkly region

3. It is recommended that a well- resourced sexual assault prevention framework and action plan for an integrated whole- of system- approach to prevent sexual assault be developed

4. Data collection and early intervention and treatment for children and young people displaying harmful sexualised behaviour

5. It is recommended that children in Out of Home Care be provided with a well- resourced holistic needs assessment process followed by a targeted intervention and support program school. His foster parents References

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SUBMISSION FOR THE ROYAL COMMISSION INTO PROTECTION AND DETENTION OF CHILDREN IN THE NORTHERN TERRITORY

PAEDIATRICS

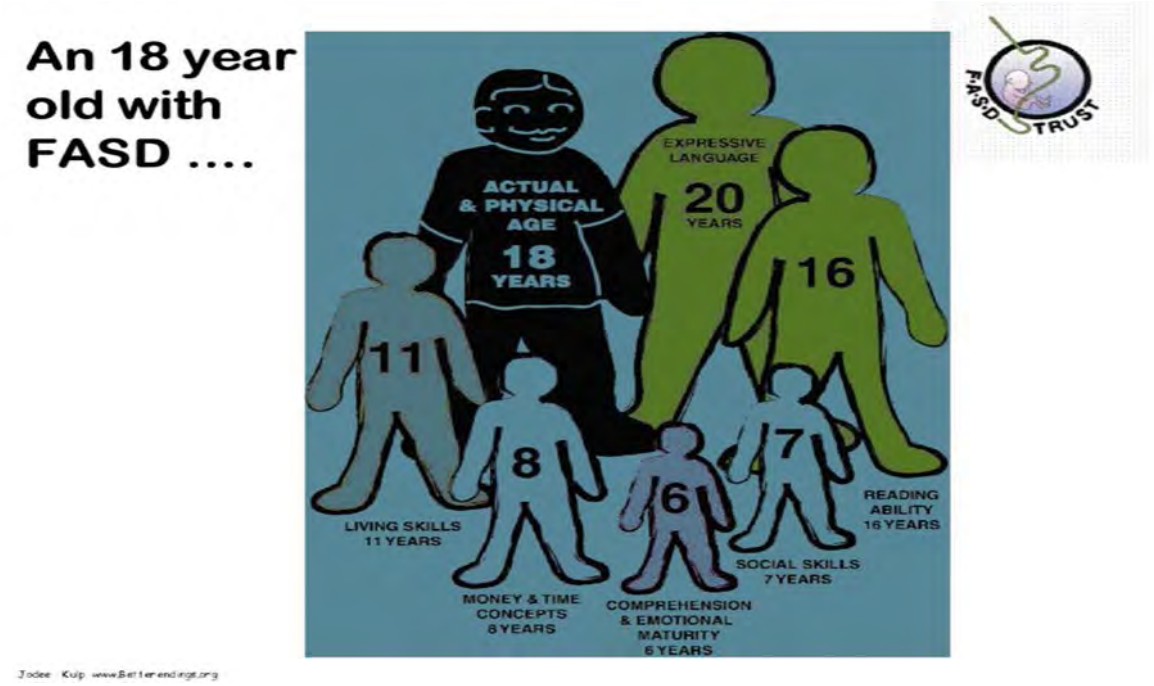
October 2016

Dr Keshan Satharasinghe

FOETAL ALCOHOL SPECTRUM DISORDERS(FASD) – AN EXAMPLE OF DEVELOPMENTAL TRAUMA

FASD are a group of conditions in which brain dysfunction and developmental delay are associated with the exposure of the developing foetus to alcohol[1,2].

The condition renders dysfunction in multiple aspects of higher brain activity and even the severity of disability can be markedly varied within an individual in separate areas of brain function. It is often referred to as the 'invisible disability' as most affected individuals will look normal and in brief, superficial encounters appear to function normally as well. It is only when challenged by the more complex areas of day to day life that deficits become obvious[3]. The picture below summarizes how an individual with FASD may appear:



Daigram 1: A physically average looking 18yo male whose abilities in different brain functions are quite varied.

The fact that alcohol is a teratogen is shown in multiple animal models. Mouse and Zebrafish embryos exposure to alcohol result in facial anomalies analogous to that seen in humans with FAS[4,5,]. As the brain and face develop from the same embryological layers, the brain can be similarly affected by the alcohol exposure. Furthermore, the effect is limited when these embryo are exposed to the same dose of alcohol in the presence of an agent that blocks action of the alcohol.

Genetics appears to play a role as in animal models again it has been demonstrated that certain gene variants are differentially vulnerable to the effects of alcohol on developing embryos[4,5,6]. Paternal alcohol exposure and influence pre-conceptionally are also thought to have a potential bearing[7,8,9].

However, each affected person will present with an array of dysfunction that is individualized. The reason for this level of variety is multifactorial. Aside from the genetic factors alluded to above, the

effects on the developing brain will be dependent on the dose and timing of the exposure as well. The diagram below depicts the varying stages of development of the foetus through gestation. Note the brain is considered to be always developing and thus susceptible to teratogenesis at all times.

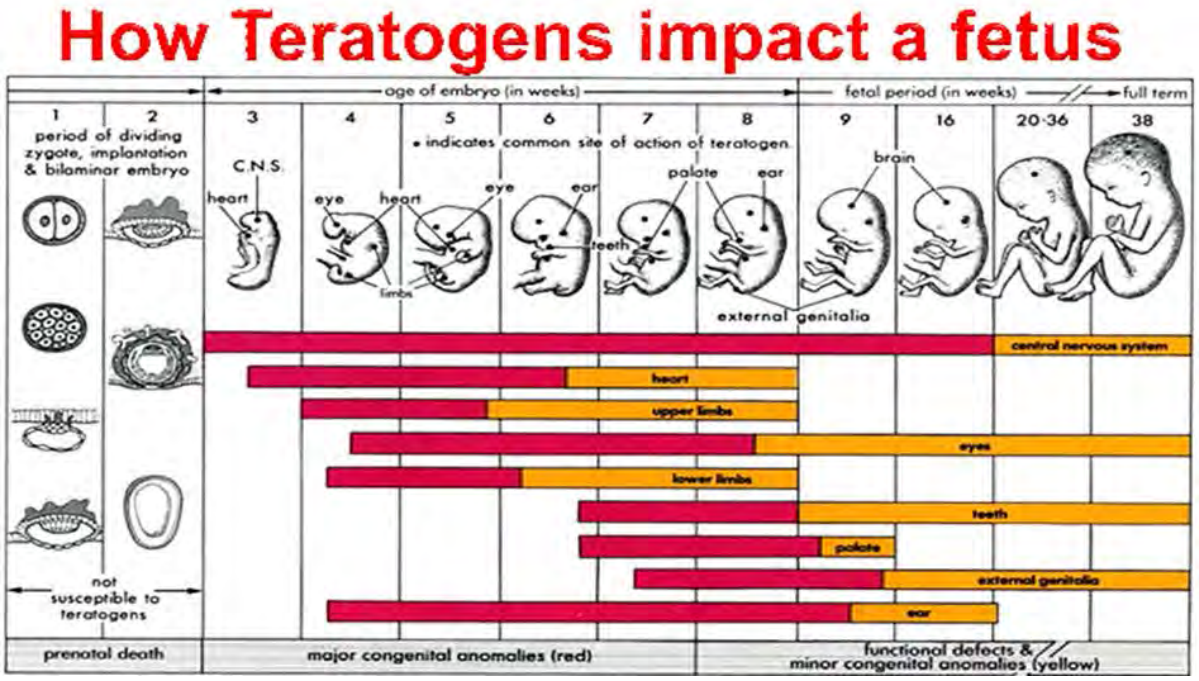


Diagram 2: The development of the brain occurs throughout gestation and is always under threat from teratogens. From Alcohol and Other Drugs Council of Australia.

Once taken together these multiple factors present the pathway for a great diversity in pathology of the individuals. Hence diagnostics becomes quite a complex process requiring a multi-specialist team to most benefit the individual from a diagnostic/therapeutic process.

FASD PREVALENCE

The worldwide prevalence of FASD is wide ranging - 14-25/1000 in Mid-Western United States to 75-119/1000 in parts of South Africa[10]. Perhaps unsurprisingly it is seen in higher rates in regions of greater social disadvantage and lower overall levels education. To the authors knowledge there is no accurate data documenting the prevalence of FASD in Central Australia.

The only FASD prevalence data available FASD with a comparable population demographic to Central Australia is that of the Lililwan project based on the populations in the Kimberley region of Western Australia specifically Fitzroy Crossing. In this study, Fitzpatrick et al[11] describe a mean prevalence rate of 120 (range 70-196) per 1000 children. The overall Australian rate is currently thought to be 0.68 per 1000 children - while this is in all likelihood a gross underestimation, given

that more than 50% of the Australian population of pregnant women admit to alcohol consumption and the fact that 60% of pregnancies are unplanned - it still describes a marked discrepancy.

It is likely that the rates of FASD among the population in Central Australia (CA) is similar to the rates of the Lililwan project as the degree of social disadvantage is comparable if not worse in CA.

Otherwise data for Australia remains scant at present as it is only recently that Australia has come to recognise FASD. The potential harm of FASD is increased by the fact in the Northern Territory, the level of alcohol consumption, remains significantly higher than the rest of Australia as seen in Dr Delima's report previously.

THE EFFECT OF TRAUMA

FASD and exposure to trauma have the effect of deepening the detrimental effects of one another. Children with FASD are far more likely to have experienced multiple levels of trauma, in particular neglect and poor growth, exposure to domestic violence and poor carer attachment. The effect of FASD is to greatly diminish the capacity of the individual to deal with the psychological insults created by the trauma. Henry et al[12] also demonstrate that experienced trauma appears to deepen the level of FASD dysfunction particularly in areas of memory, attention, and language.

As a result it is imperative that Central Australia start looking at establishing a dedicated team to the diagnostics of FASD which compulsorily provides an individualized therapeutic pathway that can be implemented reasonably in all facets of the individuals life.

FASD PLAYS A SIGNIFICANT ROLE IN YOUTH DETENTION AND CHILD PROTECTION CASES

In Los Angeles[13], the prevalence of FASD within the population of incarcerated youth are 10-fold that of FASD in the general population. In Canada[14], youth with FASD are 19 times more likely to be incarcerated than those without the diagnosis. Meta-analysis of available data[15] estimates the prevalence of FASD among the entire incarcerated population (prisons and juvenile detention) at closer to 20%.

60% of individuals 12 years and older suffering from FASD had "Trouble with the Law" - involved with police, charged or convicted of crime[16]. Rates of recidivism are also much higher in those who have FASD.

Furthermore, rates of FASD diagnosis among children with the Child Protection system is as high 210 per 1000[15]. Caring for a foster with FASD can be extremely challenging. A quote attributed to an American parent in Diane Malbin's book - Trying Differently Rather Than Harder - describe the challenges succinctly[3].

"Parenting children with FASD is like trying to find your way around Denver, using a road map of Portland. We just needed a new map."

Likewise the relationship between detention centre wardens and individuals with FASD needs to incorporate an understanding of the fact, the incarcerated individual has a disability. For the FASD affected individual continually being told they are deliberately being recalcitrant and increasing punitive actions against them will in the long run have a detrimental effect. The relationship breakdown between worker and young person will result often in the latter reacting in the only way they know how - increasingly rebellious actions.

If the warden were instead to invest in establishing a more understanding relationship with the young person and their disability, resulting in an adaptation that balances punitive actions with communication that is tailored to the latter's dysfunction, long term rehabilitation is more likely to be achieved. This likelihood of the long term outcome is greatly enhanced by a continued relationship with the therapeutic team.

The proposed therapeutic team could help educate the people involved in the lives of the FASD-affected and facilitate a pathway to better understanding of their ward's disability.

SECONDARY DISABILITIES

Young people who do not receive intervention suffer from secondary disabilities. These are namely:-

- Psychiatric co-morbidities (ADHD, Schizophrenia, Depression)
- Issues with schooling and employment
- Inappropriate Sexual behaviour
- Alcohol and Other Drug addictions
- Trouble with the Law

Among the 415 individuals followed[16] by Streissguth et al, 60% of children with FASD had trouble with the law but further to that, 94% had one psychiatric co-morbidities. Of those, more than 60% will have at least 2. The result of this is that a quarter of individuals attempted suicide and almost half(43%) threatened.

45% of those aged 12 and over displayed inappropriate sexual behaviour and this rises to 65% when looking at the adult population. 70% had experienced school disruption - suspension, expulsion or drop out by the time of adulthood. 80% are dependent adults and the same proportion have issues employment. 53% of males and 70% of females within this group had addictions to alcohol or other drugs. Only 8% of individuals were leading what could be considered a 'normal' life.

DIAGNOSTICS

The diagnostic group of Foetal Alcohol Spectrum Disorders (FASD) refers to the wide range of disabilities experienced by children and adults who were exposed to alcohol in utero. The association between prenatal alcohol exposure and disability was initially described independently

by Lemoine et al. in 1968 in France and Jones et al. in 1973 in The United States of America[2]. The term Foetal Alcohol Syndrome (FAS) was coined by Jones et al and since that time the condition has been increasingly recognized worldwide.

There are 4 major criteria to considered in the diagnostic process for FASD. More detailed description of the process can be found in Appendix 1.

The 4 components are:-

1) Growth Restriction

2) Identifying sentinel facial features - Thin upper lip, flat philtrum (Score of 4 or 5 on guide provided in Appendix), short palpebral fissures. The presence of all 3 features precludes the need for a reliable history of alcohol intake.

3) Identification of cognitive dysfunction. This includes a thorough medical, psychological and allied health assessment. The medical aspect of the examination looks for of any physical signs of brain dysfunction such as microcephaly (small head) or seizure. The wider assessment involves specialised testing in aspects of:-

- cognitive function
- attention/hyperactivity
- memory
- speech
- adaptive function
- academic achievement
- motor function.

In absence of the physical signs a significant dysfunction is required in 3 of the other listed assessed domains.

4) Documentation of a clear history of alcohol exposure in utero.

The most important aspect in the diagnostic process is the third one. Growth issues due to alcohol exposure are often difficult to separate from neglect or other causes and in fact may simply be a marker for the wider trauma being experienced by the child. The grouping of all three facial features only occurs in a small group of affected individuals[17] (<5%). The documentation of alcohol exposure is vital in providing the diagnostic label but has only a small role to play in the therapeutic pathway. In other words without the complete documentation of specific dysfunction using the multi-disciplinary team for the other 3 aspects of the diagnostic pathway will have little impact on the child's life in the long term.

There are no specific diagnostic/investigative tests that will confirm the diagnosis. The variable phenotype of the condition means people with FASD on brain imaging will have varying patterns of

abnormality. Likewise there is no blood or other bodily test that would confirm the level of disability. There is no identifiable pattern that specifically leads to the diagnosis of FASD on medical investigation as there may be for other developmental disorders. In fact standard IQ testing only identified between 10-17% of a referred cohort in one study[18]. The diagnosis and hence therapy is utterly dependent on specific behavioural, intelligence and other skills testing performed by the diagnostic team.

THE MULTI-DISCLIPINARY DEVELOPMENTAL TRAUMA TEAM (MDTT)

The roles of the individual clinicians are:-

Paediatrician/Adolescent Physician - physical examination to assess for microcephaly, seizures or other physical neurological effects. Assess facial features. Consider/exclude the effects of other trauma and diagnosis. Provide treatment for aspects of dysfunction that can be pharmacologically managed. Examples would be treatment of Attention Deficit Hyperactivity Disorder(ADHD) and sleep disturbances

Psychiatrist - Assessment in the psychiatric aspects of diagnosis in particular ADHD, attachment, PTSD.

Psychologist - provide specialist diagnostics and therapeutics in specific areas of cognitive function, adaptive ability, memory. Most of these assessments can only effectively be done after the age of 7.

Speech Therapist - Specialist contribution to the speech aspects of diagnosis and therapeutics but also help with cognitive function.

Occupational Therapist - Therapeutic role in assessing and adapting environment and nature of interactions to nature of diagnosed dysfunction. Diagnostics role in motor dysfunction as well as cognition.

Physiotherapist - Diagnosis and therapeutics in motor dysfunction.

Case Managers, ideally with significant number local Indigenous practitioners, would have a main function to ensure the delivery of services and therapeutics by educating the carers and other people involved in the child's life. They would also have a role informing and assisting the rest of the team with issues arising from the practicalities of therapy delivery.

All members of the team should be involved in the education of carers and other service deliverers as well.

A Central Australian service should have an outreach component to assess the practicalities of implementing a therapeutic pathway in a remote setting. A large geographical area of 1.2 square kilometres with more than 30 separate communities, requires the team to travel quite broadly.

For the purposes of the MDTT it would be ideal if the Allied Health staff were dedicated paediatric trained staff under the auspices of the Department of Paediatrics within the hospital setting. This

would limit issues of funding across different silos and allow a permanent reliable staffing with little barrier to communication within the team.

The estimated cost of each diagnosis is approximately $5000 (based on the assumption that each patient will require approximately 1-2 hours with each member of the MDTT plus some added ancillary costs such as travel and acquisition of diagnostic tools). This approximates well with the cost already established in Canada[19]. The cost of therapeutics would be individually tailored and difficult to predict at this time.

These costs should be weighed against the fact that in 1988 undiagnosed patients in the US were estimated to cost the taxpayer approximately $US1.4million[20] over their lifetime. In Canada, the total cost of FASD-related matters was thought to be between US$1-1.75billion dollars in 2013[21] – of which approximately 82% was for lost productivity(42%), health(10%) and incarceration(30%).

The ultimate goal of the MDTT is to prevent in particular the health issues and incarceration of FASD affected individuals and enable them enough to be productive members of society. To achieve this intervention strategies target the specific dysfunction and hence, accurate assessment of dysfunction is the most vital aspect of the assessment process.

An incomplete diagnostic procedure will have the effect of labelling a child without providing the proper guidance as to improve outcomes. A procedure poorly done risks increasing the effect of the disability on the child without providing the requisite education to relevant carers and hence further establishing the "difficult child" label. If undertaken the diagnostic/therapeutic pathway **MUST** be taken to completion.

INTERVENTION

Once specific dysfunctions are identified in the diagnostic process, the MDTT can design a program that enhances the individual's strengths and helps them overcome their weaknesses. This would include adaptations in the way they are taught, given instruction and disciplined.

A simplified example would be if the individual is dysfunctional in terms of memory and attention and as a result cannot complete multi-step instructions, a simple adaptation would be to ensure they are given 1 or 2-step instructions or have the instructions written rather than verbally delivered. This would lead to less conflict in the household or at school.

The best outcomes for people with FASD are those who are identified early and in a stable care arrangement. The other markers for improved outcomes were those with the obvious facial features or profoundly low IQs of less than 70. It is likely the latter two factors simply contribute to earlier recognition[18]. The presence locally of a MDTT increases awareness of the condition and allows and early referral pathway. The earlier the intervention, the more likely the prevention of secondary disabilities via a MDTT service. Ideally the MDTT would assist with stabilising care arrangements through effective case management. This would be particularly relevant in those in Out of Home Care – which was as high as 80% of the referred clients to one Canadian centre[18].

Affected individuals who are adolescents and adults will still gain benefit from a MDTT assessment given the potential for intervention in preventing and treating high risk behaviours such as substance abuse, inappropriate sexualised behaviour or suicidal ideation.

Aside from treating the individual and to understand and overcome the challenges they face, a vital part of intervention involves educating the significant people in their lives. Care-givers become far less frustrated once they understand the issues faced by the child and pathways to help with education can greatly enhance the effectiveness of standard education pathways.

Essentially by learning the child has a disability, the carer understands 'misbehaving' is the result of being unable to cooperate rather than refusing to do so. Therapy would attempt to bridge that issue by educating the care giver to approach the child appropriately at a level suitable to their ability.

There are models of a holistic MDTT approach that can be used an adapted to local requirements.

- Families Moving Forward - a program available in Washington state, USA is an example of a multidisciplinary holistic therapeutic program to model a therapeutic service here in Central Australia.

- The ALERT program currently being researched in Western Australia which targets improving the education profile of students with FASD is another program that can be adapted to this region.

The ultimate goal of a therapeutic pathway would be to eliminate or at least decrease the effect of secondary outcomes described above.

TARGETTING DYSFUNCTION

As previously described the imperative of the MDTT is to focus on specific dysfunction as opposed to a diagnosis. Targeting dysfunction via the diagnostic/therapeutic process allows us to circumvent the need for a label.

A specific FASD label can be difficult to obtain, given current experience in obtaining an accurate history of alcohol exposure. Targeting traumatized and affected children via a more holistic approach allows therapy to be delivered to the child without the focus on the label. As noted above up to 80-90% of juveniles in detention will not have diagnosis of FASD but may well be suffering similar symptoms that are related to other trauma. The NDIS(at an early childhood level) allows a pathway to funding that targets disability as opposed to diagnostic labels.

THE COMMUNITY BASED APPROACH

Clearly therapy does not solely fall under the auspices of the health professionals. At a wider level it requires input from the Education and Justice departments as well. Input of Non-Governmental agencies involved in the more holistic engagement activities that are currently working in the region also contribute greatly in reducing the burden of FASD. The approach to the problem at both

population and individual levels should attempt to be co-ordinated. This currently being attempted by the establishment of the Interagency FASD Network here in Alice Springs. The co-ordinated approach would be vital to final improvements in both the FASD specific and wider aspects of the issues in Juvenile Justice and Child welfare currently being experienced.

INCLUDE THE MOTHERS

Any therapeutic process must include education and treatment of the biological mother where possible. Pregnant individuals who drink alcohol in pregnancy do so as a result of not knowing they were pregnant, not knowing they were doing harm to their child or most pertinently sufferers of trauma themselves. It is vital that they are incorporated into the therapeutic process and that there is culture of attaching no blame on them. As discussed above the paternal role in FASD is also significant and should not be ignored either.

PREVENTION/EDUCATION

The Lililwan project[11] has demonstrated by incorporating a MDTT with focus on FASD in a wider community run program rates of alcohol consumption in pregnancy can be reduced dramatically. Prior to commencing the wider program, these rates were at 55% in the first trimester. Within 10 years of commencement these rates were 35% and falling[22].

A dedicated diagnostic/therapeutic program with a strong educational component can have a significant role to play in the preventative message.

RISK OF DOING NOTHING

FASD has shown a propensity for intergenerational effects. This is both biological and environmental.

There is evidence in animal models where genetic markers show an increasing vulnerability to the in-utero effects of alcohol[6,23]. Furthermore, parents with undiagnosed FASD thus, afflicted by secondary conditions described above, will model behaviour to their children that would imprint these behaviours as a norm in a developing brain.

Simply put not doing anything now means the issue will only worsen and become even harder to turn around in the future.

SUMMARY

FASD is the most common cause of preventable developmental delay in children worldwide. It is likely that prevalence within Central Australia is among the highest in the world but there is no specific data on that currently available.

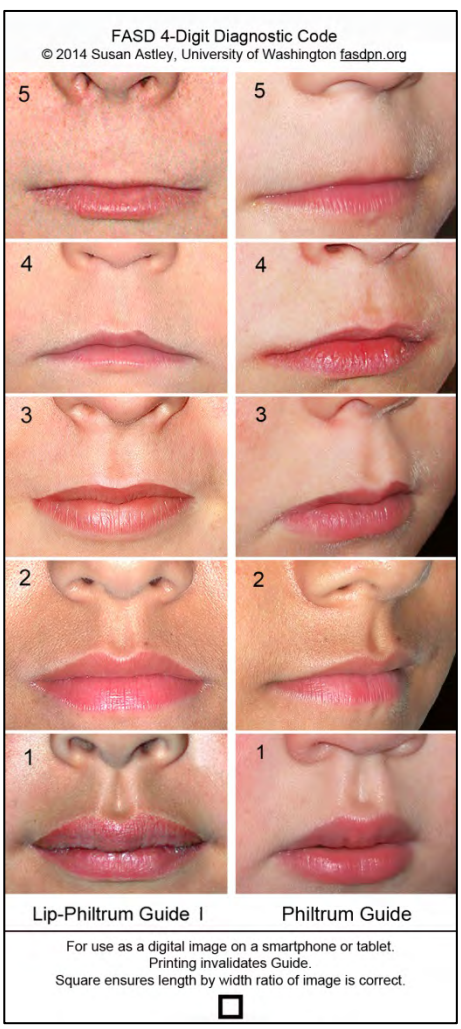
Where data is available, FASD is found in a significant population of individuals in detention and children in care arrangements, all of whom require a holistic widely encompassing approach to rehabilitate from (incarcerated juveniles) and prevent(children in care) the above described secondary complications of FASD.

The aim of therapeutics aims to identify the specific dysfunctions and provide individualised therapeutic pathways as well as education and strategy provision to the care givers and other individuals involved in the child's care. Ultimately the aim to help the child grow into an independent adult who can deal with their dysfunction appropriately and be minimally compromised by secondary conditions.

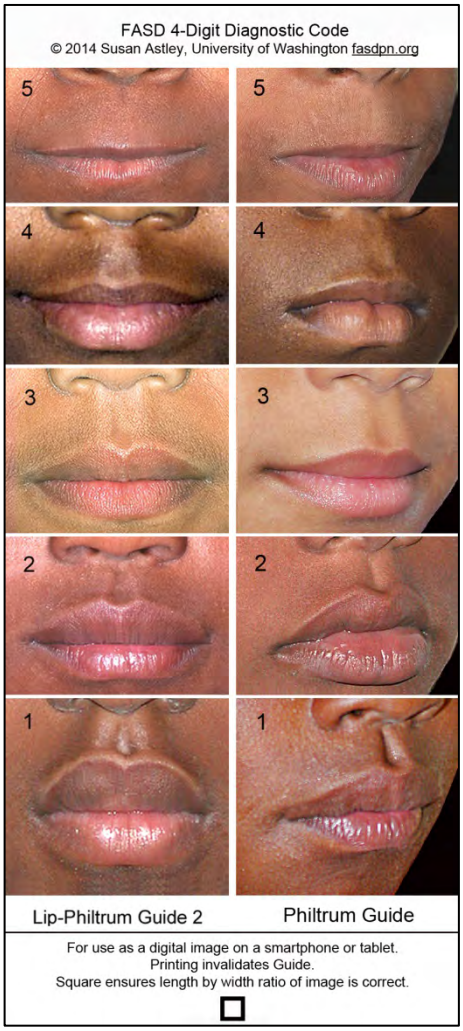
The therapeutic process is both time and cost intensive but over the long run will benefit both affected individuals and wider society. A dedicated therapeutic team should be established in Central Australia funded on top of the other efforts already in place.

A co-ordinated approach, that will both identify children early as well as attenuate those already affected by not just FASD but trauma in general, will take time to reap benefits that may not be entirely experienced for a generation but to do nothing would only exacerbate the problem. The process must be undertaken in a complete sense. Hence, it is vital that commitment to the program has to be set in the long term.

APPENDIX – Pictorial Guide for Diagnostics of Sentinel Facial Features for FASD



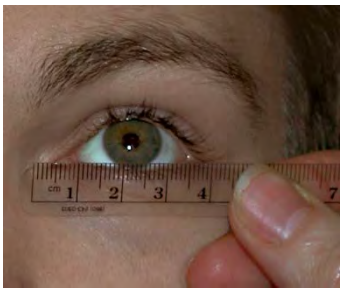
A



B

Figure 1. Lip-Philtrum Guides 1 (A) and 2 (B) are used to rank upper lip thinness and philtrum smoothness. The philtrum is the vertical groove between the nose and upper lip. The lips and philtrum are ranked separately. The guides reflect the full range of lip thickness and philtrum depth with Rank 3 representing the population mean. Ranks 4 and 5 reflect the thin lip and smooth philtrum that characterize the FAS facial phenotype. Guide 1 is used for Caucasians and all other races with lips like Caucasians. Guide 2 is used for African Americans and all other races with lips as full as African Americans. Copyright 2014, Susan Astley PhD, University of Washington.

A



B

Figure 2. A. The palpebral fissure length (PFL) is the distance from the inner corner (endocanthion) to outer corner (exocanthion) of the eye. B. PFL being measured with a small plastic ruler.
http://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm#pfl

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