

Does Your Program or Practice Help or Hinder Those With Fetal Alcohol Spectrum Disorder?

By David Gerry

On the basis of a very common and invisible lifelong condition, this article summarizes four important ways a very large group of people currently attending addiction treatment services (having mixed results) might be better identified and served.

Five percent (May et.al. 2009) of 3,952,841 (Centers for Disease Control and Prevention) people born in the United States in 2012 have an invisible, permanent life-long and little-understood birth condition. Studies of 415 people with this condition (Streissguth et al, 1996 and 2004), found that as adults, 46 percent of those with this medical diagnosis have now, or have had, problems with drugs and alcohol.



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Yet, despite the fact that this birth condition is documented to be one of the most prevalent birth conditions in the western world AND such a high percentage of people with it are known (at least in some circles) to be vulnerable to addictions, when I sought an addiction treatment program that was *demonstrably* Fetal Alcohol Spectrum Disorder (FASD) informed, none were readily identifiable in a brief, one month search in North America. This search was prompted by a plea from a family in British Columbia (Canada) looking for an appropriate addiction treatment program for their adult child who has both a diagnosis of FASD and a serious addiction to crystal meth.

While there were prior articles in French, Fetal Alcohol Syndrome was first defined in an English language journal by two Seattle researchers (Jones and Smith) in 1973. Since then, the field of research into FASD has mushroomed to the point that the June 2013 edition of the Fetal Alcohol Forum (NOFASD UK) reported that in the six months prior to publication, there had been 146 research papers on FASD published in 29 countries around the world. In contrast, at the annual FASD conference in Vancouver in 2013, Dr. Claire Coles reported that there were *only* 25 published studies evaluating the true effectiveness of programs designed to support/change behaviors of people with FASD, and only a handful of studies about treatment outcomes for people with FASD. This means that studies on the effectiveness of programs and intervention outcomes across all types of conditions for people with FASD are so scarce as to offer few details for modifying existing programs or designing future addiction treatment programs.

Suggested Addiction Treatment Modifications

#1: Understand the Importance of Adaptive Functioning

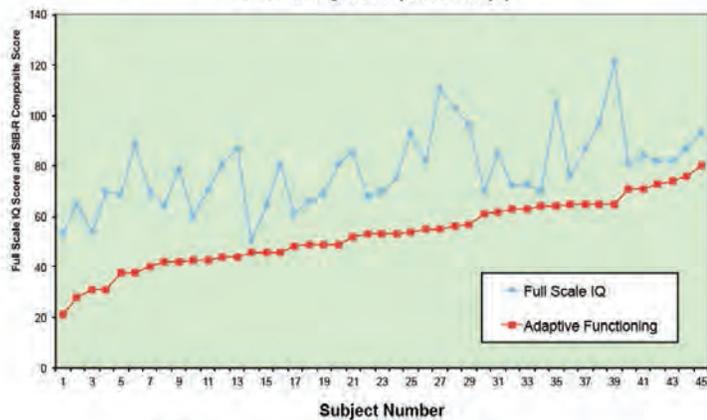
One very important and distinguishing feature of FASD (and Autism), when thinking about designing and evaluating addiction treatment services, is adaptive functioning.

Money could be used as a metaphor for the role of adaptive functioning in life. If money is a resource like intelligence, when well applied, it can improve the quality of lives. Yet, even if someone has a million dollars in their bank account (from winning the lottery), if they do not understand how banks operate and fail to make consistent mortgage or rent payments, they could face eviction despite having a seven figure bank account.

Consider a 10-year-old child with FASD (and normal intelligence) who falls from the same tree branch three times in two years. For a neurotypical child, one-trial learning would have kicked in after the first time they hit the ground and were completely winded on impact. For the child with FASD, the attractiveness of the frisbee on the tip of the branch prior to falls two and three overrode their memory of how painful the consequence of falling was.

Graph 1 is of IQ and adaptive functioning data from 45 clients of a neuropsychologist in private practice in Nanaimo, Canada. Since the cri-

Graph 1: Overall Cognitive Ability Level and Adaptive Behaviour Functioning Level (2003 study⁷)



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teria for services in many programs is IQ-based, not adaptive-functioning-based, many with FASD do not qualify for services they require. Note that based on adaptive functioning, 39 of these 45 subjects were at or below the 70th percentile, which means they fall within the developmental disability range.

Like the quintessential Buddhist concept of “living in the eternal present,” someone with FASD may repeatedly forget the consequences of a previous action. Which means (in the context of a treatment program), having a schedule that is consistent from day-to-day and posted in a prominent place can help people with FASD remember the order of daily/weekly programs. When thinking in detail about everything that is required for daily living to be successful in an addiction treatment program, imagine how navigating that daily schedule would be for you if it took you three trials before *you* learned not to go out on a tree branch tip 12 feet off the ground? For example, when providing a structured schedule to the person in treatment, you, as the counselor, are going to need to ensure that some kind of “reminder” process in place. For some, this could be as simple as a “reminder” application on their cell phone (that is properly programmed with appointments and tasks). For others, it may mean regular or periodic check-ins with a staff member.

#2: Understand that FASD may have a paradoxical (opposite) affect on the nervous system

A second noteworthy aspect of FASD to be considered when adapting addiction recovery programs so they are more “FASD informed/friendly” is an appreciation of how prenatal alcohol exposure can greatly sensitize the nervous system to subsequent drug consumption.

In a 2014 study using an animal model of prenatal alcohol exposure (PAE) (Urban et al, 2014), animals prenatally exposed to alcohol showed increased sensitivity to amphetamine compared to their control, non-alcohol-exposed counterparts.

The fact that with repeated exposure to amphetamine the PAE group became *more* responsive to the drug (i.e., showed sensitization to the drug) has important implications for our understanding of the addiction process and for delivery of addiction treatment services for those with FASD. What this means, for example, is that an FASD-informed addiction treatment program would have an FASD-aware healthcare professional who can provide appropriate advice regarding prescribing and

managing medication that addresses the underlying, and sometimes contradictory, reactions and responses that may be seen in this population.

#3: Consider all aspects of the treatment center environment

Environment is a third aspect of FASD to consider, when thinking about modifying an existing treatment program or starting anew. Since cells that are growing and changing in the fetus are the most susceptible to damage by alcohol in the womb and the brain and central nervous system are almost continuously growing and connecting all other systems, the developing brain is continuously vulnerable to the effects of alcohol. For example, some people may be very sensitive to the flicker of an overhead fluorescent light (subliminal to most of us) or the hum of an air conditioner. Filtering out those types of environmental distractions may heavily consume the energy of someone with FASD. This effect becomes very noticeable as the day wears on and they cannot effectively focus on group processes or concentrate on an individual conversation.

To find out how someone with sensory issues common in FASD might react in your treatment center, ask an occupational Therapist for an assessment of your setting. You could also follow the lead of an FASD charity on Vancouver Island (Canada) who developed a process whereby a team of young adults with FASD went to many different types of service agencies (i.e., police, hospital, social services, etc.) and did a formal ‘FASD friendly’ assessment of each service. For example, they would go through the process of being in a waiting area to receive services, filling out the required forms, and would evaluate what worked and what did not work. In their subsequent reports, they would detail their findings along with recommendations for appropriate changes to help make the services more inclusive of those with invisible disabilities, like FASD.

#4: Incorporate the Use of the New Life History Screening (LHS) Tool (Grant et al.2014)

Therese Grant et al have developed a structured screening instrument that can be incorporated into your intake protocol. The Life History Screening (LHS) tool is meant to help clinicians observe the pattern of responses within the context of screening for FASD.

Next Steps Needed

My search for an FASD-informed addiction treatment program in North America to help a late 20’s adult with crystal meth addiction and FASD revealed a huge gap in addiction treatment services. When asked how current addiction treatment programs work with those with invisible brain-based differences, all responses I received indicated a poor fit between underlying characteristics of FASD and program attributes and protocols. While there may be some appropriately FASD-informed addiction treatment programs in North America, they are not easily found. This means that of the nearly 200,000 people born prenatally alcohol exposed annually, the FASD research shows that 46 percent of these people (nearly 91,000) may have problems with drugs and alcohol at some point during their life (Streissguth et. al. 1996, 2004). Without an appropriately structured, FASD-informed addiction program, treatment results will continue to be mixed for this large, under-recognized population.

Four suggested starting points to design or modify an FASD-informed addiction treatment program are to understand:

1. The importance of adaptive functioning and how independent it is of IQ;
2. FASD may have a paradoxical or opposite affect on the nervous system;
3. How all aspects of the treatment center's environment can either help or hinder;
4. Use the new free Life History Screening (LHS) tool to use as part of your intake protocol.

A useful place to begin to address invisible, neurocognitive-based issues would be to ask a simple question like, "What if this client's brain is wired differently?"

For a practical way to assess how FASD-friendly your treatment facility is, download the 56-page manual called *Action For Inclusion: Making Community Environments More FASD Friendly*. Download a copy of the Life History Screening (LHS) tool. Get both these resources free from <http://LivingWithFASD.com/addiction>.

To learn more about FASD and addiction, check out this year's Living With FASD 2014 Summit, which features 24 interviews including six experts on FASD and addiction. Go to: <http://LivingWithFASD.com>

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David Gerry, BSc Biology and Psychology, began his intensive "home study" applied learning in the field of Fetal Alcohol Spectrum Disorder (FASD) as a direct result of becoming a foster parent to two children with FASD. In 2000, he co-founded a charity (The FASD Community Circle - Victoria) to develop programs and services for those with FASD. The Circle set up the first children's multidisciplinary FASD clinic on Vancouver Island, Canada, and also set up a multidisciplinary FASD clinic for at-risk women. Gerry is co-chair of the advisory committee of Herway Home, a comprehensive support program for pregnant and early parenting women who struggle with substance use. He also co-founded the international Living With FASD Summit.

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