The Incidence and Prevalence of Fetal Alcohol Syndrome and Alcohol-Related Neurodevelopmental Disorder - Implications for Mental Health Workers.

How many of us know, directly or indirectly, of a person with FAS or ARND between the ages of 1 and 16 years?

- How many of us know of a person with FAS or ARND, directly or indirectly, between the ages of 35 or 50 years?

FAS was first described in North America in 1973. Prior to that there had been two studies in France in 1960 and 1967, that described physical and psychological abnormalities in children, following the taking of alcohol during pregnancy. FAS has been with us since men and women first consumed alcohol.

Aristotle apparently described the relationship between alcohol taken during pregnancy and the birth of defective children. Aristotle also said - “It is not once nor twice, but times without number, that the same ideas make their appearance in the world.
What we forget or ignore from the past, we pay for in the future.

- From the Bible - “Behold, thou shalt conceive and bear a son; and now drink no wine or strong drink”.
In Carthage, there was a prohibition against the bridal couple drinking on their wedding night, for fear of producing a defective child.

Navajo tradition states that women who drink crazy water when bearing a child will give birth to a child crazy in body and mind.

A report to the British House of Commons in 1834, stated that infants of alcoholic mothers often have a starved, shriveled and imperfect look.

Incidence is the number of new cases born or detected each year - in a hospital, a province or a country.
Prevalence is the total number of cases in the population at any time, in a geographical area.

A prevalence of FAS of 40.5 to 46.4 per 1000 children between the ages of 5 and 9, has been reported in one community of the wine growing area of South Africa.
The parents of these children labour in the wine industry. The children grow up to labour in the wine industry.

Before we condemn the South Africans, let us acknowledge that many of those afflicted with FAS in North America end up in the menial, dirty and boring jobs - if they are able to work at all.
The highest rate recorded in Canada for FAS - in a small native community - is 120 per 1000 Children.

FAS, neo natal growth deficiency, characteristic facial abnormalities and CNS dysfunction, was the first to be investigated statistically - with difficulty.
Accurate statistics require an accurate diagnosis. Initially the diagnosis was made by a few concerned physicians, mostly pediatricians. Opinions might vary as to the diagnosis.
We now have more accurate, standardized assessments, that can be reproduced and verified, leading to -
- more accurate diagnoses,
- more appropriate patient care.
-earlier intervention with reduced severity of secondary disabilities
-and more accurate statistics regarding incidence and prevalence of the condition.

St. Michaels Hospital, Toronto, has a Diagnostic Clinic that uses such a system.
Each major city in Ontario should have one.

There are basically three methods by which Incidence and Prevalence are determined.
The first is Passive Surveillance , which was the first to be used. It is the least expensive but also the least accurate. Criteria for the diagnosis would be first established -(we have noted that historically the diagnosis tended to be inaccurate) - and then retroactive studies of records would be done - records such as birth certificates, hospital and physician records etc. The problem with this method was that most of those making the records knew nothing of the condition. It was therefore under reported, and still is, depending on the knowledge and diligence of those writing the records. Two retired obstetricians recently told me that they had never diagnosed a single case, during all the years that they practiced. In fairness, the facial features are not so noticeable at birth, which is one of the problems of maternity unit records of course, - if indeed FAS is considered at all. No matter how smart we are, we can only diagnose what we know.
Incident rates of 0.2 to 0.67 per 1000 births have been determined with the Passive Surveillance method.

The second method of obtaining statistics, clinic based, is pro-active and more accurate.
Here, appropriately designed studies are established in prenatal clinics. Relevant data can be obtained regarding the mother's health, alcohol intake etc. before, during and after pregnancy, and assessment of the infant can be made at birth. At the same time, this method allows for a degree of control over the variables, without which conclusions may be inaccurate. There are, however, certain problems with this method. Mothers who are most risk for FAS tend not to use such clinics. Those attending the clinic may not be representative of the general population, depending on the location of the clinic. Finally, the FAS features are less noticeable at birth, and the CNS dysfunction often not apparent.
The diagnosis is most accurately diagnosed after 3 years of age. Clinic based studies give Incident rates of 1.9 to 2.2 per 1000 births.

The third method for estimating the Incidence and Prevalence of FAS is through Active Case Centres. Here, Active Case Centres search for mothers and their children who are at risk. Referrals are encouraged, and referral networks developed. The diagnosis is made by a number of individuals, each an expert in a particular aspect of FAS.
St. Michael's is an example of such a Centre. As far as I know, St. Michael's is the only Centre in Canada that assesses individuals of all ages. Because these Centres are so pro-active, early intervention for those children at greater risk is more likely.
The main objection to this method is the expense.
The answer to that is that we can no longer afford the cost to society that this condition creates.

The cost to society for the life span on one FAS child is estimated to be 1.4 million dollars. The annual cost of FAS in the U.S. in 1998 was estimated to be 2.8 Billion dollars.

Active Case Centres provide the most accurate statistics for the referral area they serve. The greater the community is at risk, the higher the Incidence . From Active Case Centres, the overall rate for North America lies somewhere between 2 and 4 per 1000 births.
However, following the description of FAS, it soon became apparent that some children did not have the facial features although they were otherwise effected. The term, Fetal Alcohol Effects was used to cover these cases. Because different people would have different definitions of FAE, the term has been dropped in favour of Alcohol Related Neurodevelopmental Disorder (ARND), for which there are standard diagnostic criteria, including a history of alcohol consumption during the pregnancy.
Research has shown that the facial features only develop when alcohol is consumed during the first trimester of pregnancy - possibly in only one week and yet brain damage from alcohol occurs throughout the pregnancy. The most critical damage occurs in the first few weeks, when often the mother does not know she is pregnant. It follows then, that there are going to be more cases of ARND than FAS.

When we look at the Incidence of FAS and ARND combined, then the rates become more alarming. The estimated rate for FAS and ARND combined is 9.1 per 1000 births in the U.S. - i.e. almost one in a hundred. This is considered to be a conservative estimate. There is no reason to believe that it is any less in Canada.

Why is this an underestimation? First of all, the diagnosis of ARND is only made if there is a history of alcohol intake during the pregnancy. So often it is not possible to obtain such a history for various reasons. Secondly, there are very few Centres that have the ability to make the diagnosis. Thirdly, there is a tremendous lack of knowledge on the part of all professionals, regarding FAS and ARND. If it has been difficult to diagnose FAS with the facial features how much more difficult is it to diagnose ARND without the facial features?
Lastly, an unknown number of stillborn deliveries, that would have FAS/ARND, are not included in these statistics.
All of these estimations of Incidence and Prevalence relate to children. They are not a true estimation of the Prevalence in all of the population.
Mysteriously these conditions seem to disappear around the age of 16 - 18..Which brings us to our original question. How many people between the ages of 35 and 50 do we know that are FAS/ARND?

So what do we call these children, once they have become adults?
In 1996 a report was published by Ann Streissguth and others from the University of Washington, Seattle. They had followed afflicted children and determined that they developed secondary disabilities.

- Mental Health Problems,
-Disrupted School Experience,
-Trouble with the Law,
-Confinement,
-Inappropriate Sexual Behaviour,
-Alcohol and Drug Problems,
-Dependant Living,
-and Problems with Employment.

Over 90% went on to have mental health problems -
Attention Deficit Disorder,
Depression
Suicide Threats,
Suicide Attempts,
Panic Attacks,
Hearing Voices, /Seeing Visions,/Behaviour Problems, Assaulting Behaviour.
Conduct Disorder,
Sexual Acting Out, psychotic behaviour.

ADHD is the most frequent mental health secondary disability. 60% of FAS/ARND children go on to be diagnosed as ADHD between the ages of 6yrs.- 20yrs.

According to Stats Canada, 10% of Canadians are diagnosed as having mental health problems.
If 1% of Canadians have FAS/ARND and 95% of those with FAS/ARND have mental health problems, then we can conclude that almost one in ten patients that mental health professionals see, must be FAS/ARND. These are conservative figures.

The question is - what diagnosis are we giving these patients when they present as adults with mental health problems? The Diagnostic and Statistical Manual of Mental Disorders is published by the American Psychiatric Association. The Manual sets the diagnostic standards for all mental health workers - psychiatrists, psychotherapists, social workers, nurses. FAS and ARND are not mentioned in the Manual. Yet one in ten mental health patients have these conditions. The closest reference, under Predisposing Facts - Mental Retardation, states that early alterations of embryonic development may be caused by toxins such as alcohol.
However, if we look at the list of Mental Health problems that those with FAS and ARND suffer from, and compare them to the criteria used in the Manual, we can see where FAS and ARND patients might fit in.

Examples in childhood -
Mental Retardation,
Learning Disorders,
Pervasive Developmental Disorders,
Attention Deficit Disorder,
Reactive Attachment Disorder.

Examples in adulthood -
Substance Related Disorders,
Mood Disorders,
Anxiety Disorders,
Impulse Control Disorders,
Attention Deficit Disorder
And Personality Disorders.

Not all of those with these disorders are FAS/ARND. But it is surely amongst these cases that the lost FAS/ARND will be found.

ADD and FAS/ARND.

Since Ann Streissguth's report was published in1996, Clair Coles, Director, Fetal Alcohol Centre, Emory University, Atlanta, has published work that clarifies the difference between FAS/ARND and ADHD. They are two distinct conditions and may be mutually exclusive.
Whatever the final conclusions regarding the relationship of these conditions, the fact is that ADHD is the most common mental health problem that FAS/ARND individuals are diagnosed with, at this time. It is not surprising then, that many individuals diagnosed as FAS/ARND have previously been diagnosed with ADHD.

I would like to share with you my personal experience. It is anecdotal and not at all conclusive, but does seem to confirm the points raised. In my practice, I see adults, but more recently, through my involvement with FASworld, I am seeing some FAS/ARND children with their parents.
FAS/ARND children create stress in a marriage. It is not uncommon to see a couple who have an adopted child. In talking to the parents it often seems likely that the child might be FAS/ARND and when the child is subsequently assessed for FAS/ARND, the diagnosis has been confirmed. These children have usually previously been diagnosed as ADHD.
In other cases, the diagnosis of FAS has been made before the family comes to see me, and the history also includes previous diagnosis of ADHD.
Some adult patients who come for depression, anxiety, anger, often give a history of FAS/ARND secondary disabilities. They have often been diagnosed as borderline personality disorder, and their depression is of a chronic, intractable nature. A previous diagnosis of ADHD is not uncommon. In some of these cases it can be established that the mother drank during the pregnancy, and the diagnosis of FAS/ARND confirmed.

If I had to choose one word to describe those who are afflicted with FAS/ARND it would be "chaos". Their lives are chaotic and when one looks back over the life of an adult with this problem, that is what one sees - a life of continuous chaos. Often, there are moments when they say or do something that resonates with the potential that they would have had, were they not FAS/ARND. Tragically, they seem to be in some way aware of these potentials.
Their struggle is reconciling what they feel they should be able to achieve, with the fact that they are not able to achieve it.

So what are the implications for mental health workers.? The diagnosis of FAS/ARND should be considered for those clients who have a history of secondary disabilities. Especially those diagnosed with chronic mental health problems.

The importance of making the correct diagnosis of course is that the FAS/ARND person needs to be handled in ways unique for that condition.
- which is another topic.

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