

# Research Advances in Brain Disorders and Therapy

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## Clinical Review

# Management of Patients with Neuro-Developmental Disorder Prenatal Alcohol Exposure Formally Referred to as Foetal Alcohol Spectrum Disorders

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## Introduction

As a Psychologist or Child psychiatrist or other clinician working with children, families or adolescents, with a history of prenatal alcohol exposure, you are acutely aware that these individuals do not respond to 'traditional' psychological or psychiatric therapeutic approaches. These children, teens and adults are individuals who need new solutions to parenting, teaching and case management. A new approach is required now to address the challenges presented by the effect of Hidden Harms of alcohol on the developing brain, attachment and relationships and life skills affected by their exposure to prenatal alcohol misuse. These patients or clients have unique case management needs, which can only be addressed through first forming a clear neurodevelopmental diagnostic frame as a starting point to management.

There are three objectives in presenting this paper; first as a clinical review paper to describe the clinical dimensions of the global neuro-developmental disorder as it relates to prenatal alcohol exposure. Secondly this paper offers a unique clinical management thrust as a practical review of the psychological strategies and therapeutic approaches that have proven consistently useful in the prenatal acquired brain injury. This paper is a mixture of academic and over 60 years of combined multi-national clinical experiences of dealing with this condition by two senior clinicians, from two different disciplines Psychiatry and Psychology who have dealt with this condition, separately and collaborated, internationally in the United States of America, United Kingdom, Brazil and now Ireland, The management of this condition requires a multi-modal and multi-discipline approach across the lifespan of affected

individuals. The final objective is to highlight that management strategies do improve the clinical outcomes for these individuals. Green (2007) [1], Kalberg and Buckley (2007) [2] point out the benefits of early intervention and effective management strategies to minimise the effect of primary disabilities and prevent secondary disabilities.

The acquired brain injury resulting from prenatal alcohol exposure is the essence of the condition, known variously as Foetal Alcohol Spectrum Disorder, FASD or more recently Neurodevelopmental Disorder Prenatal Alcohol Exposure, ND-PAE, code 315.8, DSM 5. Fifty years of research, animal initially then human, has shown that, in 2018, we are as clinicians, confronting a non-face, non IQ driven global neurodevelopmental disorder, [3-6].

This global neurodevelopmental disorder is primarily 'hidden' as the dysmorphic FAS face is only seen in 10 to 15% of affected individuals, and the IQ under 70 in only 25% of the individuals, so IQ is also not a reliable clinical marker.

There are 6 clinical dimensions to this unique neurodevelopmental disorder which are not static and appear at different developmental trajectories.

1. Motor and Sensory Dysregulation; seen in often normal birth weight, alcohol-exposed infants and children under 5 years of age. Already these neurological deficits have been shown to include truncal and gait ataxia, decreased sensation on one side of the body.

2. Disruptive Mood Dysregulation; which is seen in infancy and young childhood as difficult to settle and slow to warm infants and young children. A family history of mood disorder in the birth mother or father is a critical factor and exacerbates the serious nature of this potential 'double origin' mood dysregulation.
3. Language Disorder; is not IQ driven and is NOT ASD, but is a true discourse language disconnection, which is now captured in DSM 5 with Social Communication Disorder. The most challenging dimension is Oppositional Defiant Disorder which blames the victim. A specific deficit called Alexithymia is poorly understood but an essential ingredient in this dimension. In other words, the inability to read emotions in others or to have words for the persons own emotions. Therefore, feelings are expressed in physical action, aggression for one.
4. Cognitive disorder. This is NOT Intellectual Disability but a mixture of metacognition problems such as dyslexia, dyscalculia, working memory deficit, executive function problems coupled with attentional and processing problems. In this situation you have the child who does not link cause and effect, does not learn from experience, and has a tendency to 'make up' stories to fill the memory deficits, a form of confabulation.
5. Growth disorder. This has been recognized from early animal studies but is not linked always to facial features and is commonly mist-diagnosed as 'failure to thrive;' due to emotional /nurturing reasons. Here the individual has a delay or negative trajectory in growth not related to birth wt. or and in the presence of stable nurturing foster or adoptive parents. Science has shown the effect of alcohol on nerve growth factor glucose transporter system and ultimately potential effect on growth hormone itself [7].
6. Facial disorder. Long noted as the link between prenatal alcohol and a neurodevelopmental disorder but only present in 10 to 15% of individuals and not related to the extent of the brain injury and the other clinical dimensions described above.

Management thus begins in the mapping out of the presence of these 6 Dimensions which then link to neuropsychiatric presentations such as ADHD, (inattention/impulsivity subtype), Atypical ASD, Mood disorder, Explosive disorder, and Social communication disorder

The World Health Organization and the American Academy of Child and Adolescent Psychiatry (AACAP) has stated that pregnant women should not drink any alcohol at any point during their pregnancy. Alcohol consumption during pregnancy has been long recognized as a major cause of intellectual disability and birth defects. (National Organization on Foetal Alcohol Syndrome's

(NOFAS), Web site , <http://www.nofas.org>. Foetal alcohol effects are present in more than one in 100 live births or as many as 40,000 infants each year in America. In addition to developmental delays, children born with foetal alcohol effects have a higher incidence of behavioural problems, including conduct disorder, depression, and attention disorders.

Foetal Alcohol Spectrum Disorders, FASD, are under-recognized and under-reported even in countries where there is much knowledge of the conditions. FASD include Foetal Alcohol Syndrome, (with or without confirmed maternal consumption of alcohol), Partial Foetal Alcohol Syndrome, Alcohol-Related Neuro-developmental Disorder and Alcohol-Related Birth Defects. The term FASD is not intended for use as a clinical diagnosis. Currently the DSM 5 has recognized that prenatal alcohol causes a true global neurodevelopmental Disorder, ND-PAE code 315.8 and so this will become the diagnostic frae in the coming generation.

The problems related to alcohol are not limited to adults or rowdy teenagers who choose to drink too much on weekends, or individuals who may present knowing they have an alcohol problem and are seeking help. Unfortunately the effects of good nights out, great celebrations of weddings or funerals or regular nights out or in having a nice meal and a couple bottles of wine can have a life time effect on the developing foetus. This is not just a concern for women but men as well. This is the very essence of understanding the trans-generational effect of prenatal alcohol seen all too often in European countries such as Ireland and in many ways the UK.

The problem for many individuals involved in risky behaviour can commonly be traced to a very early encounter with alcohol. For all too many individuals their first bottle was in utero when their mother binge drank, meaning more than 2-3 drinks depending on actual units; so ultimately did they! Unfortunately, as a foetus in embryo; they didn't even have to ask to be served his first drink, as equally unfortunate for them alcohol crosses the placenta freely.

In countries such as Ireland it has been shown that 7.8 times more Irish pregnant women drink alcohol than do their American counterparts. Given that FASD/ ND-PAE occur annually in 1% of all U.S. births. Ireland continues in 2018 to have a serious cause for concern, as there is good reason to believe that up to 1,800 babies born here each year are at risk of being affected, to a greater or lesser degree, by these avoidable lifelong effects [8]. This unique public health problem is not seen in Ireland alone but in many other European countries as the general acceptance of alcohol, especially in middle class women of child-bearing age continues to be the norm.

By the time individuals with FASD reach adolescence or adulthood, many of the physical characteristics (e.g., facial

features and growth deficiencies) may no longer be apparent. Consequently, it is the history of prenatal alcohol exposure and the behavioural manifestations of central nervous system dysfunction that provide the clinician with the primary clues to the suspected diagnosis. Diagnosis is not a means to attribute blame but rather helps to provide appropriate treatment. If an individual is fortunate enough to be working with a clinician who can recognize the aetiology of the problem behaviours and provide the appropriate support, there is a better possibility for a positive outcome. There is very little general awareness in Ireland about the risks of alcohol and especially in unplanned pregnancies.

As clinicians working with children, teens or adults who may not be responding to the typical interventions it may be important to explore as much as possible what your client or carers may know or not know about whether their mother drank at all during their pregnancy. What may have often been thought to be social or typical drinking habits we now know to be actually binge drinking; any time more than 3-4 units of alcohol are consumed in a single session there is risk for permanent damage to the foetus as there is no safe amount of alcohol that can be consumed during a pregnancy as recommended by World Health Organisation.

Children, adolescents and adults with FASD/ND-PAE present with a range of neurodevelopmental, not IQ or non –facial dysmorphology symptoms. Some individuals may display a high level of impulsivity which becomes restlessness and a tendency to “split” when situations become too frustrating. There is a marked discrepancy between seemingly high verbal skills and inability to communicate effectively. Individuals often have a long history of situations where they appear to have displayed poor judgment.

Memory problems are common, both long-term and short-term memory. Difficulty with applying knowledge and abstract reasoning is common. A severe difficulty understanding why something happened (*cause and effect*) is also common. This is particularly problematic for vulnerable, ‘oppositional defiant ‘children, as well as so called ‘acting out’ adolescents, with the damning label of ‘emerging personality disorder.’.

This patient population have additional difficulties with time and money management and with many applications involving maths or later in life with financial management.

Individuals with FASD / ND-PAE are unresponsive to social cues. They often are lacking reciprocal friendships; have difficulty distinguishing between fact and fantasy; and have difficulty with sexual expression and anti-social behaviour, and these conditions are typically first noticed during adolescence.

### **Case Management: Multi-Modal Interventions**

If trying to work with FASD /ND-PAE teens or adults in traditional psychotherapy, the clinician would find that these

individuals would demonstrate difficulty with awareness, contact and self-regulation. Their lack of awareness influences their perception of their self, others and the environment. Individuals with prenatal alcohol exposure resulting in a Neuro-Developmental Disability/ Brain Injury, have a different perception of the environment as a direct result of the effect of alcohol on the brain-how it processes sensory information.

A dramatic example of the effect of alcohol on the brain of the developing foetus is to pour two or three measures of vodka into a short clear glass. Then take a raw egg and break it into the vodka; within a few moments the white of the egg will begin to turn milky. This happens to an egg when it is beginning to be cooked. This is what happens to the cells of the frontal cortex of the foetus which is where the executive cognitive functions take place.

Individuals with FASD/ND-PAE tend to be ‘egocentric’, and don’t understand how their activities relate to others’ feelings. Thus traditional group or milieu therapy may be disorienting and upsetting to patients with FASD/ND-PAE due to their difficulty with boundaries, emotional control and suggestibility. Teens or adults often respond more successfully to a mentoring, one-on-one type of treatment where they feel a special bond with a staff member or carer who serves as their advocate and point of contact.

While insight-oriented treatment is often lost on patients with FASD/ ND-PAE, an individual therapy can be specifically designed to address treatment issues in a more structured way. Cognitive-behavioural approaches have been found to work well, because they can be specifically tailored to accommodate the judgment and organizational problems of the patient identified as having FASD/ ND-PAE. However it is essential to have standardised testing of the cognitive processing abilities of the individual completed. Attention and especially working memory of the patient with FASD/ND-PAE as all of these neurocognitive challenges negate the basic principles’ of CBT.

Instead of relying on an individual’s ability to generalize what he or she learns in treatment and to modify behaviour accordingly, a more effective approach involves the use of consistent rules of behaviour that guide and structure behaviour in any situation. This becomes more of A Reality Based therapy with a strong Cognitive guiding frame.

Individuals impaired by prenatal alcohol exposure often exhibit rapid mood swings and quick tempers. When these characteristics combine with a generally impulsive nature and a history of repeated frustration, behaviour control is difficult. Individual therapy is best suited to deal with the issue of emotion control. Role-playing may be an effective technique. In this approach, the therapist develops a number of different scenarios, each designed to trigger anger or frustration, and works out a way for the patient to respond appropriately in each case. The key to

successful generalization of these role-playing techniques to real-life situations after treatment is the amount of practice and the variety of scenarios the patient is exposed to while in treatment.

Another important intervention is family therapy. The ability of a patient to sustain progress made in treatment depends heavily on the amount of support available in the home environment. Consequently, involving the family in treatment at the outset is critical to ensure adequate understanding and support for continued behaviour change. The type of family therapy most useful is an Instrumental/Minuchin type with basic family functioning and role definition, and family hierarchy at its core. An additional Family System approach that is also demonstrating positive outcomes is PUP; Parents under Pressure [9].

Approaches such as narrative therapy with life story use, or strategic family therapy are much less useful and may in fact emotionally abuse the vulnerable child or adolescent who has experienced a severe disconnection, abuse in early childhood, and has significant processing problems, working memory problems and alexithymia.

### **A Systems of Care Management Approach is Essential**

Children and adolescents, who later become adults with FASD/ND-PAE need intensive case management, even if there is a supportive family member who can fill this role. Otherwise there is a real danger of 'burn out' in the foster or adoptive parents or extended family or partners.

It can be a complex task to coordinate the many services that the client may need, such as on-going school educational support, individual, speech and language, OT, outpatient psychiatric medication therapy, For older patients, vocational support/job coaching, housing, transportation and financial assistance. These cases require on-going case management reviews, with a consistent coordinator of their services, who will call for bi-annual or annual reviews to ensure that positive gains are maintained, versus only calling case reviews when the individuals are in crisis; too often in an overburdened health system, when things are going well, for a period, routines and supports that have enabled positive outcomes and progress become lax, leading to a crisis for the individual.

This Multimodal Treatment approach is critical in FASD/ND-PAE and within its frame has to recognize that for families of individuals with FASD/NDPAE it is of vital importance to educate the family, schools, allied health and social care professionals and in countries such as Ireland also the medical profession, including multi-discipline therapists (because of the continuing stigmas and denial of FASD/ND-PAE and transgenerational alcohol problems in general).

- a. The family have to understand it is a real condition, mourn the loss of expectations, of ideal family, especially for adoptive

parents, and in other cases also bare the guilt for the loss. Earlier diagnosis is important. Non-verbal therapy helps to reduce difficulties with processing language and those who have also experienced abuse. Non-verbal therapy helps to reduce misunderstanding.

- b. Other health care systems: It is important to have an Occupational sensory integration assessment, and Speech and Language Therapy to help focus on social use of language skills in different settings; often the use of language at home is very different than language and cues given in schools, work places or social situations.
- c. The use of medication such as Serotonin agents can be a problem when given to FASD/NDPAE individuals as it can increase suicidal tendencies, with impulsivity inherent to the condition, as it is an alcohol acquired brain injury Paroxetine is the worst agent for young FASD/NDPAE adolescents but all SSRI need careful monitoring, as they all can unmask a hypomanic episode
- d. Psychostimulants are useful with ADHD symptoms with the dextroamphetamine agents a better fit than methylphenidate derivatives.
- e. If Group therapy is employed it is important that groups be formed based on age and gender. Typical therapeutic interventions should last for 3 months, 1x per week.

### **A Strength Based Approach**

To achieving positive outcomes with individuals with FASD focuses on Identifying strengths and desires in the individual. What do they do well? What do they like to do? What are their best qualities? What are your funniest experiences with them? Identify strengths in the family or other providers. Identify strengths in the community. Strategies for Improving Outcomes for individuals with an ND-PAE include simplifying the individual's environment as much as possible. Encourage and simplify routines. Be consistent in activities and provide one direction or rule at a time. Review rules regularly and use a lot of repetition. Always check understanding and use short-term consequences. Do not use natural consequences. Additional strategies in treatment are to be consistent in appointment days and times. If possible offer short, more frequent meetings or sessions. It may be necessary to arrange for someone to get the person to appointments. Try to establish achievable short term goals and identify someone who will help with each step. It is important to avoid using students as therapists as they may not be skilled in recognising Neuro-Developmental Disorder of Prenatal Alcohol Exposure and their short term placements may recapitulate losses for the individual when they move on.

Notions to keep in mind are that both prevention and long term case management treatment supports are key in addressing

this acquired brain injury. Successful treatment is one step to effective prevention. When an intervention does not work, it is essential to examine for whom it doesn't work and why it doesn't work for that person at that time. Collaboration among agencies and systems is essential. It is essential in these times of shortages in health care funds that service providers acknowledge turf issues and pool resources. This is a human issue, it is a rights issue, it is a Public Health Issue. It is Brain Damage. It is about trauma for the individual and the family. It is about attachment and long term relationships for all. FASD / ND-PAE is about people and affects the lives of individuals, families, and communities. There are too many of these individuals who end up with secondary disabilities which too often means, incarceration and or long term mental health needs who with earlier identification and supports may have had different outcomes.

We must move from viewing the individual as failing if s/he does not do well with a program to viewing the program as not providing what the individual needs in order to succeed". This paradigm shift is a very important one. Most of the time, we provide a program that works with many people, either by experience or by research. If the person does well in the program, we say that the program is a successful program. If the person does not do well (by the program's standards), we say that the person has failed or that the person is unmotivated.

We need to change our thinking. We need to see that it is our responsibility, as service providers and caregivers, to identify methods to ensure that the person succeeds (in our individually developed definition of success for the person).

### **What the Research Says**

The prevalence of substance use has dramatically increased over recent decades. Ireland, in particular, has one of highest levels of alcohol consumption in Europe. Drug and alcohol interventions should aim to address the interaction of all risk and protective factors impacting the lives and development of affected children and families. A key challenge is treating substance misuse as part of a set of complex problems being experienced by users and their family and not solely as a problem for individual misusers. Including families and social networks of substance misusers in treatment programmes, can positively influence the direction substance use problems take, improve outcomes and reduce negative effects for families. The Multi-component interventions discussed provide support for substance users and their children, who achieve increased outcomes in terms of improved family relationships and cohesion, parental involvement in children's lives, and family communication in understanding the Hidden Harms that result from the effect of alcohol and substance misuse on the developing brain and lifelong family and social effects.

Individuals with histories of transgenerational substance misuse are more likely to engage in programmes that support a process of recovery which takes account of their family life. Support should be part of a whole systems approach where agencies respond flexibly and employ effective partnership processes in addressing the needs of both users and families. Improve co-ordination with all relevant services and utilise inter-agency partnership structures. We must publicise family support drug and alcohol services better and increase public awareness and knowledge of substance misuse. Establish best practice in drug and alcohol family support and provide regular and worthwhile training courses. Include service users and family members in development of drug and alcohol family support services: and ensure an inclusive approach which includes ethnic and cultural minorities within this development process.

### **Conclusion**

This clinical review has been written by two experienced clinicians to clarify the diverse clinical dimensions that this unique Neuro-Developmental Disorder presents, as a result of the acquired brain injury due to prenatal alcohol exposure. Many clinicians share the belief that this condition is hampered by a pervasive therapeutic nihilism which is not borne out by many years of our joint therapeutic experience. Many clinicians avoid asking questions that may clarify this condition, as they believe that the damage is done, or that this doesn't change the condition but rather simply promotes guilt and blame on mother's. It is imperative that proper diagnosis is done for this like all conditions in order to apply appropriate treatment and supports, in addition to improving awareness through education to prevent this acquired brain injury. If there was one thing that you could do to prevent a brain injury, wouldn't you do it. Through appropriate history gathering, motivational interviewing and diagnosis comes the opportunity to affect positive outcomes and family supports.

### **Suggested Screening Questionnaires for Identifying Problem Drinking**

**TWEAK** (score of 3 or more indicates heavy or problem drinker)

T(tolerance): How many drinks\* does it take before you begin to feel the first effects of alcohol? (3 or more drinks =2 points)

W(worried): Have close friends or relatives worried or complained about your drinking in the past year?

(Yes = 2 points)

E(Eye-Opener): Do you sometimes take a drink in the morning when you first get up? (Yes = 1 point)

A(amnesia): Has a friend or family member ever told you about things you said or did while you were drinking that you could not remember? (Yes = 1 point)

K(kut down): Do you sometimes feel the need to cut down on your drinking? (Yes = 1 point)

**T-ACE** (score of 2 or more indicates heavy or problem drinker)

T (Tolerance): How many drinks does it take to make you feel high? (3 or more drinks = 2 points)

A (Annoyed): Have people annoyed you by criticizing your drinking? (Yes = 1 point)

C (Cut Down): Have you ever felt you ought to cut down on your drinking? (Yes = 1 point)

E (Eye-Opener): Have you ever had a drink in the morning to steady your nerves or to get rid of a hangover?

(Yes = 1 point)

**Note:** TWEAK has a sensitivity of 79% and a specificity of 83%; T-ACE has a sensitivity of 70% and a specificity of 85%.5

\*A standard drink is commonly defined as one containing 15 g of alcohol (e.g., 360 mL [12 oz.] of beer, 150 mL [5 oz.] of wine or 45 mL [1.5 oz.] of spirits) [10].

### **Screening Questionnaire for Diagnosing Problem Drinking in Adolescent Women: CRAFFT\***

C: Have you ever ridden in a CAR driven by someone (including yourself) who was high or had been using alcohol or drugs?

R: Do you ever use alcohol or drugs to RELAX, feel better about yourself, or fit in?

A: Do you ever use alcohol or drugs while you are by yourself, ALONE?

F: Do you ever FORGET things you did while using alcohol or drugs?

F: Does your family or FRIENDS ever tell you that you should cut down on your drinking or drug use?

T Have you ever gotten into TROUBLE while you were using alcohol or drugs?

\*Each question on the CRAFFT list is given a score of 1. A cut point of 2 provides moderate sensitivity (70%) and excellent specificity (94%) for identifying alcohol use disorders in adolescents. Any positive answer on the CRAFFT list requires further assessment [11].

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