

Fetal alcohol spectrum disorder (FASD): A beginner's guide for mental health professionals

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ABSTRACT

Fetal Alcohol Spectrum Disorder (FASD) is a life course persistent disorder caused by prenatal alcohol exposure. This disorder, affecting millions of Americans, can feature a diverse range of impairments in cognitive (e.g., executive control), social (e.g., communication skills), and adaptive (e.g., problem-solving skills) functioning. These impairments are often accompanied by co-occurring mental illness (e.g., mood disorders), behavioral disorders (e.g., ADHD), substance use, traumatic brain injuries, and developmental disabilities. The presence of these co-occurring conditions creates significant

challenges for mental health professionals in terms of screening, assessment, differential diagnosis, and treatment. The key to maximizing the effectiveness of care for clients requires treating each individual's unique risks and needs in an integrated service delivery framework. Unfortunately, there is typically a lack of expertise in FASD among mental health professionals, which can only be resolved by the increased availability of advanced education and training programs on FASD. To increase awareness of these needs and FASD in general, this article provides general information on the definition and symptoms of FASD, the screening and assessment of FASD, adaptive functioning and memory-related considerations of FASD, and the treatment of FASD.

Key Words: FASD; Mental health professional; ND-PAE; Assessment; Intervention; Treatment

FETAL ALCOHOL SPECTRUM DISORDER (FASD)

Fetal Alcohol Spectrum Disorder (FASD) affects the lives of millions of individuals in North America, with researchers estimating prevalence rates of 2% to 5% of the population in the United States (1,2). This serious and complex disorder is characterized by a range of deficits stemming from prenatal alcohol exposure (3,4). Accompanied by a diverse set of neurological issues such as abnormal development of cells and nerves along with neurotransmission issues, this disorder can feature impairments in cognitive (e.g., executive functioning, memory, and disinhibition), social (e.g., verbal and non-verbal communication skills), and adaptive (e.g., decision-making and problem-solving skills) functioning (5-15). Often accompanying these impairments are psychosocial stressors like educational, work, financial, legal, and relationship issues (16-20). Not only are these signs and symptoms similar to many mental illnesses, but FASD is often comorbid with a vast array of psychiatric disorders including mood (e.g., depression and bipolar disorder), psychosis (e.g., schizophrenia), developmental (e.g., autism), personality (e.g., antisocial personality disorder), behavioral (e.g., conduct disorder), and attachment (e.g., reactive) disorders (21-25). As a result of this overlap of symptoms and comorbidity, the screening, assessment, and diagnostic processes can be complicated, resulting in individuals with FASD often going undiagnosed or receiving inaccurate mental illness diagnoses like ADHD (26-28). To ensure accurate diagnosis, a battery of psychological and neurological tests is necessary. When FASD is not identified, treatment is likely to be ineffective, resulting in a host of short- and long-term consequences for the client. To better understand why diagnosis is complicated and why misdiagnosis is all too prevalent, mental health professionals are encouraged to seek out additional education and training related to the comorbid conditions associated with FASD as well as ways to reduce misdiagnosis.

The diverse symptoms and needs of individuals with suspected or confirmed cases of FASD typically necessitate specialized services from mental health inpatient and outpatient providers. Problematically, mental health care providers often lack advanced training and expertise necessary to provide effective services to individuals with FASD. As such, it is strongly

recommended that mental health professionals seek out and attend continuing education that improves understanding, assessment, treatment, and case supervision of FASD. To increase awareness of these needs, this article provides general information on the definition and symptoms of FASD, the screening and assessment of FASD, executive and adaptive functioning and memory-related considerations of FASD, and the treatment of FASD.

DIAGNOSTIC CRITERIA

Although an historical consensus on a definition has been absent, Fetal Alcohol Spectrum Disorder (FASD) has typically functioned as an umbrella term for disorders characterized by damage resulting from prenatal alcohol exposure (Benz, Rasmussen, & Andrew, 2009). Fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD) have all been generally included within this family of disorders. For example, Stratton, Howe, and Battaglia (1996) stipulated that five different conditions composed the family of disorders, but did not identify criteria for any of these conditions. In Canada, diagnostic guidelines focus on FASD with and without facial features (29). Alternatively, the Centers for Disease Control and Prevention (CDC) identify specific criteria, but limit their focus solely to FAS. However, the CDC is in the process of working with key stakeholders to provide diagnostic criteria for other disorders that fall under the FASD umbrella. As a result of this lack of consensus, there has been no universal list of FASD symptoms.

To address this lack of diagnostic clarity, the recent Diagnostic and Statistical Manual-5th Edition has introduced the specific designation of Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure (ND-PAE) as an option under "Other Specified Neurodevelopmental Disorder" (30). Based on a growing body of evidence (31), ND-PAE is defined by neurocognitive, self-regulation, and adaptive functioning deficits that result from prenatal alcohol exposure, but does not require physical symptoms like facial malformations (32). Beyond symptoms, the basis of this diagnosis is confirmation of prenatal alcohol exposure from official

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documentation, self-report, or clinical observation (33). At this point, ND-PAE is listed as a "condition in need of further study" and is not yet ready to be employed for diagnostic use at this time (34).

In the meantime, individuals with FASD continue to require medical diagnosis to receive clinical acknowledgment and treatment for their condition, which can be difficult to obtain. Therefore, a multidisciplinary diagnostic approach is recommended when feasible (35). It is speculated that an inevitable refinement of new diagnostic criteria will allow mental health professionals the opportunity to diagnose ND-PAE in the absence of specific medical input. Nonetheless, ND-PAE holds promise improving the recognition and identification of prenatal alcohol exposure and help improve the case management and treatment of individuals with this affliction (34,36).

DISTINGUISHING PRIMARY AND SECONDARY DISABILITIES OF FASD

Comorbidity is the norm in clients with FASD. In fact, some estimate that as many as 90% of individuals with FASD have a co-occurring disorder (20,23,24). As such, it is imperative that mental health professionals distinguish between the primary and secondary disabilities of FASD to limit the likelihood of FASD being misdiagnosed as comorbid conditions (Streissguth et al.). Primary disabilities refer to the impaired mental functioning that directly results from prenatal alcohol exposure. Some examples of primary disabilities include cognition (e.g., executive functioning and memory), social skills (e.g., verbal and non-verbal communication), adaptive behavior (e.g., problem solving and decision making, and daily living skills), achievement (e.g., learning disorders), attention/hyperactivity (e.g., disinhibition), and motor skills (e.g., balance and coordination). Secondary disabilities can include mental illness (e.g., mood disorders), behavioral disorders (e.g., Attention Deficit/Hyperactivity Disorder (ADHD), Conduct Disorder (CD), and Oppositional Defiant Disorder (ODD)), substance use disorders, traumatic brain injuries, and developmental disabilities (33,37-41). Alternatively, secondary disabilities could include legal issues, employment problems, academic difficulties, and dishonesty (33,42). This latter group of secondary disabilities is often caused by a combination of inadequate support systems and difficulty learning and following rules. The impact of these secondary disabilities can be mitigated with appropriate levels of structure, consistency, and support at home and in school beginning in childhood (37,43,44). This emphasizes the need to work with families and teachers to ensure the best outcomes for children with FASD (45). Any child involved in community systems should have team members notified of these needs. Further, mental health professionals must develop a working familiarity with the overlapping conditions and behaviors associated with FASD along with typical comorbid disorders.

SCREENING AND ASSESSMENT OF FASD

Screening, assessing, and differentially diagnosing FASD is a difficult task (46). Why is FASD so hard to identify? There are at least five reasons. First, physical malformations are often not present (47). Even when physical symptoms of FASD are present during childhood, these features typically fade as the child ages into adolescence and adulthood, making accurate diagnosis less likely later in life. For example, research has found that only 10% of individuals with FASD exhibit facial feature abnormalities and as a child ages these facial features fade into adulthood (48,49). As a result, the identification of FASD tends to be easier for more severe cases where visible growth delay and craniofacial anomalies are present than less severe cases where these visible indicators are not present (50). In short, when physical features are absent, individuals with FASD are often overlooked.

Second, there is a dearth of screening and assessment instruments for FASD. Going forward, instruments must be developed and validated for use in individuals with FASD. Until then, the reliability and validity of existing screening and assessment instruments that were developed for individuals without FASD must be explored in individuals with FASD to ensure the appropriateness of their use. This is particularly true of screening and assessment instruments for use in adults, where this problem is most salient.

Third, standardized intelligence tests often do not detect the cognitive deficits of FASD (47). Although FASD is a common cause of intellectual disabilities (previously termed mental retardation), many individuals with FASD test in the average and, in some instances, the above average range on intelligence tests (20,51). Even in instances when intellectual capacities are not diminished, cognitive deficits are usually present (e.g., learning disabilities and deficits in executive functioning), which limits an individual's ability to perform everyday tasks. As such, it is imperative that mental health

professionals employ neuropsychological assessments and systematically evaluate a client's educational history and adaptive functioning rather than relying exclusively on intelligence tests (3,52,53).

Fourth, individuals with FASD often have short- and long-term memory issues (54,55). To complicate matters, individuals with FASD also are prone to suggestibility (i.e., a tendency to adopt the views and statements of others as truth) and confabulation (i.e., creating false memories) (56-59). These memory issues draw into question any information self-reported by an individual with FASD. Therefore, mental health professionals should avoid relying solely on self-reported information in favor of obtaining collateral information from official records, family members, and other professionals who are familiar with the individual whenever possible.

Fifth, confirmation of prenatal alcohol exposure is difficult to obtain, particularly in adults. This information is usually not included in official records, which often contain gaps in the individual's history (60,61). Further, the birth mother is typically not in the life of the client. This is only complicated by the fact that adoption and placement in foster care are common to the histories of individuals with FASD. Even when available for interview, mothers are reticent to admit such an exposure because of shame and fear of legal consequences. As a function of these challenges, official confirmations of prenatal alcohol exposure are rare, contributing to characterizations of FASD as a "hidden disability" (Page, 2001).

As a function of this difficulty, FASD is believed to be significantly under-identified in many mental health settings and frequently goes undetected and misdiagnosed well into adulthood. The lack of viable FASD screening and assessment tools for use in children, adolescents, and adults contributes to this failure of identification (61-65). One result of the failure to accurately identify FASD is the fact that individuals with FASD who present with no physical symptoms or facial feature abnormalities may be viewed negatively (e.g., lazy, manipulative, or malicious) or held to a higher standard of behavior in treatment and legal settings than those who exhibit the physical symptoms of the disorder. Further, those not accurately identified are often subjected to inappropriate pharmacological therapies and treatment techniques. Implementation of such therapies and techniques may not help the individual and can potentially lead to iatrogenic effects in some cases. Some of these harmful effects could include the exacerbation of education, work, family, peer, and substance use problems.

To address these and other issues, steps can be taken to improve the screening, assessment, and diagnosis of FASD. Foremost, mental health professionals must first develop a working knowledge of the disorder's cognitive, social, and adaptive impairments. As is, there is a lack of mental health care professionals with expertise in FASD (61). Once familiar with the disorder, professionals should incorporate questions about FASD into their screening and assessment protocols. Additionally, red flags can help identify individuals who should be evaluated for FASD (66). For example, out-of-home placements and foster care, chemical dependency, criminal justice involvement, sexual issues or inappropriate sexual behaviors, school issues, psychiatric hospitalizations, immature social behavior, and short physical stature may all present in clients with FASD (20,22,56,67). To improve the odds of detection, professionals should review the client's full case history when possible and gather collateral information from sources other than the client such as official records (e.g., educational, medical, social services and criminal history) and interviews with the client's family and friends. This process may require several appointments because clients with this disorder often employ a diverse collection of strategies to mask their disorder and symptoms. It will likely be necessary to work with a multidisciplinary team of professionals throughout this process, including psychologists, neuropsychologists, physicians, speech-language clinicians, education, and occupational professionals. When evidence suggests that FASD may be present, the utilization of advanced psychological and neurological testing is recommended to ensure accurate diagnosis (50).

After FASD is identified, mental health professionals are in a better position to develop case management and treatment plans and a strong support system for the client (22,68,69). The importance of screening is pronounced in individuals involved in the criminal justice system. Here, the symptoms of FASD can impede an individual's capacity to navigate the criminal justice system from investigations and trials to custodial and community supervision. Not only can accurate screening limit the likelihood of miscarriages of justice, but it can help ensure that clients receive treatment and services that truly address their risk factors and needs. It is important that mental health professionals develop expertise regarding all aspects of FASD and then use their training and knowledge to educate the lawyers, judges and juries in

FASD related cases. In most instances, lawyers, judges and jurors at best have an imperfect understanding, and at worst no understanding of FASD and how prenatal alcohol exposure can impact human behavior (70-73).

EXECUTIVE FUNCTIONING CONSIDERATIONS

One of the most common symptoms of FASD is executive functioning deficits (74,75). These cognitive processes include the capacity to regulate attention, affect, and impulse (76,77). Further, executive control allows an individual to integrate newly obtained information with memories, make decisions, solve problems, and link behaviors to their consequences. Deficits in executive functioning can contribute to poor behavioral decisions and social judgment (22,51,59,67). As a result, individuals with executive function impairments often become involved in the criminal justice system. Executive function deficits can negatively affect an individual's ability to navigate the criminal justice system. For example, these deficits may limit an individual's competency to stand trial, including participating meaningfully in the defense or behaving inappropriately during court proceedings (58,78). As such, mental health professionals should incorporate the careful and thorough assessment of executive functioning during any competency evaluations for individuals with FASD and as part of any follow-up treatment ordered by the court (58,78). The importance of this practice is emphasized by the fact that behavior related to executive functioning deficits is often misinterpreted as malicious by jurors and judges, which can result in severe sanctions. Within a mental health treatment capacity, when deficits associated with executive functioning are not properly evaluated and recognized by mental health professionals, the impacted individual with FASD may receive an inaccurate diagnosis that can result in the creation of an ineffective treatment plan. This will usually result in the individual being unable to successfully complete treatment. Better recognition and understanding of executive functioning impairments by mental health and criminal justice professionals have the potential to improve long-term outcomes for individuals impacted by FASD.

ADAPTIVE FUNCTIONING CONSIDERATIONS

Individuals with FASD often struggle with adaptive functioning deficits (41,79,80). Adaptive functioning can be characterized as learned skills that can be conceptual, social, or practical in nature. These skills are necessary to meet the expectations and standards for everyday life such as employment and independent living (81,82). Without these skills of communication and socialization, individuals with FASD often struggle to maintain social responsibility and personal independence and require external support (10,19,83).

Research indicates that adolescents and adults with FASD have the adaptive skill functioning of a 7-year-old (84). Other research suggests that individuals with FASD and individuals with intellectual disabilities have comparable levels of adaptive functioning (84,20). Further, relative to children with ADHD, children with FASD do not improve with time in the area of adaptive skills (85). In fact, research indicates that adaptive deficits worsen as a child matures into adolescence and adulthood (20,84-88) which may be the result of limited frontal lobe development during childhood (24,89).

As such, assessment of adaptive functioning is critical in individuals with FASD. Adaptive functioning skills are commonly assessed with tools like the Vineland Adaptive Behavior Scales, but it is important to remember that these instruments were not developed for individuals with FASD (39). As a result, mental health professionals also frequently turn to intelligence measures. This is problematic because adaptive functioning deficits do not necessarily correlate with intelligence measures (10,84-91). For example, despite having an average IQ score of approximately 80, individuals with FASD demonstrate the adaptive functioning of individuals with IQ scores in the range of the 60s and 70s (81,85,89,92,93). Such a large difference between IQ scores and adaptive functioning is commonplace among individuals with FASD (20,41,84,87). Improved assessment options in this area are critical.

MEMORY PROBLEMS, SUGGESTIBILITY, AND CONFABULATION

Although there has been little empirical research on the topic, the cognitive deficits and impairments of FASD, particularly in relation to memory, may confer a risk for suggestibility and confabulation (56-59). Suggestibility can be defined as an individual's propensity to alter an existing memory or create a new memory in an effort to adopt someone else's views as the truth (94-96). Traditionally, the risk of suggestibility is higher in children and adults with developmental and cognitive disabilities, but is not dependent on

intellectual functioning (59).

In contrast, confabulation happens when someone unintentionally resolves a memory gap by filling in missing information with an inaccurate or false memory (32,97,98). This inaccurate memory could be something that occurred at another point in time or be entirely imagined or fabricated (54). Such confabulations can take the form of slight alterations in memory or a grand invention of a new event. Regardless, confabulation is done with no intent to deceive or mislead (99,100). Although the etiologies of suggestibility and confabulation are not firmly understood, these phenomena are common among individuals with FASD (56-59).

When present, suggestibility and confabulation can have devastating consequences on communication, particularly in high stress settings. For example, reliance on repetitive questioning and negative feedback during interrogations increases the likelihood of suggestibility and confabulation, which can result in false confessions and ultimately wrongful convictions (17,59,101). Similarly, repetitive and complicating lines of questioning during assessments in mental health treatment settings can elicit inaccurate self-reported information that can contribute to missed diagnosis and misdiagnoses. Suggestibility and confabulation also may predispose individuals to manipulation (37) increasing the risk for criminal misconduct (22,59). In light of these consequences, mental health professionals are encouraged to carefully consider the potential for suggestibility and confabulation when choosing communication tactics as well as screening, assessment, intake, and treatment planning for individuals with FASD.

TREATMENT AND INTERVENTIONS

The cognitive, social, and adaptive impairments of FASD in combination with other mental health issues may hinder the ability to benefit from treatment (102). In fact, FASD is highly comorbid with trauma, substance use, sleep concerns, and other mental and developmental disorders (20,76,102,103). For example, FASD is likely prevalent in clients entering substance use treatment (102). Relative to individuals without prenatal alcohol exposure, individuals with prenatal alcohol exposure have been linked to higher rates of alcohol and drug problems in adolescence and adulthood (20,104-106). Nonetheless, there is a lack of research on the impact of FASD on substance use treatment participation and completion (107). To limit complications from comorbid psychopathology, mental health professionals working with FASD-affected individuals should understand the complexities associated with treating comorbid substance abuse problems and they should routinely employ FASD screening to inform the selection of treatment options (107).

Prior to starting treatment, mental health professionals should be prepared to face a number of challenges when treating FASD. For example, individuals with FASD often have difficulty comprehending information, following directions, and applying information from treatment to the real world (33,78,96,107). Nonetheless, there are a number of steps that professionals can take to maximize the effectiveness of treatment. First, professionals should speak with clients in specific, concrete language and use role-plays and other forms of communication when possible (44,73,108). Colloquialisms and idioms should be avoided to limit potential confusion. Instead, direct statements and specific step-by-step directions offer the most promise. Because the social deficits of FASD can result in limited communication abilities, these steps are important to successful communication with the client (72). Second, learning and memory deficits often necessitate that professionals employ repetition (109,110). In fact, professionals should frequently verify whether the client has retained information. Consistency is essential during the process of repeating information, which has the potential to be most powerful when the repetition is employed across different settings and situations. This can help the client learn how to generalize knowledge from one situation to another or link cause and effect. Third, individuals with FASD may have sensory stimulation sensitivities (e.g., sensitivity to sound or touch), which may result in affective dysregulation and impulsive behaviors (103,111). Professionals must account for this when developing treatment plans, and ensure this does not prevent the client from receiving the treatment that is needed. Fourth, individuals with FASD tend to demonstrate a stronger capacity to learn in stable environments with minimal change. This helps minimize anxiety, which can distract from the therapeutic process. Fifth, individuals with FASD often have adaptive functioning impairments that limit their ability to keep up with everyday responsibilities (10,19,83). One way a mental health professional can assist is by helping the client improve organizational and time management skills.

The context of treatment is an important consideration when it comes to FASD. Specifically, individuals with FASD may find more success with

treatment in structured inpatient settings or individualized outpatient treatment settings that are FASD-informed (102,107). Generally, longer term programs with opportunities to practice skills on a consistent basis are a potential source of success for FASD individuals. Part of the reason for this success may be due to the limits in decision making placed on the client in this setting. In particular, treatment programs that utilize skill building, modeling, and coaching hold the most promise for clients with FASD. In contrast, individuals with FASD may struggle in treatment settings where intact executive functioning skills like the ability to plan and organize are integral to success. Further, the language processing deficits of FASD (12,25) may limit the viability of group therapy and 12-step programs. The key may be longer term options with intensive hours spent focusing on these goals. As such, when residential treatment is not an option, ensuring adequate structure for the client is essential (44).

Expanding this consistency beyond therapeutic settings to the client's home life can only help with the application of new skills. As such, an important step for professionals will be working with the client's family members and other members of their social support system. These support system members should receive instruction in the development of coping skills and training in how to best interact with the client. Once family and friends are prepared, these individuals can play a key role in ensuring consistency from a therapeutic setting to home. This could take the form of developing reminders (e.g., hand gestures or verbal commands) that can be used in everyday life to help the client remember coping techniques. Such reinforcement leads to the development of strong behavioral habits.

The cognitive, social, and adaptive deficits of FASD can present challenges in traditional psychotherapy, cognitive-based therapy, insight-based therapy, and outpatient settings that lack an understanding of FASD. Adopting trauma- and attachment-informed therapeutic approaches and stress reduction techniques may ultimately be fruitful for individuals with FASD. Other things that warrant consideration in the treatment plan could be developmentally appropriate interventions (e.g., play therapy or art therapy), sexual education, safety education, sleep improvement techniques, and the development of social, emotional, and behavioral regulation skills (44,103,110). Throughout this challenging treatment process, care providers must remain patient. Expectations also should be adjusted to account for the client's developmental level, propensity towards frustration, and other needs. This will likely require allowing plenty of time for the client to respond to questions and complete therapy-related tasks to avoid feelings of frustration and being overwhelmed. Further, professionals should reconsider how treatment compliance and success are defined. Because participation and attendance are often limited by the symptoms of the disorder, professionals should allow leeway as the client adjusts to the confines of therapy. Ultimately, the professional will need to adjust the definition of therapeutic success to focus on enhancing strengths and minimizing the impacts of deficits rather than curing them.

Although there is no standardized set of treatment techniques and strategies that can cure a life course persistent disorder like FASD, the key to maximizing outcomes for clients with FASD lies in treating each individual's unique risks and needs in an integrated service delivery framework. This requires forging a network of cooperation, collaboration, and consistency among the different professionals and caregivers involved in the client's life. Together, this group can help teach and reinforce the knowledge and skills learned in treatment and monitor the use of medication. Cooperation among this group is imperative to ensuring all of the client's diverse needs are addressed. Unfortunately, successful treatment does not mean that clients with FASD will no longer need monitoring and treatment going forward. Clients often require on-going assistance with decision-making, for example, and thus require supervision and support even after treatment has been completed. That said, early identification and treatment offers the best prognosis for clients with FASD (67,69,112,113).

CONCLUSION

Mental health professionals can play a crucial role in the identification and treatment of individuals with FASD, a lifelong disorder characterized by a complicated set of cognitive, social, and adaptive symptoms. Although prevalence rates of FASD suggest that mental health professionals are likely confronted by the disorder on a regular basis, proper identification of FASD can be difficult for a number of reasons (114-118). First, FASD can present with a wide-ranging constellation of symptoms, sometimes in the presence of physical features and sometimes not. Second, this task is often confounded by secondary disabilities and/or comorbid characteristics that are often related to cognitive functioning in FASD-affected individuals. Third, there is

a lack of established FASD-specific screening and assessment tools. Fourth, the impairments (e.g., executive functioning, short- and long-term memory and adaptive functioning) of FASD complicate the assessment process, casting doubt on any information provided by the individuals. As a result of these reasons and others, FASD continues to be regularly misdiagnosed and undiagnosed.

To increase the likelihood that individuals with FASD receive appropriate and effective services, mental health professionals must obtain advanced education and training on FASD. The goals of such training should be to develop a thorough understanding of FASD, including the areas of development affected by prenatal exposure to alcohol. Complimenting an improved understanding of FASD, mental health professionals should familiarize themselves with each client's unique strengths and coping mechanisms. The utilization of a comprehensive battery of neurological and psychological assessments is invaluable during this process (119). Further, mental health professionals should look to establish strong working relationships with physicians, speech-language clinicians, education, neuropsychologist, and occupational professionals. Such multidisciplinary collaborations hold the potential to improve both assessment and treatment of individuals with FASD. The combination of these approaches has the potential to maximize short- and long-term outcomes for clients with FASD.

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