THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by – Dr Doug Shelton – 2013 Churchill Fellow

To understand how to build a comprehensive assessment & intervention service for children with Fetal Alcohol Spectrum Disorder

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Signed:

Date: September 7, 2014.
Acknowledgements

I would like to thank the Winston Churchill Trust for providing me with the means to explore the opportunity of a lifetime by meeting the ‘gurus’ of FASD and, hopefully, using this knowledge to advance the cause for people living in Australia with FASD.

FASD was first described in the 1970’s. Many of the clinicians who published the original papers describing the syndrome and then went to provide case definitions and develop diagnostic guidelines are still working or recently retired. I was immensely privileged to meet many of them. I was welcomed warmly and completely humbled by their generosity. I would arrive promptly at our meeting expecting to be given maybe an hour out of their busy schedules only to find they had assembled their entire team to meet me, blocked out the whole morning(day) for discussion and then were planning to take me to lunch or instead welcomed me into their homes, in one case for several consecutive days of lively discussion. Many of them then went on to arrange ad hoc meetings with other people they thought I should meet, all done on the spur of the moment with immense enthusiasm. The selfless generosity of spirit I will never forget and struggle to now make it my own benchmark.

I sincerely thank all the individuals and teams whom I visited in Canada, USA and New Zealand for sharing your knowledge, skills and fears with such openness, friendship and generosity of spirit.

All my colleagues at home deserve sincere heartfelt thanks for your personal and practical encouragement of this fellowship, your enthusiastic and humorous participation in the “Where in the world is Doug Shelton” journey and for keeping the ship sailing true in my absence. You are truly amazing people.

The wider FASD community, especially the Collaboration for Alcohol Related Developmental Disorders, in Australia have actively cajoled, encouraged and assisted in the achievement of this Fellowship. Jan Hammill, AM, deserves special mention for her quiet faith and persistence.

Thanks to my extended family for their enthusiastic and continuing support.

To my beautiful wife, Lyza, who entertained our two small sons, Ned (5) and George (3) across a succession of zoos, parks, museums, playgrounds, buses, trains, planes, ferries and ice-cream shops across three countries and multiple cities with good humor, joie de vivre and grace. To Ned and George who never failed to make the most of any opportunity with gleeful enthusiasm. The fellowship would not have happened without your unswerving support, and love, from conception to conclusion.
Executive Summary

Identifiers:
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Paediatrician 0410 433 038

Project:
To understand how to build a comprehensive assessment & intervention service for children with Fetal Alcohol Spectrum Disorder

Highlights
All the places I visited and all the people I met were a highlight to me, not once was I disappointed and always learnt many things from each interaction.

Canada and the USA have led the development of the field of FASD in centres from Vancouver to Seattle, Portland and San Diego. New Zealand has led the development of FASD services in our region. Australia can learn much from their planning, implementation and development of services.

Conclusions
Developing a network of FASD Diagnostic Clinics across the country is achievable using existing services. New Zealand has already effectively leveraged this model.

FASD is vastly under-diagnosed in the Australia. FASD is perceived as a stigmatising diagnosis. The greatest burden of FASD lies within mainstream white middle class Australia. Sixty percent of pregnancies in Australia are unplanned and sixty-three percent of pregnancies are alcohol exposed.

FASD clinical expertise in Australia is rare and training is poor or non-existent. The personnel required (child psychology, speech pathology & paediatricians) exist in government funded services around Australia. However, almost none have the training or expertise required to diagnose FASD and it is usually misdiagnosed as another condition, or missed completely.

Recommendations
1. It is cost effective strategy to deliver FASD services through existing child development services.
2. Existing staff can be upskilled using the expertise now available in Australia.
3. Support 1 & 2 by actively building FASD collaborations, across the continuum from research to service delivery, within Australia and overseas.
4. Advocate for the official recognition of FASD as a disability
5. Develop a whole of government strategy, state and federal, to provide intervention and prevention at multiple points.
6. Shift the focus of FASD activity in Australia from research to service delivery.
7. Measure the cost of FASD for communities, systems, regions and states.
8. Recognise that managing FASD across the lifespan, and across the sector-span, will provide new models for managing other chronic brain-based disorders.
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NeuroDevNet is the first trans-Canada initiative to study children’s brain development from both basic and clinical perspectives. NeuroDevNet researchers seek to understand the causes of neurological deficits, to train a new generation of researchers and to translate new knowledge into improved measurement, diagnosis, prevention and treatment of neurodevelopmental disorders.

NEURODEVNET

Jim Brookes, Executive Director.
The three main projects discussed by Jim were all of interest and I was particularly keen to understand the development of:

Eye Movement Tracking for early diagnosis of FASD
Automated. Economically viable rapid assessment method even for young children (current reliable diagnosis of FASD cannot occur until about 8 years of age, FAS can be diagnosed much earlier), and shows early promise.

EEG Helmet
Allows wireless upload of EEG from home and negates need for the child/adult to be in hospital which is currently the case.

Strongest Families
Originally designed for children with mental health problems. Once the family becomes a member they get access to purpose designed website, coaching and 24 hour hotline support. The model is scalable and adaptable. NDN is now trialing for FASD.

General
For many issues in child development, including FASD, recognition and communication of the following common themes are important, especially to government,

- Chronicity i.e.; most conditions will not get better anytime soon
- No interventions offer amazing results
- It is ethical need to offer and do something now to make their lives as good as they can be
- Whatever is to be done needs to offer economic advantages and be scalable

Clearly communicating the above points to government is the key to lobbying and getting funding. Clinicians and researchers generally do not have the skills, knowledge, experience, connections or personalities to do this. So hire someone who does!

Connecting
Australia and Canada have dispersed populations and centres. Connections need to be strong for expertise to grow. Ideas that have worked in Canada include internships, initially 18 and now 1500 per year. Provided a very strong message not to think small and scale up but to think big from the beginning.
BC Children’s Hospital provides expert care for the province’s most seriously ill or injured children, including newborns and adolescents. Based in Vancouver, BC Children’s and Sunny Hill reach across the province with vital health services that may not be available anywhere else in B.C. We provide specialized training in pediatric health care and work with renowned researchers to achieve better health for children and youth. As academic health centres, BC Children's and Sunny Hill are affiliated with the University of British Columbia, Simon Fraser University, Child & Family Research Institute, and other education and research institutions.

BC CHILDREN’S HOSPITAL

Dr Tim Oberlander

A developmental pediatrician studying how early social experience (prenatal maternal mental illness and psychotropic medication exposure) influences biobehavioral development during childhood

Regarding outcomes the quality of environment is more important than PEA or FASD diagnosis i.e.; FASD diagnosis alone is not sufficient. The questions should be

• How does the risk of the neuroteratogen play out across time?
• How can we modify this?
• How can we best optimise the environment?
• Same situation for COPMI children?

Acknowledged early paediatric training dictated the importance of FAS diagnosis where as it now recognises the spectrum and the potential development of secondary and tertiary problems as well as the importance of the prevention.

FASD is really a disorder of the pre-frontal cortex with resulting effects on attention control, cognitive flexibility and working memory. Often the totality of these problems, i.e. underlying brain damage, is not considered as it is subtle to the casual observer, e.g.; teachers, parents, and clinicians need to interpret locally and at the policy level so others can understand.

Contemplating the effects of mental health both upstream and downstream leads to questions like

• Maternal mental health - is that what led her to drink?
• Child's mental health - is it a result of underlying FASD brain damage or the family situation or genetic or a direct result to alcohol neuro-teratogenicity or a combination?

Whatever is the best prevention strategy for the cycle of poor mental health and substance abuse and thence FASD it needs to include strategies to improve executive function, mental health, social skills, healthy peer relations, places to go to get good role models and safety. Unfortunately social, legal, health services are probably not geared toward addressing the above?

Stigma, guilt and ignorance around FASD make it a very unique problem and any service must have capacity to work with birth mothers productively so therapy goes across multiple generations. Where FASD is suspected but biological mother denies alcohol intake the clinician must be able to cope with uncertainty and to develop the therapeutic relationship is the number one priority, then maintain the relationship in the long term and translate the child's brain injury problems in a way the school can understand, by using the language of neurological injury based on teratogen exposure and genetics. Ongoing alcohol use needs to be addressed in way that is going to matter in the long run by deciding what needs to be done now and what can go on the back burner.
The above system also works well with chronic pain syndromes and conversion disorder. Parents can be at the end of their tether so it is often wise to say you are not interested in a diagnosis today - then it becomes an issue of 'timing'. The parent will usually raise the issue of conversion disorder/ FASD when they are ready and recognise this is usually when the parent mentions it or asks

Dr Christine Loock
A developmental pediatrician at Children's and Women' Health Centre of British Columbia, including Sunny Hill Health Centre for Children and BC Children's Hospital. She is an Associate Professor in the Department of Pediatrics, Faculty of Medicine, University of British Columbia (UBC). In 2000 Dr. Loock was invited to sit on Health Canada's first National FAS Advisory Committee, and was subsequently appointed to its sub-committee on Diagnosis and Screening in October 2001. She is the co-author of the Canadian Medical Association's 2005 publication "Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis.

Medicolegal Community Partnership
Involves lawyers, doctors, other agencies/professionals and the community. The service has been in place for some time operating out of the Downtown east-side of Vancouver. A strategy is being trialed modeled on the Circle of the Child, which originated in Montreal mainly for teenagers in trouble with the law; the child gets to invite who they want in their circle for mediation. I was able to witness the Partnership in action.

Paradigm shift
Mary-Ellen Turpel-Lafond, the BC Children's Commissioner, has published multiple papers in last 2013-14 focused on a paradigm shift in community health around families and elders being front line workers responsible for the child and held accountable by the child as well as agencies.

This model is already here - we need to catch up

Practice Tips
Importance of tracking down families who fail to attend booked appointments especially if they are biological parents - find them see them in the car park or their house if need be.

- FASD kids usually get worse on formal testing the older they get
- ASD is the phrase that pays
- FASD is an orphan diagnosis (amongst others)
- FASD
- Family Adversity & Stress Disorder where mother self medicated with alcohol
Ron Friesen, CEO

“You may also be interested in reviewing the research on the “Victoria Integrated Court” (use this as the Google search term). There are two reports for two years - both use an intersectoral team for the high recidivist population in Victoria, BC (our capital city). The beauty of this program is that it required no new costs (a huge benefit). What it primarily did is bring together, into a common location, representatives of all the various sectors that responded to this population, which frequently had alcohol, drug and mental health issues. I expect there is also lots of FASD. This program also was started through efforts of the community to deal with the problem rather than through the justice system.”

Medico-legal partnerships

Originally commenced in hospitals in US to procure insurance funding for their patients then moved into unhealthy buildings where poor air conditioning and sanitation caused increasing rates of asthma and hospital admission as a way of forcing landlords to look after their buildings and then save the hospital money. A recent expansion of this concept is the Medico-legal-community partnership which is now part of the RICHER Initiative based on the social determinants of health in the downtown east side of Vancouver. The problems of poverty are seldom singular but multiple and cross multiple sectors hence agencies on their own do not have capability or capacity to manage. Successful programs are inter-sectoral though can be fraught at the policy level but not often at the personal/practical level.

- Their working acronym is IT HELPS
  - Income
  - Transportation
  - Health & housing
  - Education
  - Law
  - Primary care
  - Safety - personal & public

Programs that use a similar model include the Saskatchewan - Hub & Core Program for FASD, the Victoria Integrated Court. The Medico-legal-community partnership here is trialing a new format known as the Circle of the Child (Montreal) which is solely about developing a plan to support the child. This may be very practical about connecting to family, friends & community (because when people start to go down the literally dis-integrate with their connections who could normally prevent their deterioration). Practical examples of support include

- Organising people to take the child to sport
- Organising free sport
- Provide babysitting
- Contact with local police
- Parole officer support
  - Developing novel strategies to check in e.g.; mobile phone with geolocator.
The community is then focused on training up people in their own community to be mentors/supporters/workers etc so as to build their social capital. The model seems to be a natural fit for the Medico-Legal-Community Partnership and thus they have adopted it to trial in Vancouver. There are major worries about confidentiality which are surmountable but still represent a huge notional barrier.

The recidivist, FASD and child protection populations are all facing the same underlying issues as summarized in IT HELPS. Inter-sectoral partnerships are increasingly emerging as the method of dealing with these complex problems. The beauty of the model is cost because there are no increased costs in getting people, who are already working with the client individually, to talk to one another and sit in the same room with their client! Thus it represents a change in philosophy not additional funding.

As soon as someone in these cohorts commits a crime then all the responsibility falls on the justice system which does not have the skills to cope. Other sectors need to become involved to achieve the best outcome. Judges are limited in their power which is simply often bail or gaol. If the young person has good existing support systems then they are usually offered bail. If they have no support systems the option is gaol. Intersectoral partnership offers a third option. Judges can order parties to come to the table, make the final decision based on the plan of the intersectoral partnership and preside over the merging of health and law which is really the merging of the social determinants of health and the rights of the child.
The research in the Weinberg laboratory is focused on the investigation of how early life experiences alter brain and biological development. We have developed novel rodent models to examine brain-behavior relationships from prenatal life through adulthood. We also collaborate with Drs Grunau, Oberlander and colleagues to examine effects of early life experiences on human development. Overall, we are interested in how interactions between psychosocial and physiological events occurring early in development can produce long-term changes in hormonal, immune and behavioral function, and significantly alter vulnerability or increase resilience to diseases later in life.

**Research**

Current research is via animal model research with rats in HPA axis, immunomodulation, epigenetics methylation in gene expression, neuro imaging. PEA is associated with poor health outcomes in animal models via increased basal levels of cortisol as part of dysregulation of HPA axis. Cortisol is still in normal range but at higher set point i.e. not in hyperaroused state, but what are implications for this over the life course? There are implications for glucose regulation and brain development and inflammatory bias. Anecdotally FASD parents seem to concur with the 'inflammatory bias' with reports of increased chronicity of response to inflammation i.e. development of arthritis, and it is possible it may underlie some of the cognitive changes and difficulties in the development of self regulation.

The raised cortisol study was associated with early life adversity and adverse long term outcomes in people but FASD cohort was largely First Nations, the next version needs to include white middle class.

**Self regulation**

Cortisone is a biological marker of self regulation and is currently probably the gold standard vis-à-vis heart rate variability.

**Epigenetics**

Epigenetics is not her basic science field but as alcohol is something that changes gene expression has begun to collaborate with other researchers by looking at the brains of animals with increased cytokine levels to see whether there is changed gene expression, as well as methionine cycle enzymes & methylation.

**Imaging**

Imaging study via NeuroDevNet looking at salivary cortisol and imaging and genetics and epigenetics
THE ASANTE CENTRE

The Asante Centre is a not-for-profit organization providing a variety of services related to Fetal Alcohol Spectrum Disorder (FASD), Autism Spectrum Disorder (ASD) and other complex developmental needs. The Centre offers assessment and diagnostic services, family and community support, education and training, research projects, resource development, and more.

Asante Centre Staff
Dr Kwadwo Asante, Executive Director
Audrey Salahub, CEO
Allison Pooley, Program Director
Dr Julianne Conry, Psychologist
Kristal Bodaly, Speech-language pathologist
Brian Mackenzie, Business Director

The Asante Centre was very generous with their time and allowed me to understand the full gamut of what it takes to run a diagnostic service. Discussions included clinical practice points through to the financial operation required to maintain the service. A brief summary of each is provided below.

Assessments for Youth
If alcohol not confirmed they will go ahead with assessment anyway via the Youth Justice Program. Youth Probation officers are supposed to use the screening tool (written by Asante) and then, if positive, refer to Asante. The education support and upskilling for probation officers is done by the Asante centre.

Identified youth often require assistance in funding, housing security, medical care, disability applications, budgeting, sexual health, substance use, ensuring they keep appointments and providing transport and organising transition to adult care. The provision of a long term stable relationship allows the 'provision of an external brain, day to day grass roots intervention to keep the client in school, to avoid gangs, addiction and justice involvement. The youth always knows that no matter how bad it gets there is a safe person to go to. The support person can transfer this trust to others by introducing him/her to others.

Financial
The centre is predominantly supported by government grants. Funding is often "Project based" or is "per client" and no allowances provided for set up, training or administration costs and assumes a service is already fully functional and resources at the outset. The model systematically advantages larger organisations with existing infrastructure eg hospitals. Some private assessments are also done.

There are significant challenges around sourcing new areas of funding and even maintaining current funding streams. Old funding streams have remained static whilst costs have increased steadily over time. Parents as advocates to government seem to be most effective.

Most staff work there out of a sense of altruism and most could make more money working in the private sector.

The service is not funded to manage unexpected drop-ins and follow-ups. Ethically the service will always provide follow-up if people ask.

Successful businesses have margins squeezed as competition moves in; the business must decide how to cut costs in order to maintain viability. The same situation now occurring in government as the public demand better services AND lower taxes simultaneously. The government will have little option but to streamline services to contain costs by requesting that the services provide the bare minimum, for example, test the client to criteria for FASD diagnosis only rather than provide a full assessment. The net result is that clients receive a poorer service and the professionals
will be constrained from best practice standards in which they were trained and expect to deliver. The service must then reconcile between what is best and what is 'good enough'.

Non-government organisations have administration costs artificially constrained to 10% of their total budget which includes admin staff, rent, electricity, furniture, IT etc. This is impossibly small and realistically should be 25%.

**Clinical Practice**

Dr Asante is one of the trail blazers in the field. He has recently retired but I was lucky enough to find him tidying up loose ends. He has a lifetime of clinical experience and is a generous and skilled teacher and person of great humility and humanity.

One of the most difficult issues in clinical practice is establishing prenatal alcohol exposure, as sometime the only person who knows is the biological mother who may be reluctant to provide this information unless a safe rapport is established in the context of a positive and supportive environment. Dr Asante was able to provide many practical suggestions scaffolded with clinical examples.

"From what you have told me and what we have found it is possible/very likely that your child was affected by alcohol before he was born but you were not aware of it, many doctors did not advise people not to drink, and so we have a diagnosis but what we can do now is to do the best we can for the child. Whatever has happened has happened, you didn't know, no mother willingly does damage to their child."

Children seen at young age that have partial assessment often display wider gaps or more significant results at older age, also if seen at 8 and then during teens and then at adult. Cognitive factors appear to become worse with age as does mental health and physical health

Parents with adult (28-43 yrs) children with FASD still are at the cutting edge of the cohort, their children are still the guinea pigs and the full natural history of FASD is not known. FASD is still not recognised as much as ABI from MVA or near drowning. Pre-natal brain insults do not appear to be as acceptable to the community as (later) acquired ABI even though FASD is still acquired - just earlier.

We don't necessarily advocate the teaching of independence. We are all inter-dependent on each other so why not teach this instead by normalising inter-dependence, this is an especially important concept for mothers with FASD and allows them to ask for and accept help, to be somewhat independent in an inter-dependent setting. We make these allowances for children with cerebral palsy or Down Syndrome why not make the same for parents of children with FASD.

School systems and teachers need to be knowledgeable about FASD otherwise they create problems rather than relieve them. Parents of children with FASD have their greatest struggle usually with the school system. Special Needs teachers have the greatest ability to influence the school system.
PORTLAND, OREGON, USA.

FASCETS.

Diane Malbin, M.S.W.
*Executive Director is a clinical social worker, program developer, and consultant who provides information and services for individuals, families, and agencies. Research findings of improved outcomes for people with FASD based on her work have been presented nationally and internationally. She teaches and consults with parents, educators, health and social service providers, treatment professionals and others across the US and Canada. She is a published author and parent of two young adults with FASD.*

Where there is 'Anger, frustration or blame” there is usually missing information, then you ask ”what is the question?” Often the case with kids with FASD - missing piece of info is that their function is brain based not volitional.

Neurobehavioural paradigm applies to everybody in the world - as opposed to values laden interpretations of behaviour and trying to fix the child, which has implications for doing therapists out of business, or at least changing what they do - i.e. until now therapy has implied fixing the child.

US problem - Nexus of DSM 5 and insurance companies look at this to ensure patients are receiving ”proper” therapy. Often means medication is first line treatment. Now we have one size fits all therapies with no appreciation or tailoring based on aetiology - either if considered within disciplines e.g. SLP/OT etc or disease groups e.g. ASD. Clinicians become acculturated into certain courses of action without realising it themselves.

FASD has become conceptualised as an indigenous issue despite fact that white middle class, well educated women, are at significant risk for drinking during pregnancy.

The attitudes, assumptions & feelings of team members regarding alcohol are often unspoken and may influence their clinical practice. For example, anger, frustration & blame on part of the clinician. It is important to have an open discussion in team about alcohol use personally and in their families of origin.

A high correlation exists between coming from alcoholic or complex family systems and then going on to become a health care worker, which in turn raises questions about possible exposure of staff to trauma and FASD. It is plausible that some workers carry with them the despair and trauma so they do not have a language to talk about it with their clients. How does this influence their thoughts and feelings about birth mothers? It is important for team to understand their own beliefs so they can change attitudes generally.

We talk about FASD being a physical issue but we treat it morally because FASD hits close to home, for example

"I have an advanced degree but I/my wife drank during pregnancy"

**Practice tips**

It is vital to link the key findings of the report to specific recommendations for the child.

Accommodations should not be time limited as this assumes the child will be "made better” and school staff will become increasingly angry and frustrated when this does not occur.

Neuro-BEHAVIOURAL implies physical abnormality drives behaviour (i.e. the observable phenomenon).

FASD Spectrum: the question should be "does this person have something going on in terms of brain function?” - is the more useful question rather than is it FASD or not
FASD diagnosis is dependent on the fourth column of the 4-digit code - but Astley would maintain that you cannot make a cause & effect diagnosis unless it is FAS - because this is a clearly established dysmorphism caused by alcohol. The fact that mother drank is essentially irrelevant for the individual being assessed (except for prevention), the most important number for understanding the patient is the brain rank unless it is clearly FAS.

Avoid leaping to recommendations without having a good conceptual understanding of the neurobehavioural paradigm and what do we do differently because of this. The language used indicates the belief set. Use the language "physical disability" because the brain is a physical part of the person even though it is an invisible physical disability with behavioural symptoms. The team needs to use a common language. "Understood" is a better term to use than "management”

If this is not done then Sterling Clarren's metaphor "beating the blind child for refusing to read the blackboard” is analogous to what we are expecting of the child with FASD

The pivotal shift from behavioural model to neurobehavioural is from "won't” to "can't” and the emotional universe associated with both of those perceptions.

- Won't = intentional, personalised, at me, makes me feel incompetent & out of control
  - Get mad, yell, talk louder, punish
- Can't = compassion, understanding, depersonalised, not on purpose and allows relationships to build which are the most important therapy

The greater the confusion around the child the greater the number of people involved. If there is confusion then it would be good to say” gee we don't understand him very well”. When treatment doesn't work, the more anxious people get, their range of options constricts and the more brittle and controlling we become and the more outliers we get. The Neurobehavioural model celebrates diversity and there are no outliers. When systems needs are at odds with the persons needs we usually capitulate to the needs of the system? Is this sanctioned child abuse?

Team needs to discuss 'how does what we do look different” - especially re recommendations and be aware the above does not necessarily auto-transmit to new team members. Teams should aim to create the conditions that break the 'no solutions - no problem' stalemate conditional homeostasis.
Prof Sterling Clarren

Prof Clarren is one of the world’s leading researchers into Fetal Alcohol Spectrum Disorder (FASD), an umbrella term encompassing fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder, static encephalopathy: alcohol exposed and prenatal alcohol exposed. He was the Robert A. Aldrich Professor of Pediatrics at the University of Washington School of Medicine in Seattle, Washington, and doctor for the university’s FAS diagnostic and prevention clinic prior to becoming the CEO and Scientific Director of the Canada FASD Research Network.

Clarren has studied FASD since 1975 and helped to establish the definitions of FAS and FAE. He wrote the first article on the neuropathology of FAS, and developed the first non-human primate model for studying dose-response. He has testified about FASD before the United States Congress and the Washington State Legislature.

Prof Clarren was able to describe a fascinating history of the development of the field of FASD, the pitfalls encountered along the way and the barriers to the further development.

Practice tips

FASD is a population of kids who are so injured but so ignored!

Recognise that FASD is diffuse structural brain damage and the real issue is BRAIN not alcohol. Recognise that lots of things can cause diffuse brain damage and that alcohol is just a spotlight for ‘five more things here that [can] lead to brain damage’.

Originally surmised that most kids with brain 2 rank in the 4-digit code would have relatively normal brain function but may be doing badly because of emotions/environment etc but this is not what that been observed as kids in emotion/environment category have usually been seen and fixed by other clinics e.g. psychiatry, by the time they get to the FASD clinic it is only the ‘brain difference’ kids that are left. Most of the children in FASD clinic have diffuse brain damage.

Are FASD Clinics expensive? No-one ever thought having a cranio-facial clinic was expensive! No-one thinks MRI or doing MRI under GA is expensive even though it costs more than the entire psychometric work-up for one FASD child despite fact that both are looking at the brain! Is this one of the reasons it has been hard to establish teams? Is it the word "Alcohol"?

4-digit code evolution, Could it become a universal code for any diffuse brain injury if first three remained the same but last columns were developed to reflect different exposures, i.e.; columns for alcohol, drugs, abuse, genes.
Prof Susan Astley

Dr. Astley's primary area of expertise is Fetal Alcohol Spectrum Disorders (FASD). She is the director of Washington State FAS Diagnostic & Prevention Network (FAS DPN). The FAS DPN is a network of four WA State community-based clinics linked by the core clinical/research/training clinic at the Center on Human Development and Disability at the University of Washington. The mission of the FAS DPN is primary and secondary prevention of FASD through screening, diagnosis, intervention, training, education and research. Dr. Astley has developed a comprehensive system for diagnosing FASD: “The FASD 4-Digit Diagnostic Code”, the 4-Digit Code Online Course, FAS Facial Photographic Analysis Software for diagnosis and screening of the FAS facial features, and the Foster Care FAS Screening Program in King County.

FASD Clinic operates once per month and has now seen more than 2000 children in the last 20 years. Clinic is very streamlined and efficient in a deliberate attempt to maximise patients per dollar using a rationale of testing for a diagnosis only so as to assist families getting funding and services for disabilities. Prof Astley is about to open further discussions with the state re FASD kids with multiple moderate disabilities as to whether they should qualify for services. The clinic operates as a training venue and they have now trained 150 teams from around the world and established a training course online.

Problem with the FASD name is that everything with the child is blamed on alcohol, it may not, and thus blamed on the mother in turn which doesn't mean that all the other factors in the child's life didn't play a role as well. The child we see walking into clinic is the product of everything that happened to them not just alcohol.

No alcohol behavioral phenotype has been found and no specific FASD interventions have been found to be effective.

Brain rank on 4-digit code seems to be a good way of codifying disability i.e. three or more areas of damage more than 2 standard deviations below the mean. Subsequent MRI study confirmed the system by identifying underlying brain damage of proportionate rank even though it does not conform to a particular pattern. Thus the Brain rank represents a proxy for accurately measuring structural damage based on function.

Prof Therese Grant

Prof Grant is principal investigator of the Parent-Child Assistance Program, an award-winning statewide intervention model working with high-risk mothers who abuse alcohol and drugs during pregnancy. The program has been replicated at over a dozen locations in the U.S. and Canada. Grant's research focuses on the teratogenic effects of prenatal exposure to drugs and alcohol, exposure measurement, fetal alcohol syndrome, and development of prevention and intervention strategies with high-risk populations. She is principal investigator of a federally-funded study testing an innovative home-based mental health intervention with mothers who used methamphetamine during pregnancy, and their infants. Dr. Grant contracts with the U.S. Indian Health Service and Health Canada to provide training and consultation to tribes on prevention of fetal alcohol spectrum disorders.

Parent Child Assistance Program (PCAP)

PCAP is a community based program operating by providing home visiting by health professionals to high risk families as defined by involvement with the child protection system, substance use, domestic violence, poverty and tracking mental health concerns. The operating model consists of case supervision and web based data collection including keeping track of workers time spent with client and non-client activity. PCAP is based on common sense, but evidence based, strategies and has robust outcomes and demonstrated cost savings over time. PCAP is now in 12
of 39 counties in Washington State. The average cost is $5000 per client in service delivery over three years which does not include data collection and evaluation time. PCAP currently employs 13 advocates and two supervisors servicing 200 clients with a 70% long term follow-up.

**FASD EXPERTS**

FASDExperts is a group of mental health experts that specialize in the forensic assessment of persons suspected of having a Fetal Alcohol Spectrum Disorder (FASD). Although we work collegially as a "team" of experts, we each have independent practices and often work with other experts around the nation. We affiliate informally and collegially for two purposes: 1) to conduct objective multidisciplinary evaluations that meet the standard of care in FASD assessment, and 2) to educate professionals (e.g., medical, mental health, legal, corrections) about FASD and the conditions under which the cognitive deficits in FASD can lead to crime.

The FASD experts are a group of health professionals in private practice who act as expert witnesses in trials where the client may have FASD, especially if the defendant is facing the death penalty. The purpose is to demonstrate objectively to the court the role FASD has played in the client's life so as to plead diminished responsibility based on underlying brain damage. Published their own diagnostic protocol on their website to avoid the controversy of the various diagnostic systems. Overall this is a conservative derivation rather than a "squishy" one. Their diagnosis has never been overturned.

Need to have lawyer on the team for forensic work to stay up to date with current case law, so they can advise the case lawyers and advise the clinical team re court craft. They noted the importance of clinical expert witnesses to stay true to your science by being an advocate for your data and not investing in the outcome.
SAN DIEGO, USA.

SAN DIEGO STATE UNIVERSITY

Prof Ed Riley

It is well known that prenatal exposure to alcohol can affect the developing embryo and fetus and importantly can cause alterations in the normal development of brain and behavior. Dr. Riley's research focuses on these changes, how they are produced, and how we might intervene to mitigate them. Using a multidisciplinary approach, including behavioral assessments, neuropsychological testing and brain imaging, and collaborations with scientists from SDSU, UCSD, and the Scripps Research Institute, a myriad of effects has been reported.

Prof Riley expressed some concerns that the population of children with FASD identified by some diagnostic systems may be so large as to overwhelm service capability.

Current Projects include the development of 3D camera facial analysis systems, odor identification correlated with fMRI, FASD behavioural phenotype, the transition to adult care with FASD, the genetics of alcohol metabolism, dietary interventions and the use biomarkers to identify alcohol exposure.

UNIVERSITY OF CALIFORNIA, SAN DIEGO

Prof Ken Jones

He is considered to be the father of Fetal Alcohol Syndrome (FAS) since he first coined the term FAS along with Dr. David Smith at the University of Washington in 1973. Dr. Jones was the Chief of the Division of Dysmorphology/Teratology at the Department of Pediatrics at University of California San Diego and Medical Director of CTIS Pregnancy Risk Information. In these activities he has been involved in research, teaching, clinical work and University and public service.

Dr. Jones’ research has focused on the clinical delineation of birth defects, mechanisms of normal and abnormal morphogenesis and the recognition of new human teratogens. The work on recognition of new human teratogens is primarily focused through CTIS Pregnancy Risk Information, a service which he established under a different name in 1979 and which is funded by the State of California. Dr. Jones has authored over 400 publications in scientific journals as well as several books, and is the author of Smith’s Recognizable Patterns of Human Malformation.

Dr Jones regards himself as dysmorphologist and does not see genetic syndromes. He currently works as part of a multidisciplinary team with neurobehavioural paediatricians who, in turn work, with neuropsychologists and conduct extensive batteries of standardized tests for children with developmental or behavioural problems and includes an ex-special education teacher who goes with parents to schools to negotiate Individual Education Plans (IEP).

Controversies around the naming of the milder end of FASD are really just semantics but we need to be more circumspect about the certainty of the FASD diagnosis at the milder end and carefully consider the relative contributions of other exposures, environment and genetics.
Prof Jones commented that little attention has been paid to genetics of alcohol metabolism and what the implications of this might be for diagnoses, for example; for mothers who are fast metabolisers does this make the diagnosis of FASD less likely?

Prof Jones is currently involved in a Juvenile Justice Program for screening young offenders which includes a Lawyer to educate colleagues on both sides.

He speculates on the best way to mount a public awareness campaign and how not to inadvertently demonise people with FASD.
NEW ZEALAND

AUCKLAND FASD SERVICE

Dr Valerie McGinn and Dr Zoe McLaren
Dr McGinn was part of the first multidisciplinary team to diagnose FSD in New Zealand in 2008. She has now diagnosed more than two hundred children. Sometimes the diagnosis gets lost over time and services become unaware of it and revert to thinking of him as a 'naughty child'. More popular diagnoses tend to persist e.g. Reactive Attachment Disorder & Attention Deficit Hyperactivity Disorder. Always consider the need to re-iterate the assessment results and diagnoses. Always insist the child has a brain based disability.

The ongoing complexity around various conflicting guidelines and cutoffs for diagnosis, e.g.; > 2 standard deviations (SD) below the mean compared to less than this. It is important to always offer specific recommendations for children with milder difficulties i.e. between 1 - 2 SD below mean.

The model in NZ is probably not sustainable beyond the careers of the current enthusiasts in Auckland but is looking better in areas where FASD is part of multidisciplinary developmental team e.g. Taranaki and Hawkes Bay. New Zealand is hampered by a lack of service funding which is exacerbated by the fact that children with FASD can cause mayhem leading services deliberately to actively exclude FASD from their criteria. Starship Children's Hospital has no FASD team and despite two other teams being trained they are not accepting FASD referrals.

HAWKES BAY DISTIRC HEALTH BOARD

Dr Kate Robertshaw and THE Developmental Assessment Program Team
The FASD assessment process is part of an established multidisciplinary child development team in grounds of Hastings Hospital. FASD is simply part of what they do if full recognition of the fact they are already seeing children with FASD as part of a typical developmental caseload.

The team operates a number of waiting list strategies to provide services as early as possible. Home visits whilst on waiting list link the family into services early pending assessments. Paediatricians often see the child early before multidisciplinary assessments to get ball rolling, e.g.; get the disability allowance and await formal diagnoses that will come later.

FASD pre-referral packs are provided for local paediatricians as a combined professional development and referral pathway exercise.

Cultural and historical anachronisms sometime mitigate against cognitive assessments. Some services actively discourage cognitive assessments and prefer to promote strength based approaches. The team is working collaboratively to optimise the provision of cognitive assessments where they are most likely to make the greatest difference.
Conclusions

World
a. The community burden of FASD lies within white middle-class society.
b. FASD is perceived as a stigmatising diagnosis.
   i. It has not yet found popular support to increase its acceptance in society compared to other conditions e.g.; mental health, HIV, AIDS and autism.
c. The FASD community, from research lab to the clinical services, is heavily invested in scientific method and evidence based medicine.
d. Valid & reliable diagnostic systems exist and there is general agreement on key criteria though some controversy continues.
   i. Gaps exist for younger (<8 yrs) children with mild-moderate impairments.
      1. Better systems for this age group are required
   ii. FAS can be diagnosed at any age by a ‘dysmorphologist’
   iii. The gold standard for FASD diagnosis is a well trained multidisciplinary team.
e. Training in multidisciplinary diagnosis is available in Canada & the USA.
f. FASD is an ‘orphan diagnoses disconnected from service delivery and support.
g. Australia is generally disconnected from the overseas FASD scientific community, with a few notable exceptions.
h. The growth in FASD services in North America has been organic, based on the clinical interests of individuals, rather than planned.
i. Evidence for specific interventions is sparse.
j. Evidence for broad intervention philosophies and frameworks is compelling and has applicability beyond FASD.

Australia
a. FASD is vastly under-diagnosed in the Australia for several reasons
   a. FASD is perceived as a stigmatising diagnosis. Clinicians are reluctant to ask about prenatal alcohol exposure or to pursue potential diagnoses of FASD if positive.
   b. The greatest burden of FASD lies within mainstream white middle class Australia, though it remains undiagnosed or mislabeled. Sixty percent of pregnancies in Australia are unplanned and sixty-three percent of pregnancies are alcohol exposed.
   c. FASD clinical expertise is rare and training is poor or non-existent.
      a. Where pockets of expertise exist it is under utilised by omission or active commission.
   d. The majority of children with FASD (83%) are difficult to diagnose, because they ‘look normal’ they are assumed to have normal brain function when in fact they have permanent diffuse brain injuries.
   e. The personnel required (child psychology, speech pathology & paediatricians) exist in government funded services around Australia. However, almost none have the training or expertise required to diagnose FASD and it is usually missed or misdiagnosed as another condition.
      a. The cost-benefit of continuing with such a system of non-diagnosis is ludicrous.
      b. The ongoing failure to diagnose is completely unacceptable by any measure of safety, quality, equity, ethics, morality or human rights!

Recommendations
a. Bring FASD into the mainstream by actively working to decrease stigmatising public perceptions.
b. Adopt a ‘pick and stick’ approach to diagnostic systems rather than attempt to invent a unique Australian system or apply local modifications to an existing system.
c. Actively build FASD collaborations, across the continuum from research to service delivery, within Australia using pre-existing formal networks and establish new ones as required, e.g.; between medicine and justice.
   a. Build and maintain similar relationships with overseas agencies. The excuse that ‘we are not ready yet’ should emphasise the necessity for prompt action.
d. Deliver FASD services via existing government and non-government services by upskilling staff using expertise now available in this country as the most cost effective strategy.
   a. Failing the above, to actively foster, allow and encourage organic growth of expertise within services through observation, apprenticeship & supervision models.
e. Remove ‘orphan diagnosis’ status by the official recognition of FASD as a disability
f. Develop a whole of government strategy, state and federal, in recognition of the impact it has across multiple government departments so as to provide a cradle to grave system of support, including prevention.
g. Change the focus of FASD activity in Australia from research to service delivery.
h. Establish methodologies to estimate, and then accurately quantify, the cost of FASD for communities, systems, regions and states.
i. Recognise that understanding FASD across the lifespan, and across the sector-span, will provide new models for managing many other chronic brain-based disorders.