

Neuropsychological Aspects of Prevention and Intervention for FASD in the USA

Andrew S. Davis¹ · Kelly L. Hoover¹ · Brittney M. Moore¹ · Christie L. M. Petrenko²

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Abstract The USA has relatively well-developed programs focused on the prevention of and intervention for prenatal alcohol exposure when compared with most other countries. This includes federal and state government programs involving extensive efforts by the Centers for Disease Control and Prevention (CDC). Despite these efforts and widely available and publicized information about the danger of alcohol exposure to the developing fetus, prenatal alcohol exposure remains a significant problem in the USA. As such, more advocacy efforts are needed to increase the research in this area and the dissemination of these findings. Pediatric neuropsychologists are ideally suited to consider the neurological compromise associated with prenatal alcohol exposure and how risk and resiliency factors in the environment influence neurodevelopment. As such, pediatric neuropsychologists can serve as effective advocates for improved services and research for children affected by prenatal alcohol exposure. Advocacy needs include increased funding for research and intervention, greater engagement, and coordination of the medical, educational, juvenile justice, and psychological communities as well

as increased support of local, state, and federal government agencies to reduce the incidence of fetal alcohol spectrum disorder (FASD) and provide appropriate services. This article reviews the available literature regarding these concerns and discusses considerations for pediatric neuropsychologists for the current efforts on prevention and intervention for individuals with FASD in the USA.

Keywords Neuropsychology · FASD · Prevention · Intervention

Despite widely disseminated information about the potential hazards of consuming alcohol while pregnant, prenatal toxicity represents the most preventable contributor to significant cognitive dysfunction in the USA (McKenna et al. 2005; National Institutes of Health (NIH) 2000). Prenatal exposure to alcohol has the potential to result in devastating, persistent, and pervasive longitudinal effects on neurodevelopment. Educational, health care, and juvenile justice systems in the USA are making progress on providing accommodations and assistance for individuals with fetal alcohol spectrum disorder (FASD) and their families, although progress is slow when considering the resources in this country. The USA has a diverse array of intervention and prevention programs for children with FASD currently underway, which are built upon a solid history of research and clinical practice. There are some barriers to effective work in this area, including lack of knowledge of providers to diagnose and treat FASD as well as limited funding. Although federal and state governments, along with non-governmental organizations, have initiated and attempted to disseminate evidence-based interventions for children with FASD and their families in community settings, uptake to date has been very limited and much more effort in these areas are needed.

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✉ Andrew S. Davis
davis@bsu.edu

¹ Ball State University, Muncie, IN, USA

² Mt. Hope Family Center, University of Rochester, Rochester, NY, USA

Epidemiology of Maternal Drinking in the USA

Despite readily available information about the health hazards of alcohol, consumption remains high in the USA. In 2014, 87.6 % of adults 18 years and older within the USA reported drinking alcohol within their lifetime, while 71 and 56.9 % drank alcohol within the last year and month, respectively (Center for Behavioral Health Statistics and Quality 2015). The prevalence of alcohol use amongst women is slightly lower than the overall averages with 84.6 % of women 18 years and older drinking alcohol within their lifetime, 67.9 % drinking within the last year, and 51.9 % drinking alcohol within the last month (Center for Behavioral Health Statistics and Quality 2015). The national survey also determined that of women 12 years and older, 48.4 % consume alcohol, 16.4 % binge use alcohol (i.e., five or more drinks on a single occasion on at least 1 day within the last 30 days), and 3.2 % are heavy alcohol users (i.e., five or more drinks on the same occasion on five or more days within the past 30 days; Center for Behavioral Health Statistics and Quality 2015). Of particular interest to this manuscript is the prevalence of consumption of alcohol amongst women who are pregnant. Tan et al. (2015) completed a national survey of non-institutionalized adults 18 years and older through the use of a random-digit-dialed telephone survey. Data were collected between 2011 and 2013 from over 200,000 women, 4 % of whom were pregnant. Results of the survey revealed one in ten pregnant women drank alcohol within the past 30 days, and of those pregnant women who reported drinking, 1 in 33 indicated they binge drank (Tan et al. 2015).

A significant consideration for children who have been exposed prenatally to alcohol is the potential risk factors that may be present in an environment in which a pregnant mother consumed large amounts of alcohol (e.g., comorbid tobacco or drug use, low levels of education, rural residence, maternal body mass index, maternal age at delivery, marital status; May and Gossage 2011). These risk factors in turn increase the chances of future academic and cognitive problems. In addition to the potential risk factors described above, there are multiple other dynamics associated with prenatal alcohol exposure that contribute to the severity of FASD symptomatology. These include genetic background, timing of alcohol exposure during prenatal development, level of alcohol exposure, and nutrition (Warren et al. 2011). A dose–response relationship has been found between maternal alcohol use while pregnant and outcomes of low birthweight, infant born small for gestational age (SGA), and preterm birth, with heavy use increasing the risk of these conditions (Patra et al. 2011).

In essence, ecological risk factors have the capability to compound and exacerbate the organic damage that occurs to the central nervous system associated with prenatal alcohol exposure. Indeed, research has suggested that children, adolescents, and adults with FASD tend to experience high rates

of adverse outcomes including inappropriate sexual behaviors, school suspension and expulsion, legal problems, confinement, and substance use (Streissguth et al. 2004). Individuals at highest risk for these outcomes were more likely to be older at time of diagnosis, have experienced less stable and nurturing home environments, and to have been victims of violence. In response to the widely researched ill-effects of prenatal alcohol exposure, the response in the USA has been to recommend pregnant woman not to consume any alcohol. Hankin and Sokol (1995) wrote that consuming more than 1 alcoholic drink/day (0.5 oz. or more of absolute alcohol) during pregnancy is considered risk drinking and has the potential to harm the fetus. They also stated that less than 1 drink/day can be harmful if binge drinking episodes (defined at the time as more than five drinks at a time) are present (Hankin and Sokol 1995). More recently, the American Academy of Pediatrics (2016) recommended complete abstinence from alcohol during pregnancy.

Few studies have been conducted within the USA which specifically examine maternal risk and resiliency factors related to alcohol use while pregnant and subsequent effects on the child with FASD. This is a significant oversight as it will be difficult to understand the effect that targeting these risk factors through intervention has until the relationship between maternal demographic risk factors and FASD morbidity is better understood. In a sample of women from Montana, Minnesota, North Dakota, and South Dakota, Leonardson and Loudenburg (2003) found that women who had a higher risk of using alcohol while pregnant were younger and had lower levels of education than those who abstained; in addition, they tended to be single and unemployed. Furthermore, women with a history of sexual or physical abuse, those who used tobacco products or illicit drugs, and mothers whose partner abused substances were shown to be at higher risk of using alcohol during pregnancy (Leonardson and Loudenburg 2003).

Another environmental risk factor for children with FASD is the possibility of abuse and neglect termed child maltreatment. Children with FASD whose mothers continue to drink alcohol are at an increased risk of child maltreatment (Coggins et al. 2007). Henry et al. (2007) found that children with FASD who had been exposed post-natally to traumatic experiences demonstrated lower cognitive and motor abilities with more behavioral and social problems when compared with children with post-natal traumatic experiences who had not been exposed prenatally to alcohol. Children with FASD are more likely to be removed from their homes than their typical peers, and commensurate with literature examining other neurodevelopmental conditions, children with FASD can present with more developmental concerns when they have unstable living situations. Victor et al. (2008) found that children with FASD who had one foster care placement

demonstrated better cognitive abilities along with fewer behavior problems when compared with children with FASD who were not removed from their home. Indeed, rates of FASD are particularly high in systems of care, such as the foster care system. In one study of children in foster care Astley et al. (2002) found FAS to be 10 to 15 times greater than in the general population. Furthermore, Chasnoff et al. (2015) found that the vast majority (86.5 %) of children in foster and adoptive care who received an FASD diagnosis as part of a multidisciplinary evaluation in a children's mental health center had never been previously diagnosed or were misdiagnosed.

Although more research is needed regarding the effect of these variables on children with FASD, these demographic factors have the potential to influence a child's outcome and prognosis regardless of whether or not the child has FASD or another neurodevelopmental disorder. For example, parental level of education has a significant positive relationship with a child's intelligence (Neiss and Rowe 2000; Sellers et al. 2002) which is in turn a predictor of the child's aptitude for educational achievement. Similarly, parental unemployment has a negative impact on the child's intelligence (Guo and Stearns 2002). As such, there is a concern that children with FASD appear to be of higher risk for negative outcomes when born to parents with lower levels of education and employment, as these demographic risk factors could exacerbate the congenital neurocognitive concerns associated with prenatal alcohol exposure. Based on US samples, it was revealed that women at higher risk for having children with FASD have significantly lower levels of education (May and Gossage 2011). Conversely, resiliency factors which helped women abstain from drinking alcohol while pregnant include being married and not working outside of the home (Leonardson and Loudenburg 2003).

Diagnostic Considerations of FASD in the USA

The umbrella term FASD is a relatively recent iteration that encapsulates the range of syndromes associated with prenatal exposure to alcohol (Jones and Streissguth 2010; Sokol et al. 2003). One challenge currently facing the fields of medicine and psychology in the USA is the existence of multiple diagnostic systems which at times may appear contradictory in identifying cases. This can be somewhat problematic for practitioners and researchers as children with similar psychiatric and neurological presentations may be assigned different diagnostic labels resulting in a heterogeneous group of diagnoses for children with similar symptomology. Coles et al. (2016) wrote that although there are differences among the diagnostic systems, there are generally four criteria that the systems consider which are prenatal alcohol exposure, growth retardation, physical dysmorphology, and neurodevelopmental

concerns. Pediatric neuropsychologists need to be aware of these multiple approaches to diagnosis as they may receive referrals from providers who use different systems. The below paragraphs describe some of the different approaches that have been commonly used in the USA to diagnose and classify FASD.

In 1996, the Institute of Medicine, now known as the Health and Medicine Division of National Academies of Sciences, Engineering, and Medicine, proposed a set of criteria for diagnosis of the spectrum of conditions now referred to as FASD. These criteria have been criticized for being vague and neglecting assessment of family and genetic history (Hoyme et al. 2005). Hoyme et al. (2005) expanded upon the 1996 institute of medicine (IOM) criteria by proposing revised diagnostic criteria of fetal alcohol syndrome (FAS), FAS without confirmed maternal alcohol exposure, partial FAS (pFAS) with confirmed maternal alcohol exposure, pFAS without confirmed maternal alcohol exposure, alcohol-related birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND). These guidelines were again updated very recently by Hoyme et al. (2016). The authors state that their updated guidelines are based on evaluations of over 10,000 children for possible FASD as part of NIH-funded studies. These published guidelines include more precise definition of prenatal alcohol exposure and neurobehavioral impairment, which will improve their utility. Diagnostic categories include FAS (exposure information not required), pFAS with confirmed exposure, pFAS without confirmed exposure, ARND (must have confirmed exposure), and ARBD (must have confirmed exposure). The updated criteria utilize a straightforward diagnostic algorithm and are presented along with an easy to follow flow-chart. Recommendations are also provided for dysmorphology evaluations. Readers are directed to their tables for more detail on each of the diagnostic criteria.

The National Center on Birth Defects and Disabilities (2004) also has guidelines for diagnosing FAS which include facial dysmorphology, growth deficits, and abnormalities in the central nervous system. While confirmed prenatal exposure to alcohol is helpful in determining the presence of FAS, it is not absolutely necessary.

Another set of criteria was developed by Astley and Clarren (2000) and produces a four-digit diagnostic code which ranks the magnitude of expression for the four key diagnostic features: growth deficiency, facial phenotype, central nervous system dysfunction, and gestational alcohol exposure. Each of the four key diagnostic features receives a rank on a 4-point Likert type scale where "1" represents an absence of the feature and a "4" is a strong feature. The resulting four-digit code (one code for each feature) corresponds with the individual's diagnosis. The possible 256 four-digit code combinations are grouped within 22 diagnostic categories. Although this

system may initially appear overwhelmingly complex, these 22 diagnostic categories essentially break down into four primary classifications (FAS, pFAS, static encephalopathy, neurobehavioral disorder), with appropriate signifiers (no alcohol exposure, alcohol exposure, alcohol exposure unknown, presence of sentinel physical features). The development and detailed methodology including instructions, charts, and pictures, which can be found in a 114 page manual available from the University of Washington in Seattle (Astley and Clarren 2000; FAS Diagnostic and Prevention Network 2004) may appeal to pediatric neuropsychologists who are used to standardized instructions and clear scoring criteria.

The *Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition* (DSM-5; American Psychiatric Association 2014) is the most recent iteration of the guidebook widely used by psychologists and psychiatrists in the USA to assign diagnostic labels and codes to a wide range of psychiatric disorders, including those conditions which have neurodevelopmental features or neurocognitive deficits and/or decline as the hallmark feature. One of the advantages of using the DSM-5 is that it provides a very thorough description of the behavioral criteria used for diagnosis as well as additional information about the prevalence, associated features, course of the condition, risk and prognostic factors, functional implications, and ways to facilitate diagnosis. Although there are a number of neurodevelopmental and neurocognitive disorders typically diagnosed in childhood, FASD is not included as a diagnostic category currently. There is, however, a disorder listed in the Conditions for Future Study section, titled neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE). There are several key criteria including “more than minimal” (American Psychiatric Association 2014, p. 798) prenatal alcohol exposure and impaired neurocognitive functioning via low IQ, executive functioning, learning, memory, and/or visual-spatial reasoning. Additionally, patients are required to demonstrate impairments in self-regulation and adaptive functioning. In regards to adaptive functioning, two areas of deficit are required with at least one of the areas being in communication (e.g., delayed language acquisition, receptive language) or social communication/interaction. The other two areas of adaptive functioning deficit could be in motor skills and activities of daily living.

Consistent with other disorders found in the DSM-5, there is the requirement that the condition cause significant distress or impairment in a key area of functioning. This description is of high import to pediatric neuropsychologists given a key component of the diagnostic criteria involves the assessment of neurocognitive deficits and self-regulation, both of which can be measured via typical neuropsychological assessment techniques. As of now, ND-PAE is not a codeable disorder, and pediatric neuropsychologists may differ among their use of codes when treating children with FASD; however, they could consider

diagnosing 315.8 other specified neurodevelopmental disorder. This appears on page 86 of the DSM-5, and there is an example listed for this disorder titled neurodevelopmental disorder associated with prenatal alcohol exposure. Kable et al. (2016) discuss diagnostic guidelines via the DSM-5 format which pediatric neuropsychologists who work with this population are encouraged to review.

Although there are indeed some similarities in the diagnostic approaches presented, it is important to note there are also differences and professionals with different backgrounds and training may classify children with the same central nervous system dysfunction using different terminology. Coles et al. (2016) compared five different diagnostic systems used in North America to diagnose and classify children with prenatal alcohol exposure. The systems they compared were the Emory-Fetal Alcohol Center Clinical Criteria (Blackston et al. 2005 as cited in Coles et al. 1997, 2016), the Seattle 4-Digit System (Astley 2004, 2006, 2013; Astley and Clarren 2000), the FAS Guidelines for Referral and Diagnosis (National Center on Birth Defects and Disabilities 2004), the Canadian Guidelines (Chudley et al. 2005; Loock et al. 2005), and the Hoyme et al. (2005) approach. Coles et al. (2016) evaluated the records of 1,581 patients who were seen in a clinic specializing in children with prenatal drug and alcohol exposure. They applied the diagnostic criteria of the above five systems to each patient. They found significant variability in the percent of individuals who were diagnosed with FASD ranging from 4.75 % (for the CDC system) to 59.58 % (Hoyme et al. 2005 modifications) and noted that the same individual may receive different diagnoses under the FASD umbrella of terms depending upon the system employed. The authors concluded,

Consistency in diagnosis is important to move this field forward. Our results indicate that that improvement in diagnostic consistency could be made by further attention to specification of physical features and neurobehavior. Standardization of these criteria, including agreement on the underlying norms to be used, could lead to improved application and greater reliability (Coles et al. 2016, p. 8).

Prevalence and Cost of FASD in the USA

As there are a range of presentations and likely many children exposed prenatally to alcohol who remain unreported, accurately estimating the prevalence rates of FASD in the US population is difficult; however, it is evident that alcohol-exposed pregnancies (AEPs) represent a significant public health problem. The most recent prevalence estimates from the CDC (2015a) suggest the prevalence of FAS is 0.3/1000 children

(ages 7–9) based on passive reporting and a review of records. Prevalence rates are highest for American Indian/Alaskan Natives and lowest for Hispanic children (CDC 2015a). Some other recent estimates, however, are alarmingly higher, particularly when FASD (the full spectrum of conditions) is considered. For example, using active case ascertainment, May et al. (2014) estimated the prevalence of FAS alone to be 6 to 9/1000 and FASD to be 24 to 48/1000 children (i.e., 2.4 to 4.8 %) in one Midwestern city representative of the US population.

The lifetime cost per child of FAS (excluding other FASDs) is approximately two million dollars; this cost is estimated to equal over four billion dollars annually for the USA (Lupton et al. 2004). Amendah et al. (2011) compared the 2005 Medicaid expenditures of children with FAS and those without FAS. Children with FAS had Medicaid expenditures nine times higher than those without FAS (i.e., average cost of \$16,782 vs. \$1859; Amendah et al. 2011). It was further revealed that 12 % of children FAS were also diagnosed with an intellectual disability (ID) whereas only 0.5 % of those without FAS were diagnosed with ID. This is of importance because children with comorbid FAS and ID had a 2.8 times higher medical expenditures than those with FAS without ID (Amendah et al. 2011). These costs are likely to be much higher when considering the full spectrum of effects associated with prenatal alcohol exposure.

Conceptualization of FASD in Educational, Justice, and Healthcare Systems in the USA

Children with FASD in the USA are typically able to be served in the public education system albeit with support. This support may be available through access to additional services or with educational accommodations via Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. § 794) to ensure adequate access to free and appropriate public education. In most states, FASD is not a recognized classification under special education law. As such, simply because a child has FASD does not automatically entitle them to special education services in the USA, and the determination to enact a 504 plan occurs at the discretion of a school-based committee. This leads to substantial variability in how states and individual school districts and schools work with children with FASD. Some children may be classified as students with an Other Health Impairment, a Specific Learning Disability, an Emotional Disability, or a Cognitive Disability. This latter category may not fit all children with FASD as many present with IQs higher than would be seen in this classification (i.e., over 70). Although the specific classification does not automatically equate to a set system of services or accommodations, the variability in classifications may cause confusion among the special education personnel about which behaviors

and/or academic deficits should be the focus of the intervention.

The Individuals with Disabilities Education Act (IDEA; P.L. 108-446) requires local education agencies to start planning for students' with disabilities transition from school to adult life at the age of 16 years through the use of an individualized education transition plan. Transition plans are designed to help students meet their goals for vocation and independent living as they transfer away from the structured school environment. Transition plans outline the specific services which will be used to help the student transition including direct instruction, community-based experiences, setting of goals for employment and/or post-secondary schooling, and the development of successful activities of independent daily living (P.L. 108-446). Although federal law requires that transition planning occur for individuals receiving special education services due to any disabling condition, there appears to be a dearth of research conducted within the USA on transition planning for individuals with FASD. This is a concern as children with FASD have a myriad of cognitive, behavioral, psychological, and medical needs which affect them not only throughout their childhood, but also through adulthood. Therefore, individuals with FASD need adequate services to help them make the transition from school and childhood dependence to adulthood as research has indicated prenatal alcohol exposure leads to negative adaptation in the early years of adult life (Lynch et al. 2015).

A unique and salient neurocognitive profile has not emerged for individuals with FASD given the wide array of pathology captured under the umbrella term of FASD as well as the different ecological risk and resiliency factors that contribute to outcomes. However, there does seem to be an emerging set of neurocognitive deficits associated with FASD. As previously mentioned, the DSM-5 suggests a set of diagnostic criteria for this condition that includes impaired neurocognitive functioning in at least one of the following areas: global intellectual functioning, executive functioning, learning, memory, and visual-spatial reasoning. More research will be needed to establish the validity of this tentative neuropsychological profile as well as to investigate if subtypes of FASD could be considered based on these deficits which will enhance the ability to design and provide unique interventions.

While all individuals with FASD have some level of neurocognitive impairment given various definitions, there is a wide range of individual variability by domain. For example, substantial variability has been found in IQ with Mattson and Riley (1998) noting the average IQ of children with FAS is approximately 70, while the range of IQ scores for children with FAS spanned from 20 to 120. Other studies have shown individuals with FASD have specific deficits in executive functioning (EF), memory, learning, language, visual-spatial ability, and attention (e.g., Kodituwakku 2009; Mattson et al.

2011). When present, these deficits can have a salient effect on a child's emotional, behavioral, and academic functioning as well as on their ability to independently carry out activities of daily living. Neurodevelopmental delays at one stage may have a ripple effect on subsequent hierarchically-dependent abilities and pediatric neuropsychologists should consider serial assessments of these children.

A concern with these neurocognitive deficits, particularly those involving lower intellectual processing and executive dysfunction, is the propensity for poor and impulsive decision making that can result in involvement with the juvenile justice system. Children with FASD have been identified as, "a potentially vulnerable group of offenders in the context of a criminal prosecution owing to substantial cognitive, behavioral, and social challenges commonly seen in those with the diagnosis" (McLachlan et al. 2014, p. 10). Indeed, involvement with the criminal justice system seems to occur at a high rate for children with FASD. Streissguth et al. (2004) examined adverse life outcomes in a sample of 415 individuals with FASD and determined that 14 % of the children and 60 % of adolescents and adults in their sample had trouble with the law (defined as being charged, arrested, convicted, or in other trouble with the law). For those children who encountered trouble with the law, 13 % of the children were charged, arrested, and/or convicted.

One of the advances in the last couple of decades in the USA is the increased awareness of children with FASD in the court system. Bisgard et al. (2010) reviewed three programs in the USA that screen youth offenders for FASD. Each program used a variation of a screening tool for children aged 8–18 which can be found in an Appendix of the Bisgard et al. (2010) article. The authors describe each program in detail, and pediatric neuropsychologists looking to advocate for increased screening, identification, and intervention for children and adults with FASD in their local court system are encouraged to closely review this article; we briefly discuss one program described by Bisgard et al. (2010) below as an example.

The probation officers in the Juvenile Delinquency Court of the Seventeenth Judicial District of Colorado have been conducting screenings for FASD since 2005. When there is a positive screen, the child is assigned to an intervention specialist who helps the family of the child meet with a diagnostic and intervention team which includes a pediatrician, psychologist, physical and/or occupational therapist, and a speech pathologist. When this process is complete and a child is diagnosed with FASD, the specialists and probation officer work with the family and child to develop an intervention plan and modify the child's probation; modifications were described to include calling the child for provider appointment reminders and helping the child meet curfew. Bisgard et al. (2010) listed accomplishments of this program to include increased awareness and understanding in the court system of

FASD, children with disabilities being given appropriate sentences, and accommodations allowed.

The USA legal community seems to be aware of the effect that prenatal alcohol exposure can have on the propensity to become involved with the legal system as well as the need to provide accommodations and support to these children. In 2012, the American Bar Association wrote,

RESOLVED, That the American Bar Association urges attorneys and judges, state, local, and specialty bar associations, and law school clinical programs to help identify and respond effectively to Fetal Alcohol Spectrum Disorders (FASD) in children and adults, through training to enhance awareness of FASD and its impact on individuals in the child welfare, juvenile justice, and adult criminal justice systems and the value of collaboration with medical, mental health, and disability experts. FURTHER RESOLVED, That the American Bar Association urges the passage of laws, and adoption of policies at all levels of government, that acknowledge and treat the effects of prenatal alcohol exposure and better assist individuals with FASD (American Bar Association 2012, p. 1).

Pediatric neuropsychologists are encouraged to work with attorneys, judges, and the juvenile justice system in their local area to provide systemic education as well as support for these children and their families. Brown et al. (2015) provide a detailed guide that pediatric neuropsychologists may wish to consult if they plan on working with their local court.

Efforts to address prevention, diagnosis, and treatment have also been spearheaded by professional organizations. The American Academy of Pediatrics organized an FASD Risk Communication Workshop in July, 2012 along with a number of professional organizations in the USA including the American Academy of Family Physicians, American College of Obstetricians and Gynecologists, Association of Women's Health Obstetrics, and Neonatal Nurses, National Association of Pediatric Nurse Practitioners, National Organization on Fetal Alcohol Syndrome, and the Society for Physician Assistants in Pediatrics. A call to action was issued at this workshop and supported by the above organizations which encouraged, "target audiences to increase awareness, engage in education, and improve public health efforts about the message that women who are thinking about becoming pregnant or who are already pregnant should abstain from alcohol" (American Academy of Pediatrics Website, <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Joint-Call-to-Action-on-Alcohol-and-Pregnancy.aspx>; retrieved 2016). The American Academy of Pediatrics also includes a toolkit for the "medical home management for a child with an

FASD”: <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/The-Toolkit.aspx>.

Federal agencies, such as the CDC, the Substance Abuse and Mental Health Services Administration (SAMHSA), and NIAAA, have been instrumental in funding prevention and intervention trials and disseminating evidence-based messaging about the dangers of alcohol use during pregnancy and effective strategies to prevent and manage the effects of prenatal alcohol exposure (PAE). Further details of these funding and dissemination initiatives are described in later relevant sections.

In 1990, the National Organization of Fetal Alcohol Syndrome (NOFAS) was founded, and is the only international non-profit organization committed solely to FASD prevention, advocacy, and support. Over time, a number of state and local affiliates have joined to educate the public, practitioners, and policymakers about the risk of PAE and FASD. NOFAS offers a vast array of programmatic activities including a media center to disseminate accurate information, webinar series, a peer mentoring birth mother’s network, state-by-state resource directory, curriculums for K-12 and professional student education, legislative and policy agendas, and educational and marketing activities for a large international research consortium.

Prevention Efforts for FASD in the USA

Prevention of FASD faces several significant challenges, including that messages discussing the potential serious harm of prenatal alcohol exposure directly compete with widely viewed commercial marketing of alcohol (Glik et al. 2008). Additional concerns are marketing of alcohol to young adults via social media; a recent study suggested that marketing of alcohol on Facebook may lead users to consume more alcohol (Alhabash et al. 2015). Recently, following their release of updated data on the rates of alcohol-exposed pregnancies in the USA (CDC 2016; Green et al. 2016), the CDC emphasized a consistent message to the public which reads, “women of reproductive age should be informed of the risks of alcohol use during pregnancy, and contraception should be recommended, as appropriate, for women who do not want to become pregnant. Women wanting a pregnancy should be advised to stop drinking at the same time contraception is discontinued” (Green et al. 2016, p. 91).

Despite challenges, prevention of FASD in the USA has taken multiple approaches. These approaches can be summarized across the three levels of prevention: universal, selective, or indicated (Barry et al. 2009; Hankin 2002). Universal prevention efforts aim to educate the general public, particularly women who are of childbearing age, about the risks associated with consuming alcohol while pregnant. Hankin (2002) stated

that universal prevention efforts might include public service announcements, billboards, posters/brochures in doctors’ offices, warning labels on alcohol packaging, etc. Other universal prevention efforts include broader strategies like taxes on alcohol (Abel 1998; Barry et al. 2009). Selective prevention efforts target a more specific audience (e.g., women who are of childbearing age who consume alcohol; Hankin 2002). Hankin (2002) and Floyd et al. (2009) noted these prevention efforts could include counseling for women of childbearing age who use alcohol and alcohol use screening of all pregnant women. The third tier of prevention, indicated prevention, targets the highest risk women (e.g., women who have had a child with FASD, women who are known to have abused alcohol while pregnant in the past, etc.; Hankin 2002). These prevention efforts can include pregnancy prevention and/or alcohol abuse treatment for women at risk (Hankin 2002).

There are some federal guidelines in the USA applicable to the prevention of FASD. For example, since 1989, it has been illegal to manufacture, import, or sell alcoholic beverages in the USA unless they contain the following warning: “according to the Surgeon General, women should not drink alcoholic beverages during pregnancy because of the risk of birth defects” (Alcoholic Beverage Labeling Law 1988). Interestingly, it was not until the early 2000s that another country, France, required a similar warning label on alcohol (Warren 2015).

The alcohol policy information system (<https://alcoholpolicy.niaaa.nih.gov/Home.html>) provides information about policies of the USA government as well as individual states for a variety of alcohol-related concerns, including prenatal alcohol exposure. This includes rules surrounding federal grants to states which specify that pregnant women receive priority services for substance abuse treatment. Readers are encouraged to review the website, and pediatric neuropsychologists practicing in the USA are encouraged to review both the federal guidelines as well as those for their particular state. Practitioners in other countries will likely also benefit from reviewing this list as there may be some programs which are a good fit for their country or region.

Overall, research suggests prevention can reduce the risk of an alcohol-exposed pregnancy (AEP) in preconceptional women, thereby reducing the risk of FASD (Floyd et al. 2007, 2009; Ingersoll et al. 2005). One well-researched selective prevention program based on recommendations from the IOM and funded by the CDC was developed with the goal of preventing AEP (CDC 2013; Floyd et al. 1999). This program, Project CHOICES (originally an acronym for the Changing High-risk Alcohol Use and Increasing Contraception Effectiveness Study), was designed to target women at risk for an AEP. Project CHOICES is a brief, motivational intervention which involves four hour-long, client-centered counseling sessions in which participants receive information about alcohol use and pregnancy, discuss readiness

for change, set goals, and participate in follow-up sessions (Floyd et al. 1999, 2007). Results suggested significant reductions in risk for AEP, “risky” drinking behavior, and ineffective contraception use for participants who completed the Project CHOICES intervention (Floyd et al. 2007). Participants who completed the intervention showed reductions in the number of binge-drinking episodes and number of drinks per week, and they were more likely to use contraception and have alcohol consumption at ‘below risk levels’ (Floyd et al. 2007, p. 7). A one-session motivational intervention for women at risk of AEP delivered remotely by telephone and mail also reduced alcohol consumption and use of unreliable contraception (Farrell-Carnahan et al. 2013).

Estimates of binge drinking behavior of college-aged young adults (i.e., 18–25-year olds) in 2014 suggested 37.7 % of young adults report engaging in binge drinking in the past month (Center for Behavioral Health Statistics and Quality 2015). This, coupled with high rates of inconsistent contraceptive use among college students (Morrison et al. 2016), puts college-aged women at increased risk for AEPs. Given rates of binge drinking and ineffective use of contraception in college-age populations, the BALANCE (Birth Control and Alcohol Awareness: Negotiating Choices Effectively) program was developed as a selective prevention program for sexually active, college-aged women in a mid-Atlantic, urban university setting (Ingersoll et al. 2005). Like Project CHOICES, the BALANCE program combines counseling (with motivational interviewing as a key component) with information on contraception. This program includes one 60–75-min counseling session in which the participant and the counselor complete activities focused on analyzing risk, setting goals, and creating a plan for change (Ingersoll et al. 2005). Results of a randomized controlled trial which compared data from participants who completed the BALANCE intervention with participants who received an informational brochure on women’s health suggest significant decreases in risky drinking and increases in effective use of contraception for the BALANCE intervention group when compared with the control group (Ingersoll et al. 2005). At 1-month post-intervention, participants who received the BALANCE intervention reported significantly less binge drinking and significantly less average drinks per day than the control group; in addition, a significantly larger proportion of intervention participants effectively used contraception, and 73.9 % of the intervention group was identified as ‘no longer at risk’ for AEP (Ingersoll et al. 2005).

AEP prevention programs for pregnant women in the USA have also been studied (e.g., Chang et al. 2005; O’Connor and Whaley 2007). Chang et al. (2005) examined the efficacy of an AEP prevention program developed for pregnant women and support partners of their choosing. Participants were recruited from obstetrics practices in Boston, Massachusetts. Participants in the treatment and control groups and their

support partners completed a diagnostic interview and a series of questionnaires. The treatment group then completed a brief, 25-min intervention which included a knowledge assessment, a discussion of prenatal drinking goals and rationale, and a behavioral modification exercise. Participants returned for a postpartum follow-up interview where participants and their partners also completed questionnaires related to alcohol use. Results suggest that although all participants (i.e., both the treatment and control group) demonstrated decreased alcohol consumption at the follow-up, there was a statistically significant interaction between the intervention and level of prenatal alcohol consumption, that is, the intervention was more effective for participants who reported greater alcohol consumption at the outset of the study. In addition, the intervention was found to be more effective when a support partner was involved; this idea is consistent with the idea that being married is a resiliency factor (i.e., a factor that reduces risk of AEP; Leonardson and Loudenburg 2003); although, results of the Chang et al. (2005) study suggest the support partner need not be a spouse to be effective.

Another prevention program designed to help pregnant women abstain from alcohol was implemented through the Public Health Foundation Enterprises Management Solutions Special Supplemental Nutrition Program for Women, Infants, and Children (PHFE-WIC) in Southern California (O’Connor and Whaley 2007). Twelve women, infants, and children (WIC) centers were randomly assigned to assessment only or brief intervention conditions. Three-hundred and forty-five participants completed an alcohol screening questionnaire, the tolerance, worried, eye-opener, amnesia, cut-down (TWEAK) alcohol tolerance scale; participants who positively endorsed alcohol screening questions also completed the *Health Interview for Women* (O’Connor and Kasari 2000). Participants in the intervention group completed a brief intervention administered by nutritionists which included education, feedback, cognitive-behavioral techniques, setting goals, and contracting. Results of the study suggest participants who received brief intervention by non-medical professionals (i.e., the nutritionists) had more positive outcomes (e.g., reduction in alcohol use, higher infant birth weight, lower fetal death rate) than those who were in the assessment only condition. The results of this study are quite encouraging given the brief nature of the intervention.

The CDC funded studies in 2004 that looked at reducing AEP through the promotion of guided self-change programs at the community level. As described by the CDC, this type of intervention relies upon assisting individuals who are motivated to make changes and are in the early stages of an alcohol abuse disorder as opposed to more traditional intense programs aimed at more serious or chronic abusers of alcohol (<http://www.cdc.gov/ncbddd/fasd/previous-state-community.html>). One of the funded studies took place at Nova Southeastern University with women at risk for AEP.

Participants assigned to the treatment group completed a motivational intervention (i.e., the Healthy Lifestyles Guided Self-Change Program). Results of clinical studies of this program support its efficacy for self-change, and the guided self-change component is now an American Psychological Association (APA) recognized Empirically Supported Treatment (EST; CDC 2015b) listed on APA's Division 12 (Society of Clinical Psychology) Website (<http://www.div12.org/psychological-treatments/treatments/guided-self-change-for-mixed-substance-abusedependence/>).

Streissguth et al. (2004) found alcohol and drug problems for 35 % of patients 12 and older in a sample of individuals with FASD, which renders women with FASD a high risk group for having their own child with FASD. Grant et al. (2004) attempted to address this concern via a 12-month pilot program with 19 women with FASD using a community assistance and provider collaboration program. They modified the parent-child assistance program (PCAP; Ernst et al. 1999; Grant et al. 1999; Grant et al. 2002; Institute of Medicine 1996) which was originally designed to reduce births of children who were exposed prenatally to drugs and alcohol via intervening with high-risk pregnant woman, as described by Grant et al. (2004). Participants in the Grant et al. (2004) study were selected for a 12-month pilot program from women diagnosed with FASD who were already enrolled in the 3-year PCAP intervention and had at least 1 year remaining. The authors found their intervention resulted in decreased drug and alcohol use, increased contraceptive use, improved medical and mental health care, and an increase in obtaining stable housing.

In addition to federal efforts and non-governmental organizations in the USA, individual state governments within the USA have developed policies and procedures to prevent the occurrence of and monitor the incidence of FASD. For example, the Colorado Department of Public Health and Environment requires health care providers to report suspected cases of FAS in children 10 years old and under (<https://www.colorado.gov/pacific/cdphe/fetal-alcohol-syndrome>). The state of Michigan has implemented a 5-year plan to both prevent prenatal alcohol exposure and support children with FASD. The plan is multidimensional and includes health promotion, prevention of FASD, intervention for children with FASD, and the enhancement of support systems. The plan is quite extensive, including multiple goals and objectives, and readers are directed to the full text of the plan at: http://www.michigan.gov/documents/mdhhs/Michigan_FASD_Five_Year_State_Plan_2015-2020_516784_7.pdf. In all, as of 2014, 34 US states have mandatory reporting requirements for known or suspected use/abuse of alcohol by pregnant women; however, only 20 of those states require reporting to a child welfare agency (Drabble

et al. 2014). Twenty-one states have legal provisions in place by which alcohol exposure in utero are reportable as neglect (Drabble et al. 2014).

A review of the Alcohol Policy Information Systems by Drabble et al. (2014) revealed that there have been state-by-state increases in regards to policies related to alcohol consumption by pregnant women from 2003 to 2012. This includes an increase in mandated reporting of alcohol use during pregnancy (26 to 35 states), child welfare (14 to 20 states), and mandated warning signs about the potential risks of consuming alcohol while pregnant (20 to 24 states). Some policies remained largely stable during the same period including priority substance abuse treatment for pregnant woman. The authors also investigated what type of approach states and the District of Columbia took towards FASD. They determined 19 jurisdictions mostly used a *supportive* approach, 12 jurisdictions had a *punitive* approach, 12 had a mixed approach, and eight jurisdictions had no statutes related to alcohol and pregnancy. This widely disparate array of policies strongly suggests that pediatric neuropsychologists in the USA become advocates at both the federal and state level for the most effective evidence-based policies towards the prevention of prenatal alcohol exposure.

Evidence-Based Interventions for FASD in the USA

Evidence-based interventions for children with FASD aim to increase positive developmental trajectories, decrease secondary-related conditions, and improve the outcomes for the family system; however, choosing an appropriate intervention must be based on the skills which have been affected for the specific individual with FASD (Bertrand 2009). Petrenko (2015) summarized two existing theoretical models for intervention development for FASD and highlighted how these models can be integrated at different levels of analysis from a developmental psychopathology perspective. The first model (Kodituwakku 2010; Kodituwakku and Kodituwakku 2011) is based on the concept that repetitive experiences can drive neural plasticity as well as the formation of neural circuitry to sustain the desired behavior. This model recommends that interventions should target the patient's zone of proximal development, include direct intervention and parental support, combine pharmacological and behavioral approaches, and that early intervention in attention and self-regulation is likely to be more efficacious than other domains. The second model (Olson et al. 2009) proposes interventions attempt to reduce risk factors and increase resiliency factors to improve the patient's adaptive development trajectory under the auspice that the individual's characteristics interact with their family and other social systems. Relevant family-level risk and protective factors for families impacted by FASD include a stable and nurturing home, attachment, parent-child interaction patterns,

caregiver cognitive appraisal, self-efficacy, parent stress, and family resource needs. Petrenko (2015) also summarized a model derived from the lived experiences of families and service providers that identifies the types of multi-system intervention needs for the affected-individual, the family, and service system. The model emphasizes the need for a proactive and comprehensive approach that is well coordinated and takes into account the individual needs of the person and family across the lifespan.

A significant complication in intervening with children with FASD is that a comprehensive intervention plan should address not only the neurocognitive and academic problems associated with FASD but also the ecological concerns which are often associated with the condition. For example, Paintner et al. (2012) recommend goals to:

- (1) Prevent multiple foster home placements, which are extremely detrimental for optimal development;
- (2) maximize parent or caretaker understanding of the age-related changes in behavior and age-related risk; and
- (3) anticipation of future development of age-related impairments common in fetal alcohol spectrum disorders (p. 6).

A consideration in intervening with children with FASD is that interventions need to focus not only on the child's individual concerns but also the potential wide array of environmental risk factors that may be present in the child's environment. For example, attending to the basic needs of the family, assessing the level of parent stress and marital conflict, or linking family members to appropriate mental health supports may be necessary to promote an environment that will be able to enact positive changes for the child's development. Streissguth et al. (2004) identify a stable/nurturing home environment as "the most influential protective factor" against identified negative outcomes such as inappropriate sexual behavior, disrupted school experience (e.g., suspensions, dropouts), trouble with the law, confinement (i.e., hospitalization, incarceration), and substance problems. In some cases, pediatric neuropsychologists may consider using evidence-based interventions that were developed for different populations but are designed to target the behavioral problems exhibited by children with FASD, which could include the trauma-informed literature. Pediatric neuropsychologists are also encouraged to consult SAMHSA Treatment Improvement Protocol (TIP) 58 for additional guidance about adapting interventions for children and adults with FASD found at: <http://store.samhsa.gov/shin/content//SMA13-4803/SMA13-4803.pdf>.

A review of the extant literature conducted in 2006 revealed a lack of published evidence-based treatments for individuals with FASD (Premji et al. 2006). Coles et al. (2009) indicated that the lack of information regarding interventions

for children with FASD may have been related to an assumption that there was little optimism in improving outcomes for these children. Indeed, an updated review of the literature reveals that there remain relatively few evidence-based interventions published for children with FASD; however, there has been significant progress in this area over the past 10 years, and while more work still remains to be done, researchers in the USA are making advancements in the area of evidence-based interventions.

Psychopharmacological Treatment and Nutritional Studies

The evidence-based literature on using psychopharmacology to treat children with FASD is quite limited. Much of the available literature is based on animal models and has not yet been translated to human clinical trials (Murawski et al. 2015). Due to the overlap in some symptoms between FASD and ADHD, one pharmacological approach that has been used to treat individuals with FASD is stimulant medication; however, results thus far have been contradictory and inconclusive (Murawski et al. 2015). In a review of the literature, Peadon and Elliott (2010) noted that there is not much empirical evidence regarding medicinal treatment for ADHD in patients who have comorbid FASD; there may be a possible preferred response to dexamphetamine compared with methylphenidate although the evidence is weak. Although it was conducted in Canada, a study by Doig et al. (2008) can likely be extrapolated to children in the USA. Doig et al. examined the medical records of 27 children with FASD referred for ADHD medication and found that 41 medication trials suggested better response for hyperactivity, impulsivity, and oppositionality than compared with attention. Similarly, Oesterheld et al. (2009) found that methylphenidate improved hyperactivity in a small group of Native American children with FASD according to parent and teacher report, although no improvements in daydreaming attention were detected.

Neuroleptics have also been investigated in the treatment of FASD. In a review of the literature, Hosenbocus and Chahal (2012) indicated that no psychotropic medications are specific for individuals with FASD although children with FASD are frequently prescribed a combination of a stimulant and atypical neuroleptics. Ozsarfaty and Koren (2015) wrote, "very large numbers of children with FASD are treated with neuroleptics, with risperidone being the most prevalent; yet the published experience in these children is very limited" (p. 64). Frankel et al. (2006) compared children with FASD who were participating in a friendship and social skills intervention study who were prescribed either neuroleptic or stimulant medication, no medication, or both of these medications. Results demonstrated that the children who were prescribed neuroleptics showed better social outcomes according to parent and teacher report when compared with children who were prescribed other medication or not taking medication. The children taking stimulant

medication did not show significant improvements on the outcome measures or had poorer outcomes compared with the children not taking stimulant medication.

Research has been published on choline supplementation in children with FASD following successful rodent models showing reductions in cognitive and behavioral problems (e.g., Schneider and Thomas 2016). Wozniak et al. (2015) assessed young children (aged 2.5–5 years) with FASD who received 500 mg of choline daily for 9 months compared with a control group that received a placebo. Choline supplementation was associated with improved explicit memory, but only in younger children, suggesting a possible critical developmental period for this intervention (Wozniak et al. 2015).

Neurocognitive and Academic Abilities Executive dysfunction is a common neurocognitive deficit seen in children with FASD and executive dysfunction can interfere with the demonstration of more intact neurocognitive abilities. Executive dysfunction is a risk factor for adverse outcomes and thus addressing these concerns through evidence-based interventions is paramount. A neurocognitive habilitation program was designed to increase the executive functioning skills for children with FASD, specifically their ability to self-regulate (Wells et al. 2012). The intervention was based on and adapted from the Alert Program© (Williams and Shellenberger 1996), and it was delivered in a group setting with teaching skills focused on self-regulation strategies, cause and effect reasoning, sequencing, planning, and problem solving (Wells et al. 2012). Additionally, occupational therapy, family psychoeducation, and cognitive interventions were used. Results of the study revealed children in the intervention group demonstrated significantly greater improvements than the control group in executive and emotional functioning.

A recent program was developed by Coles et al. (2015) to improve self-regulation and adaptive skills for children with FASD. Children were assigned to one of two experimental groups and a control group; the experimental groups differed in the type of computer instruction game used. Both experimental groups received: 1) child computer instruction (either GoFAR or FACELAND games), (2) parent training, and (3) parent–child behavior analog therapy (BAT). The parent training and BAT sessions were the same for both intervention groups and focused on teaching metacognitive control the focus and plan, act, and reflect (FAR) strategy. The difference between the groups is that children in the GoFAR group completed a computer game explicitly teaching the FAR strategy, whereas the FACELAND group completed a game focusing on emotion identification. Both intervention groups had significant reductions in disruptive behavior problems relative to controls by post-intervention; however, the group receiving the GoFAR game (congruent with parent training) showed quicker decreases prior to completing the

BAT sessions relative to the FACELAND group (incongruent with parent training).

Given the significant behavioral and neurocognitive problems typically exhibited by children with FASD, it stands to reason that children with FASD will exhibit multiple academic and learning problems. Although some of the interventions designed to target behavioral problems and/or neurocognitive problems may also help improve academic skills, there is paucity of literature on specific academic interventions for children with FASD in the USA. Coles et al. (2009) evaluated the effectiveness of an intervention for children with FASD which was designed to target pre-math and mathematical skills. The program was titled the Math Interactive Learning Experience (MILE) and involved parent training and individual tutoring sessions with the children. Participants were children aged 3 to 10 who had been diagnosed with FASD from the Atlanta, GA area. Children in the intervention group showed significant math improvement when compared with the control group after controlling for pre-intervention math functioning and intelligence. The MILE program has also been shown to be effective in a community setting (Kable et al. 2015).

Behavior Given the array of neurocognitive deficits that can arise when a child is exposed to alcohol prenatally, it is not surprising that children with FASD tend to exhibit disruptive and problematic behavior. A study examined the use of two 14-week evidence-based group therapeutic interventions on the reduction of disruptive behavior (Bertrand 2009). The two interventions used were Parent–child Interaction Therapy (PCIT) and Parent-Only Parenting Support and Management. PCIT is typically delivered in 12–16 sessions and provides the family with therapist-led behavioral practice that, “seeks to enhance the parent–child relationship, increase appropriate social skills, reduce inappropriate behaviors, and institute a positive discipline program” (Bertrand 2009, p. 997). Both group interventions led to decreases in parental distress and child problem behaviors, but they did not significantly differ from one another (Bertrand 2009).

A parent consultation model, called Families Moving Forward (FMF), has been deemed a Promising Practice in Washington State, with associated improvements in parenting self-efficacy, self-care, family needs met, and child behavior problems (Study no. 5 in Bertrand 2009). The FMF intervention was specifically designed for caregivers of preschool and school-aged children with FASD who demonstrated externalizing behavior problems (Olson et al. 2009). FMF integrates positive behavior support, motivational interviewing, and cognitive behavioral strategies and is typically delivered in families’ homes every other week. A primary goal of the FMF program is to change parenting attitudes and responses towards the problematic behavior of children with FASD (Petrenko 2015). Petrenko (2015) commented that in the

program, based on social learning theory, “families are taught how to observe and reframe their children’s behaviors and subsequently create and advocate for appropriate accommodations (modifications to the physical or caregiving environment). Therapists also provide advocacy assistance and work with parents to identify appropriate social supports and self-care” (p. 10). Clinicians who want to learn more about FMF as well as how to become an intervention specialist using this framework can find this information at their homepage (<http://depts.washington.edu/fmffasd/>).

The FMF program was also recently evaluated by Petrenko (2016) in a pilot randomized control trial as part of a multi-component intervention program that included a 30-week child skills group using the Promoting Alternative THinking Strategies curriculum (Domitrovich et al. 2005). Both the intervention group and the assessment and community referral groups had similar improvements in child behavior problems. Significant intervention effects were found for child emotion regulation and self-esteem, caregiver FASD knowledge, and family needs met, representing medium to large effects. Medium effects were also found for reframing, or caregivers’ tendency to view their children’s behavior from a neurodevelopmental perspective than as willful misbehavior. Effects were smaller than expected for measures of parenting efficacy, satisfaction, and stress. However, many families were already within normative ranges on these measures.

Social skills deficits can have multiple causes in children with neurological concerns. Children with FASD have well-documented difficulties with social cognition and social functioning (Kully-Martens et al. 2013; McGee et al. 2009). In addition, other factors such as missed school due to medical and psychiatric treatment can limit exposure to social interaction with typically developing peers, and sensory-motor dysfunction can also limit opportunities for play with typically developing peers (Kim et al. 2016). Thus, social skills interventions are an important area of intervention for children with FASD. An intervention using Children’s Friendship Training (CFT) for increasing appropriate social skills in children with FASD was found to not only lead to a significant increase in knowledge about social behavior but also actual implementation of that knowledge in a social context with gains maintained over a 3-month follow-up (O’Connor et al. 2006). Laugeson et al. (2007) provided an overview of how this evidence-based program was adapted to adequately meet the neurocognitive and behavioral needs of children with FASD while maintaining the integrity of the program. Furthermore, O’Connor et al. (2012) found that children with PAE did as well as children without PAE in a community-based setting using CFT with both groups demonstrating improved social skills compared with a standard of care control group.

Adaptive functioning deficits are frequently seen in children with FASD. Adaptive skill deficits increase the chances

that a child is likely to both experience as well as react poorly to home emergencies which renders this an important area for intervention. Coles et al. (2007) evaluated the effectiveness of a computer game to teach fire and street safety skills in 32 children aged 4 to 10 with FAS and pFAS. Two groups of 16 children were assigned to either a fire safety or street safety computer game condition which they played until they mastered it. Both groups completed a pretest and post-test about both types of safety skills and following playing the game were asked to demonstrate their learning behaviorally. Children were also assessed 1 week later. Results of the study indicated that the children were able to be taught these skills through the computer game format and were able to demonstrate their skills behaviorally; these results were maintained at the 1-week follow-up. This type of learning has obvious implications and hopefully future research will use this type of technology to work on other adaptive and safety skills in safe manner that appears useful for generalization.

A recent study was conducted by O’Connor et al. (2016) which attempted to prevent or reduce alcohol use in a group of 54 teenagers with PAE. Participants were assigned to a control group or an experimental condition. The treatment condition involved Project Step Up which consisted of 6-h-long group sessions with about six to eight participants over 6 weeks. Project Step Up was described by the authors as, “motivational enhancement techniques, normative feedback, education, risk assessment, coping, and alcohol refusal skills training in working with adolescents within a developmentally sensitive group framework in order to target adolescents experiencing common developmental transitions with varying levels of alcohol use from no use to light/moderate use” (O’Connor et al. 2016, p. 2). Results of this study indicated the participants classified as light/moderate drinkers of alcohol had a significant reduction in alcohol-related risks when compared with the control group, which was in part sustained 3 months later. Caregivers in the experimental condition also participated in training and educational sessions separate from their child. Both the adolescents and caregivers reported very high levels of satisfaction and feelings of competence following the treatment.

Future Directions and a Call to Action

Despite action by the CDC, other federal agencies, universities, state governments, and non-governmental organizations in the USA, the prevalence of FASD is estimated between two and five percent in the USA (May et al. 2014). As such, more initiatives are needed in the USA to prevent the consumption of alcohol by pregnant women. Another concern is the high cost, both financial and emotional, of treating children and adults with FASD. The neurological, academic, behavioral, social, and physiological problems that accompany FASD

are persistent and developmental; thus, interventions are needed at multiple stages and modalities to address these concerns. Most of the FASD intervention research in the USA has focused on children and the research needs to be extended and broadened to include adolescents and adults. Research on FASD is growing in other countries, so researchers and practitioners in the USA need to be vigilant of findings from other areas of the world.

All health care professionals, including pediatric neuropsychologists, should advocate for increased governmental research funding into the prevention of and intervention for FASD. This is particularly true since the funding for the SAMHSA FASD Center for Excellence was recently eliminated after being significantly cut in recent years; readers wanting to learn more about this and to take action can visit: <http://www.nofas.org/2016/02/22/nofas-action-alert-end-of-funding-for-samhsa-fasd-center-for-excellence/>. Moving forward, increased funding and research should be focusing on as early intervention as possible, including interventions that can be implemented prior to the child being born. Although obviously outside the area of current pediatric neuropsychological practice, prenatal detection and intervention could eventually lead to pediatric neuropsychologists working to establish effective intervention plans as early as possible. Another area of emphasis must be to increase the focus on systemic research to translate basic findings into clinical trials and community dissemination.

Efforts are made in the USA by the federal government to combat the marketing of alcohol to young people (e.g., including the warning labels about the detrimental effects of alcohol on developing fetuses on bottles containing alcohol), yet more needs to be done. It may seem obvious that the public is aware of the effects of prenatal alcohol exposure, but education is needed on how these effects are manifested for children and adults and how to effectively support affected individuals and their families. Indeed, research has suggested that informational packets, group workshops, and internet training are all effective in improving parent knowledge of FASD and how to advocate effectively for their children, with workshops and internet training being relatively more effective (Kable et al. 2012). Pediatric neuropsychologists are in a unique position to provide and consult with developers of these types of community/societal interventions given their knowledge of FASD and their ability to answer questions and correct falsehoods about the academic, social, emotional, and behavioral effects of the condition. Increased education about the effects of FASD could lead to earlier diagnosis and earlier intervention. Streissguth et al. (2004) found the chances of having increased adverse life outcomes were increased by two to four times when children were diagnosed with FAS or FAE after the age of 12.

Another area the USA must further address is improving the academic outcomes of children with FASD. Despite the well-researched and obvious effects of FASD on academic functioning, there remains a paucity of evidence-based academic interventions for these children in the USA. This leads to a concern that children with FASD will be placed in special education under a general classification category such as Other Health Impairment which will entitle them to services but lacks the specificity associated with other conditions with neurological concerns (e.g., children with dyslexia or autism spectrum disorders being classified as children with specific learning disability or autism, respectively).

Given the ecological risk factors associated with FASD, interventions need to be systemic and also target affected individuals, parents, and systems across developmental periods (Petrenko et al. 2014). It is also critical for researchers and practitioners to consider individual risk and resiliency factors that affect the child's outcome. Paintner et al. (2012) wrote,

It is important to note that the early prenatal environment for children with a fetal alcohol spectrum disorder is often one of exposure to multiple teratogens, including alcohol, smoking, other drug use, inadequate nutrition, high rates of depression, violence, and suboptimal living conditions. It is useful to acknowledge the link between prenatal alcohol exposure and increased risk for postnatal environmental adversity. Persistence of these adverse conditions through childhood and into adolescence increases the risk of abuse, neglect, academic failure, injury, and mortality (p. 6)

In general, more intervention and prevention research on FASD is needed in the USA. Indeed, a review of the literature and governmental organizations in the USA reveals that most efforts are focused on preventing alcohol consumption by pregnant woman. From a far-looking societal perspective, this may be an effective long-term solution; however, the high prevalence of this condition mandates that more interventions are available as long as pregnant women are consuming alcohol. Perhaps a component of the limited focus on FASD is the perception that prenatal alcohol exposure is a moral/legal problem and thus does not warrant as much sympathy and attention by the public, which leads to fewer research dollars, than a condition with similar or less prevalence, such as Autism Spectrum Disorders, which is perceived as being non-preventable. As an example, a search of PubMed using the search terms FASD and Evidence-Based Intervention yields 14 results while a search using the terms Autism and Evidence-Based Intervention yields 152 results. Existing evidence-based interventions often have very limited impact at the broader community level and may not be extended or disseminated beyond the local area in which they are developed. Increased collaboration and multi-site trials would

increase the power of significant findings and allow for more testing of theoretical outcome mediators and moderators.

Another area of concern is that there are only a few groups in the USA consistently publishing research on interventions for FASD, and they can be limited by an absence of graduate students due to being in medical centers or relying upon external grant funding. This could potentially limit the amount of researchers being trained at the graduate level to conduct research in this area in the future.

Pediatric neuropsychologists should work closely with the medical professionals in their community to facilitate early diagnosis of FASD. This mandate for early diagnosis is tied to the dilemma currently facing US health care providers via the multiple diagnostic approaches that have found to identify different labels for children with similar presentations. All health care professionals, including pediatric neuropsychologists, should work to reduce the stigma associated with FASD, advocate for more funding for FASD research, and work with training programs to ensure this important condition receives relatively equal focus as conditions of relatively commensurate prevalence.

Unfortunately, a general lack of knowledge about FASD and multiple systems-level barriers remain that interfere with the identification and appropriate treatment for affected individuals and their families (Petrenko et al. 2014; Ryan et al. 2007). Although most health care professionals are aware of the harm of drinking during pregnancy, many have limited knowledge about how it affects individuals and lack competence in how to serve children and adults with FASD effectively. This lack of knowledge contributes to many systems-level barriers including delayed diagnosis, qualifying for services, general lack of availability of appropriate services, poor implementation of services, and problems with maintaining effective services. Qualitative research (Petrenko et al. 2014) suggests these systems-level barriers likely contribute to the high rates of secondary conditions (e.g., mental health conditions, school problems, legal problems, and substance abuse problems) in individuals with FASD. Petrenko et al. (2014) advocated for public health campaigns and continuing education for providers to increase knowledge about FASD as well as public policy changes to address the identified systemic barriers to diagnosis and intervention for individuals with FASD across the lifespan.

It is important to recognize there is a strong need to increase awareness of the mental health challenges faced by children with FASD within the mental health community. Multiple barriers to treatment exist which may lead some therapists to conclude the patient is resistant to treatment when in fact their behavior is consistent with the pattern of neurocognitive and social difficulties frequently seen in these children and adults (Substance Abuse and Mental Health Services Administration 2014). These difficulties may include following complex multistep directions, remembering appointments, following through on decisions discussed in therapy, interpreting social

cues from the therapist, not disrupting group or family therapy sessions, and remembering and following therapy rules (Substance Abuse and Mental Health Services Administration 2014). More work also needs to be done in educating health care professionals about FASD as a study showed that only 34 % of predoctoral family medicine departments included FASD in the teaching curriculum, and 61 % of residency directors in the American Association of Family Medicine Residency Directors indicated FASD is included in the curriculum (Zoorob et al. 2010).

Finally, there is a substantial need in the USA to increase the integration and collaboration across the systems with which a child with FASD and their family interact. These children encounter multiple organizations and networks which have different classification and treatment protocols which can create confusion for the family. Children and their families must often work with child welfare systems, bureaus of developmental disabilities, school systems, mental and physical health care, juvenile justice, social work, insurance agencies, and the social security system. Families often find these systems confusing and difficult to navigate. Limited coordination exists across systems and provision of services in one system can even preclude or limit participation in another (e.g., in some regions a child in foster care cannot access services through Medicaid-waiver programs in developmental disabilities or mental health systems).

In sum, while the USA is one of the world leaders in regards to producing research and disseminating information about FASD, prenatal exposure to alcohol remains a significant problem and continues to be the most preventable form of significant intellectual and developmental disability in this country. Pediatric neuropsychologists have a unique set of skills given their training to work with children with FASD. A typical pediatric neuropsychological evaluation includes a diagnostic interview and medical records review in which biological, medical, genetic, psychosocial, and environmental risk and resiliency factors are elicited to better understand how prenatal alcohol exposure effects neurodevelopment. Along with neuropsychological test data, this allows for the design of strength-based interventions. Pediatric neuropsychologists, along with other health care professionals, in the USA should continue to be involved, and work to increase their involvement, in the provision of clinical services for these children and families as well as to increase their advocacy at the community and governmental levels.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval This article does not contain any studies with human participants or animals performed by the authors.

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