Screening for Fetal Alcohol Spectrum Disorders:

A Critical Step Toward Improving Treatment Success

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"My son had motor reflex symptoms that led a neurologist to believe that he had a fetal alcohol spectrum disorder (FASD) at the age of seven. It took another 12 years to finally get a diagnosis of fetal alcohol syndrome (FAS). In the meantime, my son received multiple mental health diagnoses, including Attention-Deficit/ Hyperactivity Disorder, Reactive Attachment Disorder, and Oppositional Defiant Disorder. As these were misdiagnoses, the treatments were ineffective and, in some cases, harmful. He was in psychiatric hospitals several times and was in residential treatment, community living settings, day hospital programs, and vocational programs. None of these programs had any methods for recognizing FASD (much less modifying treatment in response to the diagnosis), thus his behaviors were viewed as willful, and he was labeled non-compliant, unmotivated, and uncooperative. He failed in every program in which he was involved. I knew that my son was at high risk for becoming homeless, getting into difficulty with the law, and dying. In fact, he did get into difficulty with the law, and he did die early because clinicians did not recognize his FAS and programs were not able to meet his needs. If there had been a screen available and routinely used in mental health and substance abuse treatment programs to identify adults with an FASD, and if all program staff were knowledgeable about treatment modifications that could improve outcomes, I believe my son would be alive today."

Dan Dubovsky, co-author

The issue of how to respond effectively to mental health and substance abuse disorders is recognized worldwide. In 1961 the United Nations introduced drug control policy recommendations "to pursue the early identification, treatment, education, aftercare, rehabilitation and social reintegration of drug abusers (article 38, paragraph 1)" (UNODC, 2012). The United Nations has resolved that "All persons have the right to the best available mental health care" and in 1991 adopted principles related to treatment provision (UNGAR, 1991). Millions of people who suffer from substance abuse and mental health disorders are now treated every year. In the United States alone, approximately 20 million adults received treatment for mental illness in 2012, and over 2.5 million people entered substance abuse treatment (NIMH, 2012; NIDA, 2011). While these statistics suggest that a large number of people are receiving treatment, the reality is that a high proportion of these individuals do not *complete* treatment (SAMHSA, 2012).

When clients are unsuccessful in completing substance abuse treatment, they tend to blame their providers, while providers often attribute the failure to clients' poor motivation. We suggest another possible reason for treatment disruption is that clients have unidentified conditions associated with neurocognitive deficits and learning disabilities that impair their ability to learn and benefit from treatment. Fetal alcohol spectrum disorders (FASD) are such conditions. FASD conditions are caused by prenatal alcohol exposure (PAE) in amounts sufficient to cause brain damage. Individuals with FASD cannot be identified by emblematic facial characteristics alone because in many cases these features are not present. However, all FASD conditions, including Fetal Alcohol Syndrome (FAS), partial FAS, and Alcohol Related Neurodevelopmental Disorder (ARND), involve similar neurodevelopmental problem profiles (Hoyme et al., 2005). These

common neurodevelopmental problems are due to underlying cognitive deficits (e.g., intellectual, attention, memory, sensory integration, executive functioning) that together reduce ability to attend to, process, store, retrieve, and apply information (Kodituwakku, 2007; Kodituwakku, Kalberg, & May, 2001). Based on research indicating that up to 5 percent of the United States population may suffer from an FASD (May et al., 2009) and at least a third of these individuals may have substance abuse problems (Streissguth et al., 1996), it is likely that a sizable number of people with undiagnosed FASD who enter substance abuse treatment programs each year have brain-based disabilities that significantly reduce their ability to benefit from typical treatment approaches. If so, screening for FASD at treatment intake is an important step toward individualizing treatment planning so as to maximize potential.

Overview of FASD Screening Measures

In a critical review of published screening measures that met World Health Organization screening criteria, Goh and colleagues (2008) described the essential attributes of a good screening test for FASD:

> "A good screening test must demonstrate both high sensitivity and high specificity. Sensitivity is the ability to correctly identify persons with the condition in the population who screen positive. Specificity is the ability to correctly identify persons without the condition in the population who screen negative. The higher the sensitivity and specificity reported, the greater the accuracy of the test. A reference standard (an alternative method

to determine the condition independent of the screening test) is required. At present, such a standard is not available for FASD other than a full diagnostic work-up." (p. E345)

Ideally, screening tools not only should be statistically reliable but also should be easy to administer so that clinicians and non-clinicians in a variety of settings could screen without needing extensive training. Most methodologies designed to screen for FASD involve informant-based protocols that ask caregivers, family members, and friends (or probation officers in the case of youth in the juvenile justice system) to rate or score individuals on life history, behavioral difficulties, and other factors associated with FASD. The first attempt to develop such a screen was the Fetal Alcohol Behavior Scale (FABS) (Streissguth, Bookstein, Barr, Press, & Sampson, 1998). Administered to caregivers and suitable for adults as well as children, the FABS demonstrated good psychometrics in research settings but has not been tested in clinical contexts where performance data would substantiate its usefulness (Boland, Burrill, Duwyn, & Karp, 1998).

The most widely published effort to develop an FASD screening tool is based on the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001). Researchers in Toronto (Nash et al., 2006) used factor analysis to identify a combination of 10 items that accurately separated children 6-13 years of age with FASD from two comparison groups (ADHD and typically developing children). The resulting neurobehavioral screening test (NST) is a simple checklist that can be administered by a health or social services professional to a parent or caregiver. In 2011, this research was replicated in a larger sample of children, including those with FASD, ADHD, ODD/CD, and typically developing controls (Nash, Koren, and Rovet, 2011). Study

results were corroborated: while children with FASD displayed poor attention and impulse control like those with ADHD, the FASD cohort exhibited relatively less remorse after misbehaving, relatively more cruel behaviors along with lying and cheating, and a greater tendency to act younger than their chronological age. These studies were subsequently replicated in Western Canada, where the NST again showed strong screening capability (LaFrance et al., 2014). The NST is now an official screening tool in the FASD toolkit of the Public Health Agency of Canada (2011).

There also have been efforts to develop screening tools in the youth justice population. For example, a screen developed by the Asante Centre for Fetal Alcohol Syndrome in Vancouver, British Columbia, to aid probation officers in identifying youth offenders at risk for FASD also is included in the FASD toolkit of the Public Health Agency of Canada. Like the NST, the Asante Probation Officer Tool is user-friendly and self-explanatory. Completed for all youth adjudicated on probation orders in the Vancouver area who are suspected of having FASD, the measure collects information on behavioral history, and referrals are made based on requisite combinations of environmental/social factors and neurobehavioral factors (Goh et al., 2008). Similar to other screening tools that have been developed for young offenders in other Canadian provinces, the Asante Probation Officer Tool has not yet been validated.

Impetus for Developing the Life History Screen

While information from unimpaired collateral informants may be more accurate than self-reported information from individuals with FASD, most treatment programs, and particularly

those for adults, do not involve such informants in the intake process for a variety of reasons. Using self-reported screening data from individuals who have FASD may produce inaccurate histories because of memory difficulties, suggestibility, executive function problems, and other cognitive deficits characteristic of the disorder (Brown, Gudjonsson, & Connor, 2011). Nevertheless, self-reported data often is the only available data at time of treatment.

As researchers, we observed that a subset of clients enrolled in our Washington State Parent-Child Assistance Program (PCAP) intervention struggled disproportionately with the learning and behavioral expectations of substance abuse treatment, and we surmised that their difficulties might be associated with alcohol-related brain damage. In the only study conducted to date that has examined FASD and treatment outcomes, we found that women with FASD and those with PAE/suspected FASD (N=86) had higher treatment failure rates than did women without PAE (N=463) (Grant, Brown, Graham, & Ernst, 2014). At the same time, in the course of training treatment program staff throughout the United States on the impact of FASD on their programs, co-author DD found that clinicians consistently asked this critical question: "How do we identify individuals in our program that may have an FASD?" Thus, in 2012 we developed, and began to test, the first self-report tool designed to quickly screen for brain-based difficulties such as FASD that might interfere with treatment: the Life History Screen (LHS) (Grant, Brown, Graham, Whitney, Dubovsky, & Nelson, 2013).

Construction of the Life History Screen (LHS)

In the FASD screening guidelines published by the Centers for Disease Control and Prevention (Bertrand et al., 2004), two domains appear appropriate for adult screening in cases involving either known or unknown PAE: social and family history and Central Nervous System (CNS) abnormalities. Regarding the latter, Boland and colleagues (1998) describe a general FASD behavioral phenotype for adolescents and adults: a mix of primary cognitive and neurodevelopmental deficits (e.g., memory, attention, executive function, adaptive behavior) and associated disabilities that could potentially be mitigated by treatment (e.g., easily victimized, unfocused and distractible, difficulty handling money, trouble understanding consequences and learning from experience, problems perceiving social cues, poor frustration tolerance, inappropriate sexual behavior, mental health problems, trouble with the law). Together, the screening guidelines suggested for the CDC (Bertrand et al., 2004) and behavioral phenotype described by Boland and colleagues (1998) provide the rationale for the 27 items included in the LHS. For each category of items selected for the LHS, at least four independent studies found an association between the category and FASD (see Table 1).

The 27 LHS items are carefully-worded questions that do not screen for FASD symptoms and impairments in an obvious way, thereby minimizing the effects of conscious or unconscious self-presentation bias in FASD and improving the odds of detecting actual cognitive impairment, even when a practitioner does not have a great deal of experience with this population. The LHS is designed as a structured screening instrument that can be embedded within a treatment program's existing intake interview protocol and administered by service providers and clinicians trained in implementation of the screen. The screen, which requires approximately 15 minutes to administer, should be introduced after client detoxification and as early as possible in

the treatment process in order to implement strategies that will help avoid treatment failure. The protocol for administration is described in the published paper. Based upon self-report, LHS questions are framed within the context of a client's customary behavior. Thus, in the case of clients presenting for substance abuse treatment, "customary" would not include behaviors that only manifest while under the influence of alcohol or drugs. Although clinicians may have reservations about asking clients to divulge personal information and family history, fearing that if such probing is too intrusive it might negatively impact the therapeutic relationship, we have found that when the need for such questioning is explained non-judgmentally and with compassion, clients usually respond positively and candidly.

Establishing LHS Psychometrics

As a first step in determining the utility of the LHS for screening adults, we conducted a pilot study using data derived from clinical records of women enrolled in the Parent-Child Assistance Program (PCAP), an intervention program in Washington State for high-risk women who abuse alcohol and/or drugs during pregnancy. (See study details in Grant et al., 2013). As part of standard PCAP intake protocol, the widely used Addiction Severity Index interview instrument (ASI) (McLellan et al., 1992; Mäkelä, 2004) was administered to participants. Eleven ASI questions correspond to items on the LHS, and we subjected these eleven items to preliminary statistical analysis to assess their potential utility in identifying adults with possible FASD. The 27-item LHS itself was not administered to participants in this study because it had not been developed at the time the women were enrolled in PCAP. Thus, data are not available for LHS items that do not have corresponding variables on the ASI (e.g., specific problems in school).

Study participants (N=549) included 463 women who had no PAE (Group 1) and 86 who had FASD or PAE with suspected FASD (Group 2). Research findings indicated that women in Group 2 had significantly higher rates of endorsement of nine of the eleven ASI/LHS items compared to Group 1, including: childhood history/raised by someone other than their biologic parents (64.0% vs. 26.4%, $p < .001$); maternal alcohol use/client's mother had a problem with alcohol (79.8% vs. 29.9%, $p < .001$) and mothers drank during their childhoods (89.5% vs. 37.7%, $p < .001$); education/10th grade education or lower (48.8% vs. 33.3%, $p < .01$); substance use/client began using alcohol or drugs before age 12 (47.0% vs. 28.1%, $p < .001$); employment/longest full-time job was less than 12 months (72.1% vs. 48.6%, $p < .001$); mental health/more than one psychiatric diagnosis (30.2% vs. 13.8%, $p < .001$), suicide attempt (45.9% vs. 31.7%, $p < .01$), and day to day behaviors/history of trouble concentrating (78.8% vs. 52.7%, $p < .001$). There was no difference on the item "one or more arrests (and charged) since age 18" (76.5% [354/463] vs. 76.5% [65/86], ns), a finding due to the high base rate of arrest in the study sample (overall, 76% reported prior incarceration, with a mean of 5.6 arrests). Results of the receiver operating characteristic analysis suggested the cut-point with the most favorable balance of sensitivity and specificity was a score of ≥ 5. At this cut point, these 11 LHS items had a sensitivity of 81% and a specificity of 66%, with 68% of cases correctly classified.

These results suggest promising psychometric properties, but additional prospective studies are needed to further validate the LHS instrument. In particular, to determine the LHS overall classification accuracy, sensitivity, and specificity as well as determine optimal cut-points for

programmatic purposes, it will be necessary to test the LHS against a formally established criterion (namely, results of FASD diagnostic evaluation).

Treatment Modifications

The most important reason to screen for the possibility of FASD is to use that information to inform and modify therapeutic approaches that will improve the potential for treatment success. Our research group has published treatment recommendations that are based on scientific understanding of areas of the brain affected by PAE, the behavioral manifestations of that brain damage, and our clinical experience in interviewing and treating individuals with FASD (Grant, Novick Brown, Dubovsky, Sparrow, & Ries, 2013). Additionally, given that people with FASD have five times greater risk for suicide attempt than those in the general population, we have described the clinical profiles of a sample of people with FASD, identified their suicide risk and protective factors, and made recommendations for reducing suicide attempts among people with FASD (Huggins, Grant, O'Malley & Streissguth, 2008). We have emphasized the utility of administering neuropsychological assessments to individuals with PAE and possible FASD and illustrated how results have been used to help multidisciplinary teams respond effectively to affected individuals (Sparrow, Grant, Connor & Whitney, 2013).

Functional treatment approaches used successfully in the fields of special education and cognitive rehabilitation are relevant to individuals with FASD. These approaches include making the environment more user-friendly by using checklists, visual cues, color coding and labels; using notebooks and technology to aid memory; and training family members and service

providers to use these accommodations in order to enhance autonomy and independence (Hutchinson & Marquardt, 1997; Watson & Westby, 2003; Weinberger, Dolan, & Dolan-Templeton, 2009; West & Niemeier, 2005).

The Substance Abuse and Mental Health Services Administration (SAMHSA) has recently published a Treatment Improvement Protocol (TIP) #58, entitled "Addressing Fetal Alcohol Spectrum Disorders" (SAMHSA, 2014). This document offers best-practices guidelines based on an evidence base of scientific research findings and clinical practice theory and principles and includes appropriate counseling strategies, program recommendations, and an extensive literature review.

Motivational Interviewing (MI) deserves special mention as it has been touted (not always accurately) as a treatment strategy that might be used effectively with people who have FASD. MI, which is based on stages of change theory, was developed by Miller and Rollnick not as a technique but as a way of thinking and approaching behavior (Miller & Rollnick, 1991; Prochaska & DiClemente, 1986). MI differs from many other treatment approaches in that if a client demonstrates resistance, this signals that he/she and the therapist are not at the same stage of change. The therapist's response in MI is to "roll with the resistance" instead of attempting to "break through the resistance" by providing facts and pointing out discrepancies between the client's intentions and his/her current behavior. The client then takes this information and thinks about how it affects his/her life. Traditional MI is an entirely verbal brief intervention in which the individual is expected to do most of the work independently between sessions.

For individuals with FASD, the traditional MI concept often will not be useful. Individuals with FASD have impairments in verbal receptive language processing, short-term memory, and executive functioning, all of which are essential for motivational interviewing to be effective. For example, as typical MI strategies are verbally presented, individuals with impaired verbal receptive language processing skills will have difficulty understanding the information presented, processing what it means personally, and identifying what they might do differently. In addition, as MI relies on ability to remember what was discussed in the brief sessions and think about that information between sessions, problems with working memory and generalizing will impair the ability of the person to follow through with those tasks.

This does not mean that MI cannot be utilized with individuals who have FASD. The concept of stages of change is a very powerful one, and the strategies developed for use in MI may be particularly effective if modified, taking into account the brain damage that we most frequently find in FASD. Typically, MI for these individuals would be a more lengthy approach with all of the work, including behavioral practice and rehearsal, being done between the client and the therapist during sessions. In addition, the opening strategies in MI such as "The Good Things and Less Good Things" about a behavior could be modified so that they are completed visually over several sessions rather than just verbally. Thus, incorporating MI into work with individuals who have FASD can be very effective if such a strategy is modified in a way that recognizes their altered cognitive processing and is implemented with patience and an eye towards identifying and building on strengths and abilities.

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Table 1.

Life History Screen (LHS). Note: "Red flag response" indicates risk of possible cognitive impairment.

Life History Item	**Red Flag Response**	**Basis for Screening Factor (Source)**
Childhood History		• Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004 • Löser, Bierstedt, & Blum, 1999 • Streissguth et al., 1991 • Streissguth, Barr, Kogan, & Bookstein, 1996
Were you raised by someone other than your biologic parents? [a]	(yes)	
How many living situations did you have while you were growing up (up to the age of 18)? *Prompt: living with your parents, relatives, foster homes, juvenile justice, etc.*	(more than 2)	

Maternal Alcohol Use	**(Red flag response)**	• CDC, 2004 • Jones & Smith, 1973 • Jones, Smith, Ulleland, & Streissguth, 1973 • Streissguth et al., 1991
Did your mother ever have a problem with drinking alcohol? [a]	(yes)	
Did she drink alcohol when you were young? [a]	(yes)	
Did she drink alcohol while she was pregnant with you? *Prompt: "Has anyone ever said anything to you about your mother's drinking? Is there anyone around who knew your mother when she was pregnant with you?"*	(yes)	

Education	**(Red flag response)**	• Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004 • Löser, Bierstedt, & Blum, 1999 • Spohr, Willms, & Steinhausen, 2007 • Streissguth, Barr, Kogan, & Bookstein, 1996
What's the highest grade in school you completed? [a]	(10th or lower)	
If you didn't finish school, why did you leave?	(too hard, bored, got kicked out, or another reason)	
Were you ever in "special ed" or did you get any kind of special help in school?	(yes)	
Criminal History	**(Red flag response)**	• Mattson & Riley, 2000 • Roebuck, Mattson, & Riley, 1999 • Streissguth et al., 1991 • Streissguth et al., 2004
Were you ever arrested? [a]	(yes)	

Substance Use	**(Red flag response)**	• Alati et al., 2008 • Baer, Barr, Bookstein, Sampson, & Streissguth, 1998 • Baer, Sampson, Barr, Connor, & Streissguth, 2003 • Barr et al., 2006
In what grade (or at what age) did you start using alcohol or drugs? [a]	(before age 12, or alcohol/ drug use began after school problems started)	
Employment and Income	**(Red flag response)**	• Famy, Streissguth, & Unis, 1998 • Spohr, Willms, & Steinhausen, 2007 • Steinhausen, 1996 • Streissguth, Barr, Kogan, & Bookstein, 1996
What's the longest time you've worked at the same job? [a]	(less than one year)	
Have you ever received state disability income? [a]	(yes)	

Living Situations	**(Red flag response)**	• Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004 • Löser, Bierstedt, & Blum, 1999 • Spohr, Willms, & Steinhausen, 2007 • Streissguth, Barr, Kogan, & Bookstein, 1996
As an adult have you ever lived on your own (paying your own rent, etc.)?	(no)	
Mental Health	**(Red flag response)**	• Astley, Bailey, Talbot, & Clarren, 2000 • Huggins, Grant, O'Malley, & Streissguth, 2008 • O'Connor & Paley, 2009 • Roebuck, Mattson, & Riley, 1999 • Spohr, Willms, & Steinhausen, 2007
Other than a substance abuse disorder, what kinds of mental health disorders have you been told you have? [a]	(more than one)	

Have you ever tried to commit suicide? [a]	(yes)	
Day-to-Day Behaviors	**(Red flag response)**	• Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004 • Hellemans, Sliwowska, Verma, Weinberg, 2010 • Kodituwakku, Kalberg, & May, 2001 • Mattson, Goodman, Caine, Delis, & Riley, 1999 • Streissguth et al., 1998
Do you often have difficulties with any of the following?		
▪ Concentrating and paying attention [a]	(yes)	
▪ Understanding what others are telling you	(yes)	
▪ Remembering things	(yes)	
▪ Following rules and instructions	(yes)	

▪ Getting along with others, arguing, or fighting	(yes)	
▪ Being on time	(yes)	
▪ Keeping enough money to last you throughout the month	(yes)	
▪ Doing things that later you wish you hadn't done	(yes)	
▪ Getting upset at little things	(yes)	
▪ Forgetting or missing appointments	(yes)	
▪ Being surprised when you get into trouble	(yes)	

[a] Data on this item was available from the Addiction Severity Index.