September 23, 2019

Fetal Alcohol Spectrum Disorders: Policy Challenges and Opportunities

Technical Expert Panel

Draft Meeting Summary

Prepared for

Kristina West, MS, LLM
Mir M. Ali, PhD
Office of the Assistant Secretary for Planning and Evaluation (ASPE)
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Prepared by

Julie Seibert, PhD
Carol Council, MSPH
Alexander Besser, BA
Jesse Hinde, PhD
Sara Karon, PhD
RTI International
3040 Cornwallis Road
PO Box 12194

RTP, NC 27709-2194

RTI Project Number: 0215288.006.002.002.002.007

Contents

1. Introduction

On behalf of The U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation (ASPE), RTI International (RTI) convened a Technical Expert Panel (TEP) to seek input on the current status and future direction of policy research regarding the prevention, identification and intervention efforts related to individuals affected by Fetal Alcohol Spectrum Disorder (FASD). The TEP meeting consisted of a full-day conference held on September 12, 2019. This report provides a summary of the TEP proceedings, detailing the TEP presentations and discussion regarding key barriers and solutions in the prevention, identification and interventions for individuals with FASD.

2. Background

In-utero alcohol exposure may lead to disruption in fetal development, contributing to a wide range of neurobehavioral outcomes known as Fetal Alcohol Spectrum Disorder (FASD) (Mukherjee et al., 2006; Riley et al., 2011). FASD is a non-diagnostic umbrella term used to describe the range of effects that can result from prenatal alcohol exposure (Cook et al., 2016). The term FASD includes diagnoses such as fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD), which may include congenital physical malformations as well as possibly severe physical, mental, behavioral, and/or learning disabilities with possible lifelong implications (ICCFASD, 2011, p. 1; Astley et al., 2010). FASD is estimated to affect between 31 to 99 per 1,000 children in the United States (May et al., 2018). One systematic review found that the estimated cost of FAS in 1980 ranged from $1.937 to $9.687 billion in the United States, with a median estimate of $3.236 billion (Russell, 1980; Harwood et al.,1984). Total lifetime costs of FAS have been estimated to be approximately $2 million per affected individual after adjusting the 1980 cost estimate of $596,000 per individual to 2002 dollars.

The prevalence of FASD in the United States is a significant public health concern. FASD affects a person throughout the course of their life and can involve overlapping physical, mental and behavioral disabilities, so interventions can be very costly. Efforts to prevent FASD through the implementation of effective social policies and intervention programs can be 30 times more cost effective than later treatments and interventions (SAMHSA, 2014; Williams et al., 2015).

To accomplish this and ensure appropriate prevention, identification, and treatment of FASD, we must better understand the current state of the FASD policy landscape and identify gaps in policy research. ASPE contracted with RTI to help identify current and potential areas in which policy may be an effective instrument in FASD prevention, identification, and intervention. RTI began by scanning published and grey literatures, reviewing multiple datasets, and examining the policies in 10 states to gain knowledge about the policy challenges and

opportunities related to reducing the burden on children and families from in-utero alcohol exposure. In addition, RTI organized and hosted a technical expert panel (TEP) to discuss the issues identified through the literature review and the opportunities to move forward.

3. TEP Logistics and Attendees.

The TEP took place in-person at the Hubert H. Humphrey Building in Washington, DC on September 12th. Ten experts participated in the TEP, representing academic researchers and providers, legal representatives, and state officials. They were joined by stakeholder representatives from the American Psychological Association, Child Welfare League of America, National Organization on Fetal Alcohol Syndrome (NOFAS), American College of Obstetricians and Gynecologists, as well as representatives from federal agencies. Staff from ASPE and RTI also participated in the meeting. The participants were nationally recognized as possessing in-depth expertise in the provision and funding of prevention, identification and intervention services for individuals with FASD. ***Exhibit 1*** includes a list of the participants and the organizations they represented. The TEP meeting agenda is located in the ***Appendix***.

Exhibit 1. Technical Expert Panel Attendees

Academic Researcher and Providers/State Officials	
Attendee	**Affiliation**
Christopher Boys, PhD, LP	Pediatric Neuropsychologist, Associate Professor Department of Pediatrics, University of Minnesota School of Medicine
Larry Burd, PhD	Director North Dakota Fetal Alcohol Syndrome Center Department of Pediatrics, University of North Dakota School of Medicine
Susan Carlson, JD	Former Minnesota First Lady; Minnesota Organization on Fetal Alcohol Syndrome (Proof Alliance); Retired Minnesota District Court Judicial Officer
Michael E. Charness, MD	Chief of Staff, Professor, Faculty Associate Dean Harvard Medical School; Boston University School of Medicine; VA Boston Healthcare
Claire Coles, PhD	Director Maternal Substance Abuse and Child Development Program (MSACD) Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine
William Edwards, JD	Deputy Public Defender Los Angeles County
Heather Carmichael Olson, PhD	Professor Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine
Marilyn Pierce-Bulger, MN, FNP-BC, CNM	Vice President Alaska Center for FASD
Edward Riley, PhD	Distinguished Professor of Psychology Department of Psychology, College of Sciences, San Diego State University
Yasmin S. Senturias, MD	Medical Director, Professor Atrium Health & Department of Pediatrics, University of North Carolina, Chapel Hill
Stakeholders	
Attendee	**Affiliation**
Maggie K. Butler, PhD, CRC	American Psychological Association
Julie Collins, MSW, LCSW	Child Welfare League of America, Inc.
Tom Donaldson	National Organization on Fetal Alcohol Syndrome
Mishka Terplan, MD, MPH, FACOG, FASAM	American College of Obstetricians and Gynecologists

Federal Officials	
Attendee	**Affiliation**
Tatiana Balachova, PhD	National Institute on Alcohol Abuse and Alcoholism (NIAAA)
Jon Dunbar-Cooper, MA, CPP	Substance Abuse and Mental Health Services Administration (SAMSHA)
William Dunty, PhD	National Institute on Alcohol Abuse and Alcoholism (NIAAA)
Shahla Jilani, MD	Office of the Assistant Secretary for Health
Dawn Levinson, MSW	Health Resources and Services Administration
Sharon Newburg-Rinn, PhD	Administration on Children, Youth and Families
J. Alice Thompson, MA	Center for Medicare & Medicaid Innovation, Centers for Medicare & Medicaid Services (CMS)
Mary Kate Weber, MPH	Centers for Disease Control & Prevention (CDC)
Tineka Yowe-Conley, MPA	Centers for Disease Control & Prevention (CDC)
Brenda Destro, MSW, PhD	Office of the Assistant Secretary for Planning and Evaluation
Arne Owens, MS	Office of the Assistant Secretary for Planning and Evaluation
Erin Bagalman, MSW	Office of the Assistant Secretary for Planning and Evaluation
Emily Madden	Office of the Assistant Secretary for Planning and Evaluation
Project Team Members	
Attendee	**Affiliation**
Kristina West, MS, LLM	Office of the Assistant Secretary for Planning and Evaluation
Mir Ali, PhD	Office of the Assistant Secretary for Planning and Evaluation
Julie Seibert, PhD, MPH, MA	RTI International
Carol Council, MSPH	RTI International
Alexander Besser	RTI International

TEP attendees were asked to discuss the key issues related to reducing the toll on children and families that comes from neonatal exposure to alcohol, and to help ASPE and RTI obtain answers to the following overarching research questions:

1. What is the state of the evidence to support policymaking related to *preventing FASDs*?
    a. Is the evidence in public health, medical care, child welfare, or other fields?
    b. Where are the gaps in the evidence base?
    c. Where are the opportunities to improve the evidence base?
    d. What evidence-based practices are not currently supported by policy?
2. What is the state of the evidence to support policymaking related to *identifying FASDs*?
    a. Is the evidence in public health, medical care, child welfare, or other fields?
    b. Where are the gaps in the evidence base?
    c. Where are the opportunities to improve the evidence base?
    d. What evidence-based practices are not currently supported by policy?
3. What is the state of the evidence to support policymaking related to *intervening with affected individuals*?
    a. Is the evidence in public health, medical care, child welfare, or other fields?
    b. Where are the gaps in the evidence base?
    c. Where are the opportunities to improve the evidence base?
    d. What evidence-based practices are not currently supported by policy?

This document serves as a summary of the panel discussion.

4. TEP Discussion Summary

Environmental Scan Summary

In preparation for the TEP, RTI conducted the aforementioned environmental scan and provided the results of the scan to TEP attendees prior to the meeting. In addition, RTI presented the major findings from the scan during the TEP meeting for attendee consideration.

The results of the scan fell along eight topics: (1) FASD prevention, (2) identification, and (3) intervention; (4) the role of health and community providers in FASD prevention, identification, and intervention; (5) the role of the criminal justice system in FASD prevention, identification, and intervention; (6) state punitive versus supportive policies impacting pregnant women with substance use conditions; (7) the current status of state FASD programs and policies; and (8) the current status of databases.

In reviewing the policy literature regarding prevention of FASD, RTI found a lack of conclusive evidence for risk factors for an alcohol-exposed pregnancy (AEP). Studies have yet to determine the role of age, race, and education level as risk factors for an AEP. However, other factors, such as pre-pregnancy alcohol consumption, homelessness, and abuse were noted as general predictors of FASD. The policy research literature suggests that identifying the risk factors for an AEP may greatly facilitate the development of a targeted prevention approach to FASD to focus prevention efforts on women at greatest risk of an AEP. The other prevention approach discussed in the literature, a universal approach, targets all women and aims to prevent alcohol exposure prior to and during early pregnancy (Roberts et al., 2017; Floyd et al., 2009; SAMHSA, 2014; CDC, 2016; CDC, 2019; Dejong et al., 2019; Green et al., 2016; O'Leary & Bower, 2012; Waterman et al., 2013). Challenges and opportunities were identified for both targeted and universal approaches and a third approach that utilized a combination of these approaches. The combined (third) approach was first proposed by the Institute of Medicine (IOM) in 1996 and adopted by other federal agencies, including the Centers for Disease Control and Prevention (CDC) and the Substance Abuse and Mental Health Services Administration (SAMHSA).

If alcohol exposure during pregnancy is not prevented and results in FASD, screening and diagnosis often require an in-depth assessment involving a comprehensive family history, consultations with occupational and speech pathologists, genetic testing, and several types of standardized testing (Hoyme et al., 2016; Jirikowic et al., 2010). Because all these components are necessary to make an official diagnosis, cases of FASD are frequently underreported or misdiagnosed (Peadon et al., 2010; Pomeroy et al., 2013; Brown et al., 2012; Chasnoff, Wells, & King, 2015). The use of multidisciplinary teams, consisting of pediatricians, psychiatrists,

occupational therapists, and special educators, was identified as a means to effectively identify, diagnose, and intervene in cases of FASD (Hoyme, et al., 2016).

Once individuals are accurately diagnosed, interventions can be implemented to lessen the impact of FASD, with early interventions generally having the greatest potential impact on developmental outcomes (Peadon & Elliott, 2010; Zarnegar et al., 2016). Intervention approaches vary by diagnosis and individuals. Some experts recommend that interventions for FASD begin with a comprehensive neuropsychological examination to evaluate deficits and create a tailored care plan. In order to successfully implement behavioral interventions, providers must understand the needs of children with FASD at each stage of development.

FASD is a multifaceted condition, and interventions can be applied from several different perspectives, some outside the medical and social services fields (Jirikowic et al., 2010; Kodituwakku et al., 2010). As noted in the literature, the most effective interventions come from within the community that is being targeted. Culturally competent care is essential to identify at-risk mothers and encourage them to reduce their drinking habits, and to provide appropriate services among those with FASD (Rentner, et al., 2012; Brems, et al., 2010). Through effective identification and interventions, providers can significantly help parents and caregivers of FASD-affected children, particularly those who are foster or adoptive parents. Once parents or caregivers are aware of their child's condition, they can begin to access resources from their child's pediatrician, online, or even through engaging with other families who have children with a similar diagnosis (Dewane, 2011; Kable, Coles, Strickland, & Taddeo, 2012). With the help of these resources, caregivers can structure home life in a way that is conducive to the child's growth and protective against the adverse effects of the condition (Dejong, et al., 2019; Paley & Auerbach, 2012).

The findings of the scan suggest that FASD is a particularly significant challenge in the context of the United States criminal justice system. One study of adolescents with FASD found that 60 percent had been arrested (Bisgard et al., 2010) or charged with a crime, and 55 percent had been confined at some point in inpatient treatment facilities, psychiatric hospitals, or corrections facilities (NOFAS, 2014). It is very likely that individuals with FASD are disproportionately represented in the criminal justice system (Brown, Connor, & Adler, 2012) and the true number of cases of FASD among inmate populations could be as high as several hundred thousand. There are opportunities to prevent or lessen the societal impact of FASD by working within correctional settings to curb alcohol use among women at risk of AEP and provide opportunities for diagnosis or intervention services among those affected by FASD within these settings.

The environmental scan found that since 1974, there has been a dramatic increase in the number of state policies targeting women's alcohol use during pregnancy (1 in 1974 to 43 in 2013) (Roberts et al., 2017). However, many of these policies are punitive, which are found to be

less effective than supportive approaches such as increasing the availability of prenatal care and substance abuse treatment (Pomeroy & Parrish, 2011).

The scan found limited database resources for studying FASD, although several databases were identified with variables that can be isolated to identify risk of AEP. The augmentation of datasets to support further analysis of FASD populations is one potential opportunity for improving our understanding of FASD. Claims data provides another opportunity to research the implications of FASD. Other potential focus areas for future research include identifying risk factors for AEP, multidisciplinary approaches for FASD identification, and improving FASD diagnosis and care within the criminal justice system (Howard et al., 2019).

State Approaches to FASD

The presentation on the environmental scan was followed by presentations on state efforts to prevent, diagnose and provide support to individuals with FASD.

Minnesota

Christopher Boys, PhD, and Susan Carlson, JD, provided an overview of the history, current status and future directions of FASD programs and policies in the state of Minnesota. The momentum for much of the initial work on FASD in the state came from a 47-member Governor's Task Force of FAS convened in 1997. The Task Force released a report which provided the impetus for approximately $5 million in funding for public awareness efforts, special treatment programming and research on the incidence of FASD in the state. The funding also supported the creation of a state FASD Coordinating Board and supported polices for voluntary reporting of alcohol abuse during pregnancy. Unfortunately, in 1999 much of the funding was folded into other state chemical dependency programming and the FASD Coordinating Board, research, and diagnostic clinics were eliminated. In 2004, however, the state secured funding for prevention and intervention programs under a program called MOFAS/Proof Alliance. MOFAS/Proof Alliance has become a model public/private partnership in FASD prevention, reaching over 5,400 individuals training in FASD topics, over 293,000, individuals through social media efforts and over 1,200 contacts with caregivers of individuals with FASD, during fiscal year 2018. The state of Minnesota identified many lessons learned in provision of prevention, identification and intervention services for individuals affected by FASD, which included the need to understand the evidence base, the need for the involvement of community stakeholders, and the need to build partnerships outside the FASD world.

The Hennepin County FASD Screening Program was cited as a successful component of Minnesota's programs addressing FASD. This project involved FASD screening and identification of adjudicated delinquents in Hennepin County District Court. From 2008 to 2012 a significant number of youths were screened and subsequently diagnosed with FASD. This

program resulted in a better understanding of FASD among professionals treating youth and better outcomes in recidivism and school success for identified youth.

Minnesota currently benefits from a strong resource for identification of individuals with FASD through the University of Minnesota Fetal Alcohol Spectrum Disorders Program. This program conducts approximately 450 evaluations per year and supports multiple ongoing research projects. The program also provides training on FASD to school districts. The Minnesota Department of Health, as a part of Newborn and Child Follow-Up, screens for FASD in all newborns. Since 2017, the state has supported training for foster parents regarding FASD, a result of a state law mandating newly licensed foster parents to receive training on parenting strategies for children with FASD.

Additional policies in Minnesota that have an impact on FASD include Chapter 361-H.F.No. 3184, , passed in 1998, which outlines voluntary reporting requirements of alcohol abuse during pregnancy. The 1998 law was modeled after reporting laws for illicit drug use during pregnancy and mandated that reporters under the child abuse reporting act (known as the Maltreatment of Minors Act) were permitted, but not required, to take one of the three actions if they had reason to believe a pregnant woman knowingly abused alcohol during pregnancy. These actions included arranging for a chemical use assessment, reporting to a local Maternal Child Substance Abuse Project, or reporting to a local child welfare agency. This law further ensured follow up occurred. More specifically, the law clarified that if a pregnant woman completed the chemical use assessment and followed recommendations, no further action needed to be taken. If the woman refused to cooperate, a report had to be made to the appropriate agency. If the assessment indicated the woman needed treatment, treatment services had to be arranged. Refusal on the part of the woman could provide the basis for civil commitment procedures. In 2007, the Minnesota law was revised to update the definition of chemically dependent and mandate reporting of chemical use. Specifically, chemically dependent became defined as a pregnant woman who was engaged in habitual or excessive substance use and determining a woman's chemical dependency no longer required an assessment to substantiate it. The revised law also mandated reporting for professionals such as social workers.

Washington

Heather Carmichael Olson presented a description of FASD activities and policies underway in the state of Washington. During the early 1990s the State acknowledged the problem posed by FASD and undertook a statewide prevention program to counter this growing health problem. She presented evidence that a well-organized statewide prevention program could impact FAS and noted that the prevalence of drinking during pregnancy dropped in Washington State from 15% to 4% and the prevalence of FAS births dropped from 7% to 2% between 1993 and 1998. Growing interest in FASD led to the development of important resources within the state including:

- Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN)-housed with the University of Washington. Includes a rich database for use by researchers as well as a resource to inform state policy;
- Fetal Alcohol and Drug Unit (FADU)-housed at the University of Washington. Includes multiple datasets available to be used in research;
- Families Moving Forward (FMF) Program and Research Lab – Based at the Seattle Children's Research Institute – includes a database available to be used as a model for program evaluation and to create derivative intervention products and programs;
- Parent-Child Assistance Program (PCAP) – Has database available to inform state policy and to enable program evaluation and is vital to the identification of best practices and to guide the development of effective state policies addressing FASD;
- Washington State FASD State Coordinator – part of Washington's Division of Behavioral Health. A state coordinator can manage FASD-related activities and enhance the effective utilization of limited resources and actively advocate for needed funding and/or policy adjustments to the state legislature.
- NOFAS Washington State (NOFAS WA) – parent support and advocacy organization;
- Numerous community partnerships.

Washington has also implemented an approach to diagnosis with an interdisciplinary evaluation team that uses a 4-Digit Diagnostic Code. This code is a simple, comprehensive, evidence-based method for diagnosing the full spectrum of outcomes observed among individuals with prenatal alcohol exposure. It provides accurate and reproducible diagnoses by using quantitative, objective measurement scales, and specific case-definitions. It has been used to diagnose thousands of patients in the WA State FAS DPN clinics over the past 20 years. Additionally, Washington has developed key policies in establishing Developmental Disabilities Administration (DDA) eligibility for FASD cases diagnosed with the 4-digit code, and a foster care screening program. The PCAP database has proved invaluable to policy makers and program developers in demonstrating outcomes from policies.

With regard to FASD intervention efforts, the State is providing family, parent, foster parent and adoption training and support. The State is working closely to develop its workforce, including child welfare workers and chemical dependency workers as well as educators.

FASD Prevention – Barriers & Solutions

Presentations made about FASD initiatives in Washington gave compelling evidence that improvements in prevention can result in reductions in FASD diagnoses. For example, the prevalence of drinking during pregnancy dropped from 15% to 4% and the prevalence of FAS births dropped from 7% to 2% between 1993 and 1998 in Washington State due to prevention initiatives undertaken (Astley, 2004). The goal of all prevention activities should be zero alcohol consumption by pregnant women. However, since approximately half the pregnancies in the US

are unplanned and the number of women who binge drink also remains high, more prevention activities are needed (Dejong et al., 2019 and Mitchell, et al., 2018). Prevention activities should be based on accurate estimates of the prevalence of these disorders. During the day's proceedings, the TEP was divided into three subgroups. The prevention subgroup was charged with identifying key challenges to FASD prevention and identifying possible solutions to each. Three prevention approaches considered by the TEP were:

- Universal prevention-an approach targeting the entire population without regard to individual risk factors.
- Selective prevention - an approach focused on one or more subgroups of the population determined to be at risk of having a child with an FASD.
- Indicated prevention - targeted prevention directed at individuals who are manifesting signs or symptoms of an alcohol use disorder (AUD) who are of childbearing age, possibly pregnant or not using birth control or women who have already given birth to a child with FASD.

Barriers: Several TEP attendees reported that public service announcements (PSAs) and screening and brief interventions (SBIRTs) which are supposed to be universally applied to women of childbearing age are not reaching the entire target population but rather are focused on select socio-demographic groups that are believed to be more vulnerable to exposure than others. The TEP attendees cited evidence from the literature that white middle-class women cut down on their drinking but do not stop. This may be due to messaging that it is acceptable to have one or two drinks while pregnant. TEP attendees reported that even when screening occurs and women are identified as pregnant, they do not always receive the same message/guidance that consuming even one drink may be harmful to the unborn child.

> **Solution:** Health care providers need to provide the same guidance to all pregnant women. Further, messages should be consistent across state agencies, i.e., social services, child welfare, public health, community health and behavioral health providers. As a first step, training needs to be provided to health care providers/screeners to alert women from all socioeconomic groups of the risk. As described in the environmental scan, culturally competent care is essential in identifying at-risk mothers and encouraging them to reduce their drinking habits (Rentner, et al., 2012; Brems, et al., 2010). The scan suggested that universal prevention to reduce disparities in screening by removing ad-hoc judgements as to who should be targeted and capture women who might not be targeted due to preconceptions regarding risk factors (O'Brien, 2012). One TEP attendee spoke of the importance of developing messaging for tribal groups suggesting that researchers work with tribal leaders, especially those on the National Indian Health Board, to develop effective messages.

Barriers: Most prevention messages are perceived to convey negativity and shame toward women who drink while pregnant. Examples of negative messaging were warning labels on alcohol bottles and signs posted in bars and restaurants. The TEP attendees believed that such negativity contributes to underreporting of alcohol use by pregnant women.

Solution: Reframe FASD prevention messaging to project a positive message – "So you want to have a healthy baby- to have a healthy baby, take care to eliminate alcohol." The TEP also recommended including males in messaging. Fathers want to have healthy children and could be supportive by cutting down the amount of alcohol they drink around their female partners.

To reframe messaging, the TEP suggested that ASPE or NIAAA set up a national task force to review alcohol and public health messaging and develop targeted messaging for different age and cultural groups. Also suggested was the use of a media company. Advertisers, especially those working with the alcohol and tobacco industries are very knowledgeable about pathways to promote use of alcohol. The TEP felt that they could put this knowledge to use in creating positive messaging that would promote a focus on having a healthy child. The TEP underscored the fact that prevention messages can bring about change and cited the effectiveness of seatbelt campaigns as an example.

The aforementioned task force could also be used to create a less stigmatizing messaging for pregnant women using alcohol that offers help to them so they can take steps to obtain chemical dependency treatment and improve the likelihood of a healthy baby. A caution was added that every effort should be made provide rapid access to care for pregnant women when they indicate they are ready for AUD treatment. Often people placed on waiting lists change their minds and may be lost to treatment.

Barrier: Lack of knowledge regarding which prevention messaging is most effective. This is absent for all three types of prevention described above.

Solution: TEP suggested conducting research on effective messaging and thought this might be accomplished through the use of a media company with evaluation capabilities.

Barrier: Lack of political support, perhaps as the result of strong lobbying efforts by the alcohol industry, combined with a growing focus on opioid misuse, Neonatal Abstinence Syndrome (NAS) babies and opiate deaths has resulted in declining interest in prevention efforts around FASD. The lack of credible surveillance of this problem also contributes to this barrier.

Solution: Develop a national communication strategy using new messaging. This solution would work to identify and recruit celebrities to act as FASD champions. Additionally, the development of positive social media campaigns would be beneficial. To overcome these barriers, several TEP attendees discussed the use of celebrity influences and working of messaging into TV programming and social media.

Barrier: Failure of health care providers to screen for, identify and provide referrals for services. This is coupled with providers not being adequately trained to talk with patients and refer them for needed addiction treatment services as well as FASD services. TEP attendees reported that

some providers do not want to identify AEP women because AUD treatment for them is not readily available.

> **Solution.** As mentioned in our environmental scan, implementing evidence-based approaches to reduce both risky drinking and using effective contraception in primary care settings could dramatically reduce the risk of alcohol-exposed pregnancies (Velasquez, et al., 2017). The TEP was supportive of training health care providers to teach them to effectively screen all women of childbearing age and provide brief guidance on the importance of alcohol abstinence if not using contraceptives and engaging in unprotected sex. These providers also need to be instructed on how to connect women needing treatment to providers in the community.

Barrier: Limited funding for prevention activities including universal screening and elimination of SAMHSA's Center for Excellence in FASD has resulted in development of many prevention messages that remain untested or not evaluated for efficacy.

> **Solution:** Approach foundations and public private donors to contribute to funding a national FASD communication strategy. Include insurers and managed care companies in developing strategies to incentivize alcohol cessation for women in Medicaid managed care and enhance mechanisms for getting women rapid access to care when they present for it. Also, explore pro-bono contributions from media companies and perhaps the liquor industry. One TEP member mentioned that the liquor industry frequently sponsors the development of targeted anti-alcohol messages to discourage underaged drinking.

Other barriers mentioned by the TEP for which solutions were not identified include:

- *Integration of FASD screening and diagnosis into the system of care*. The TEP felt that additional work was needed to incorporate screening and, when appropriate, diagnosis into systems such as Medicaid. This could also be supported by health insurers that could benefit substantially from decreases in the incidence of FASD.
- *Explore the use of civil commitment options to promote women to get treatment*. The TEP highlighted that this was a complicated policy challenge and that more research was needed in the development of various forms of civil commitment to better understand its impact on reporting of alcohol use by pregnant women to lessen the punitive effect of such policies. One TEP mentioned that in their state, if a woman sought obstetrical care while pregnant, the providers was not required to report her to the authorities.
- *Identification and engagement of influencers*. Several TEP attendees suggested that research be undertaken to identify best role models to promote abstinence during pregnancy.

FASD Identification – Barriers & Solutions

As previously described, TEP attendees were invited to convene into three subgroups in order to address the primary policy research topic areas of prevention, identification and intervention. The identification subgroup was charged with building upon the information provided through the environmental scan, the state presentations and their individual expertise, identifying key barriers or challenges to identification of FASD and brainstorming possible solutions for the most pressing barriers. The most important, or pressing, barriers for identification were identified through TEP attendee "votes." The identified barriers and solutions are outlined below.

Barriers: Although not identified in the policy FASD policy environmental scan, TEP attendees concurred that a major barrier to identification of FASD is the lack of a single, unifying FASD diagnosis. Some TEP attendees stated that the current diagnoses functioned as silos and that the field would be better served by a single diagnosis that harmonized different diagnostic schemes. Some TEP attendees discussed the need to configure the FASD diagnostic criteria to address diagnostic subgroups or clusters based on functional status.

> **Solution:** One solution that is already planned is the establishment of a task force to harmonize the research classification system. The National Institute on Alcohol Abuse and Alcoholism (NIAAA), will convene a group to review FASD classification from a research perspective in October 2019. Several TEP attendees were hopeful that the proceedings from this meeting would pave the way for consolidation of a FASD diagnosis.
>
> One TEP attendee suggested following the example that the American Psychiatric Association (APA) employed with previously existing multiple autism diagnoses. With the APA publication of the Diagnostic and Statistical Manual of Mental Disorders V, multiple disorders were collapsed into a single diagnosis of Autism Syndrome Disorder. TEP attendees suggested this strategy could be applied to FASD.

Barriers: TEP attendees concurred that lack of resources to diagnose FASD was a major barrier. The lack of resources included the lack of multidisciplinary teams to conduct thorough assessments, as well as lack of trained staff such as pediatricians, psychologists and occupational therapists who could effectively screen and diagnose, or refer out for diagnosis, affected individuals. One TEP attendee stressed the disconnect between available resources and the estimated five percent of first graders in the United States that have been affected by in utero alcohol consumption. Existing staff who are trained to provide FASD screening and diagnosis cannot even begin to meet the estimated need. Additionally, it was noted that rural areas have even fewer professionals to provide needed screening and diagnostic services.

> **Solution:** TEP attendees stressed that multidisciplinary teams are not required for an adequate FASD assessment; but that an assessment should be conceptualized as a multidisciplinary diagnosis. TEP attendees indicated there is no need for all professionals to be located in the same building. Telemedicine can be utilized to expand existing screening and diagnostic resources. Models such as Project ECHO, a hub and spoke model that links expert specialist teams at an academic 'hub' with clinicians in local communities

- the 'spokes' of the model could be adapted to expand FASD resources. Programs which provide psychiatric teleconsultation to pediatricians and family care practitioners, such as the program supported by the Massachusetts Child Psychiatry Access Program, should also be considered.

Barriers: A lack of screening tool or universal screening process was cited as a barrier to identification of individuals affected with FASD.

Solution: One TEP attendee mentioned that technology, such as artificial intelligence (AI), shows promise in assisting with screening for FASD diagnoses that involve craniofacial dysmorphologies however, availability to the public is likely three to five years in the future. Using this technology, individuals could simply have pictures taken of their face which could be uploaded for screening purposes using AI. Individuals with positive screens could be referred for intensive clinical screening and diagnostic assessment. The TEP attendee indicated there are presently barriers to use of this technology which include barriers to payment for telehealth, barriers to protecting personal health information, barriers to training or resistance in clinicians in using AI. Potential barriers raised by one TEP attendee included the need to create norms using the AI technology across different races, cultures and other populations. Also, the lack of harmonization of the FASD diagnostic schemes impedes the implementation of AI to assist in screening and diagnosis.

Barriers: Associated with the lack of professional staff available, TEP attendees cited the lack of training for screening and identification of FASD for frontline professionals as a major barrier. TEP attendees noted that pediatricians were hesitant to diagnose or refer for a multidisciplinary assessment and that even with training many pediatricians did not feel competent to diagnose. TEP attendees stated that early intervention professionals are also not sufficiently trained to screen or identify for warning signs for FASD in order to ensure appropriate referral for diagnosis. Child welfare workers were also identified as requiring additional training and resources. It was noted that child welfare workers are currently not asking the right questions to identify FASD as part of their routine assessments.

Solution: Several solutions were mentioned by TEP attendees to address the lack of training for professionals who work with children who are at risk for FASD. Some solutions were targeted for physicians, including changing medical school policies so that medical school curricula include training in FASD. Other solutions aimed towards increasing FASD training opportunities for physicians included requesting the American Board of Pediatrics add a board question related to FASD and developing training modules specific to FASD for residents. FASD training that offered continuing education credits for pediatricians was also offered as a solution. TEP attendees stated there are several existing training resources, such as those developed by the American Academy of Pediatrics that should be marketed to pediatricians and other health care professionals. Additionally, TEP attendees cited the CDC-funded FASD champions, stating these individuals could be tapped to provide talks and grand rounds focusing on screening, referral and diagnosis of FASD.

Barriers: Funding was cited as a barrier in the identification of individuals with FASD. Some TEP attendees indicated that this could impact multidisciplinary evaluations since third party payers typically do not allow "stacked" appointments or multiple appointments with different professionals on the same day. This requires well-coordinated appointments for evaluations for several different professionals. Once the evaluations are complete, there is no funding for the interpretation of the different evaluations which are critical in making a diagnosis and determining the plan of care.

Solution: Some TEP attendees pointed to the emerging alternative payment models as a way to resolve some of the funding concerns regarding screening and performing an adequate assessment. One TEP attendee suggested adapting the concept of the medical home and include it as a part of the multidisciplinary team. Care coordination funding could be used to pay for coordination of assessment appointments as well as the interpretation of the assessments. One TEP attendee also pointed to the Virginia Medicaid system which supports a "preferred" clinic category. These clinics receive a higher per member per month payment that could be leveraged to cover FASD screening and diagnosis costs that are not currently covered.

Other barriers to identification discussed by the TEP attendees for which solutions were not identified include:

- *Stigma associated with FASD.* TEP attendees noted that due to the stigma associated with FASD, pediatricians were hesitant to mention this diagnosis to mothers and were also more likely to use less stigmatizing diagnosis for their children.
- *Identification of adolescents and adults with FASD.* TEP attendees noted it can be very difficult to obtain exposure histories for individuals when they are older and potentially estranged from family members, thereby making diagnosis of FASD difficult. Facial changes that occur as individuals age also pose difficulties in screening and diagnosing older individual who potentially have FASD. Also, there are difficulties in determining if other environmental factors, such as abuse or neglect, are the cause of behavioral characteristics of FASD, thereby posing barriers in differential diagnosis in adolescents and adults.
- *Provider burden*. Some TEP attendees noted that increasing requirements for physicians to receive training and universally screen for FASD could be met with resistance. TEP attendees noted that if the focus is increasing identification of FASD, providers may request that other requirements be dropped so as not to overburden them.

FASD Interventions – Barriers & Interventions

The intervention subgroup was charged with identifying key barriers or challenges to implementation of interventions for individuals affected with FASD. After voting for the most

important barriers, the group outlined possible solutions for the top barriers. Identified barriers and solutions are provided below.

Barrier: Many TEP attendees identified that state and federal disability definitions do not currently include FASD among qualifying disabilities. TEP attendees noted that the FASD diagnostic category is absent from many human services system disability definitions which could support needed services and interventions. This includes the educational system, corrections, child welfare, behavioral health and other human services agencies.

> **Solution:** TEP attendees stressed the importance of the inclusion of FASD in state and federal disability definitions. Some TEP attendees noted that the inclusion of deficits in adaptive behavior or adaptive functioning in the disability definition would help solve the issue of individuals with severe deficits unable to receive needed disability services and supports.
>
> Since so many children with FASD receive their services primarily through the school system, TEP attendees emphasized the importance of weaving the FASD definition into the Individualized Education Plan (IEP) definition. One TEP attendee noted that in Alaska, children with FASD are automatically referred for special education services. It was noted that not all children received an IEP but were covered under a Section 504 plan instead.

Barrier: With regard to model FASD programs, TEP attendees in the intervention breakout group echoed the sentiments of the identification breakout group, stating that the existing model programs are insufficient to meet the needs of individuals affected by FASD who require specialized services. These programs also do not typically serve individuals with FASD across the lifespan. Finally, some TEP attendee noted that model programs are not implemented with fidelity. Despite these barriers, some model programs and effective interventions were noted by TEP attendees including the Math Interactive Learning Experience (MILE), Parents and Children Together (PACT), Families Moving Forward (FMF) Language to Literacy Program and USFA Kids.

> **Solution:** TEP attendees advocated for strategic planning to enhance existing model programs, stating this process could identify gaps in the current system and could identify ways to address the issue. One example promoted by TEP attendees was for model programs to engage in implementation of telepsychiatric consultation for pediatricians in order to expand outreach efforts.

Barrier: The majority of TEP attendees indicated that funding and reimbursement were major barriers in accessing adequate services for individuals with FASD. TEP attendees noted that due to lack of inclusion of FASD in many disability definitions, reimbursement for services is typically tied to the co-occurring disorder; therefore, service needs are addressed in an uneven fashion. Also, TEP attendees discussed state level variation in how services are reimbursed, an additional barrier to access.

Solution: TEP attendees noted that alternative payment models may offer solutions in paying for identification and provision of services and supports for children with FASD. For example, the Integrated Care for Kids (InCK) Model could be used by states as a funding mechanism to increase screening and treatment of children with FASD. InCK is a child-centered local service delivery and state payment model designed to reduce expenditures and improve the quality of care for children covered by Medicaid. The model includes prevention, early identification, and treatment of behavioral and physical health needs and will serve to support care integration across all types of health care providers. States are currently applying for funding for these models and, as of September 2019, applications are under review. States who are awarded funding have a two-year planning window, which is an opportunity for FASD stakeholders to contact states to advocate for inclusion of FASD in the model.

Barrier: TEP attendees noted that many individuals with FASD are being served by the correctional system, which, as noted in the environmental scan, is stretched to provide appropriate services and supports.

Solution: TEP attendees suggested that provision of education to critical staff in the corrections system could alleviate this barrier. Suggested staff include prison staff, parole officers, and juvenile court officers.

TEP attendees noted that Alaska engages in best practices in working with the corrections systems by providing training in FASD to parole officers, judges, district attorneys, and public defenders. TEP attendees remarked that state law in Alaska requires judges to consider FASD in defendants as a mitigating factor. A law passed in 2012 allows judges flexibility in sentencing people with FASD in certain cases where there is clear and convincing evidence that the defendant's judgement or behavior was impaired due to an FASD diagnosis. Also, TEP attendees discussed a special FASD court in Barrow, AK in which the judge uses his background and learning about FASD to attempt to make the justice system more understandable and fairer to persons affected by FASD. TEP attendees suggested that other states could adopt the strategies and policies implemented in Alaska.

Other barriers to interventions for persons affected by FASD discussed by the TEP attendees include:

- *Health workforce.* TEP attendees noted the wide range of providers that are required in treatment interventions for persons with FASD, making care coordination difficult. TEP attendees also stated that the configuration of necessary providers changes as the individual with FASD ages, causing further issues with care coordination efforts.
- *Location of identification of FASD influences treatment.* TEP attendees observed that early intervention services, which typically include interventions that lessen developmental delay and include such services as speech therapy, occupational

therapy and physical therapy, can only be provided up to age three through Individuals with Disabilities Education Act (IDEA) Part C. After the age of three, services for children are provided through the school system by way of IDEA part B. Depending upon when a child is diagnosed, the types of services and supports may vary. One TEP attendee remarked that schools typically focus on learning skills instead of life skills and that a child with FASD might not receive needed skill development through the school system.

Future Considerations/Research Topics

TEP attendees provided several suggestions for research topics to support future effective policy making. Interestingly, one TEP attendee mentioned that there appears to be little evidence-based policy making or evaluation on this topic. TEP attendees determined that minimally definitions of policy and policy-relevant outcomes are needed.

Specific policy research areas identified included:

Surveillance System Databases. Several TEP attendees stressed that the key to all prevention, identification and intervention planning, evaluation and research is the development of an effective surveillance system that can identify the nature and extent of the problem. Based on the literature and opinions of TEP attendees, it is believed that a comprehensive surveillance system is needed to understand the magnitude of the problem. A TEP mentioned that "a good identification system could reduce the likelihood of misdiagnosing and missing numerous cases." At the present time, we do not even know the number of newborns prenatally exposed to alcohol. The existence of a comprehensive database would enable policy makers to determine the incidence and prevalence of various types of FASD and to quantify expenditures related to them. Such a database would also require the identification of tools to categorize types of FASD. Additionally, the database should also contain demographic characteristics of mothers of these FASD children as well as other substances they may have used during pregnancy. An interesting research study could compare existing protocols for identification of women using alcohol while pregnant. Several TEP attendees advocated the enhancement of existing databases to this end and commented that the existence of such a database would enable outcome evaluation of different approaches to prevention and intervention.

Definition and Classification Systems. The need for precise definitions and the generation of a classification system for FASD is a research requirement called out by many TEP attendees. At the present times, states, Medicaid systems, insurers, tribal entities and the medical profession use different definitions and classification schemes. The field needs research to refine these and to develop guidelines for using them when establishing eligibility for treatment. For example,

within school systems FASD should be an IEP category. Ideally these definitions and classification system would be consistently applied across the U.S.

Health Systems of Care. Some TEP attendees asked for research on effective ways to include FASD screening and referral as well as screening and referral for alcohol abusing women of parenting age in medical and nursing school curricula. Training of physicians and other health workers should include the need for universal prevention messaging to all women of childbearing age not just those of select cultural groups. Similarly, one TEP attendee mentioned that potential fathers also be included in messaging. Additionally, behavioral health clinicians need FASD-specific training to understand that many evidence-based practices that they currently employ need modification to be effective with FASD clients.

Criminal Justice System. Many attendees of the TEP requested that more research be conducted to identify the prevalence of FASD in the criminal justice population with separate consideration given to adult versus adolescent offenders. TEP attendees were also interested in identifying which interventions have been used and which of these produced positive outcomes for criminal-involved inmates and which have produced positive outcomes.

*Funding***.** Several TEP attendees discussed the complicated funding environment that exists for FASD and the need for a comprehensive assessment of expenditures related to FASD, especially across the lifespan. Several attendees mentioned how complicated it is for states and programs to understand the funding environment for FASD and to identify how much is actually being spent on FASD, particularly in those areas that use braided funding. Similarly, they thought that a good assessment of the actual costs associated with best practices in FASD care across the lifetime would enable states to compare their actual funding need with their current funding/service capacity. As a starting point, some suggested identification of states with sustainable funding and an exploration of how they evaluated the need for services and their state's capacity to address those needs. (Additionally, when generating cost estimates, it is important to remember that current treatment to address the problem is not universally available even in those children diagnosed with FASD.)

Effective Practices. TEP attendees support the identification of best practices currently utilized to deal with FASD clients in special population groups such as child welfare, adoptive and foster parents. More research is needed to identify current practices, and which generate supported or promising outcomes that could meet Family First Prevention Services Act requirements. Especially needed is research in terms of effective medication regimens and for which subcategories of FASD they are most effective.

Prevention. Several TEP attendees underscored the need for positive messaging related to FASD and suggested that it would be valuable to understand which messages work with various subgroups of the population. One suggested that a countervailing force to alcohol advertising and

social normative behavior might be the identification and engagement of a celebrity as an 'influencer' to promote the creation of healthy babies. Additionally, it would be very valuable to conduct research into approaches to civil commitment that are perceived as supportive rather than punitive.

5. References

Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *The Canadian Journal of Clinical Pharmacology = Journal Canadien De Pharmacologie Clinique*, 17(1), e132-164.

Astley, S. J. (2004). Fetal alcohol syndrome prevention in Washington State: Evidence of success. *Paediatric and Perinatal Epidemiology*, 18, 344-351.

Bisgard, E. B., Fisher, S., Adubato, S., & Louis, M. (2010). Screening, Diagnosis, and Intervention with Juvenile Offenders. *The Journal of Psychiatry & Law, 38*(4), 475–506. doi:10.1177/009318531003800406

Brown, N. N., Connor, P. D., & Adler, R. S. (2012). Conduct-Disordered Adolescents With Fetal Alcohol Spectrum Disorder: Intervention in Secure Treatment Settings. *Criminal Justice and Behavior, 39*(6), 770–793.

Brems, C., Boschma-Wynn, R. V., Dewane, S. L., Edwards, A. E., & Robinson, R. V. (2010). Training needs of healthcare providers related to Centers for Disease Control and Prevention core competencies for fetal alcohol spectrum disorders. *Journal of Population Therapeutics and Clinical Pharmacology = Journal De La Therapeutique Des Populations Et De La Pharamcologie Clinique*, 17(3), e405-417.

Centers for Disease Control and Prevention. (2016). *More than 3 million US women at risk for alcohol-exposed pregnancy [Press Release]*. Retrieved from https://www.cdc.gov/media/releases/2016/p0202-alcohol-exposed-pregnancy.html

Centers for Disease Control and Prevention. *Fetal Alcohol Spectrum Disorders (FASD) Training And Resources*. Retrieved from https://nccd.cdc.gov/FASD/

Centers for Disease Control and Prevention. (2016). *More than 3 million US women at risk for alcohol-exposed pregnancy [Press Release*]. Retrieved from https://www.cdc.gov/media/releases/2016/p0202-alcohol-exposed-pregnancy.html

Centers for Disease Control and Prevention (2019). *Basics about FASDs.* Retrieved from https://www.cdc.gov/ncbddd/fasd/facts.html

Chasnoff, I. J, Wells, A. M., King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics, 135*(2), 264-270.

Cook, D. M., & Walsh, M. L. (2015). Unintended Consequences of Policy Responses to Fetal Alcohol Spectrum Disorders: Civil Commitment and Community Sentiment in North Dakota. In M. K. Miller, J. A. Blumenthal, & J. Chamberlain (Eds.), *Handbook of Community Sentiment* (pp. 215–225).

Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E…Rosales, T. (2016). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ, 188*(3), 191-197.

Dewane, S. L. (2011). *Alaskan physicians' knowledge, attitudes, and behaviors related to fetal alcohol spectrum disorders*.

Dejong, K., Olyaei, A., & Lo, J. O. (2019). Alcohol Use in Pregnancy. *Clinical Obstetrics and Gynecology*, *62*(1), 142–155. doi:10.1097/GRF.0000000000000414

Floyd, R. L., Weber, M. K., Denny, C., & O'Connor, M. J. (2009). Prevention of fetal alcohol spectrum disorders. *Developmental Disabilities Research Reviews*, *15*(3), 193–199. doi:10.1002/ddrr.75

Green, P. P., McKnight-Eily, L. R., Tan, C. H., Mejia, R., & Denny, C. H. (2016). Vital Signs: Alcohol-Exposed Pregnancies--United States, 2011-2013. *MMWR. Morbidity and Mortality Weekly Report*, *65*(4), 91–97. doi:10.15585/mmwr.mm6504a6

Harwood, H. J., Napolitano, D. M., & Kristiansen, P. L. (1984). *Economic costs to society of alcohol and drug abuse and mental illness: 1980*. Rockville, MD: Alcohol Drug Abuse and Mental Health Administration.

Howard, J., Costilow, E., Ferrell, A., Mulmule, N., Besser, A., & Seibert, J. (2019). Fetal Alcohol Spectrum Disorders: Policy Challenges and Opportunities: Environmental Scan. Office of the Assistant Secretary for Planning and Evaluation, Washington, D.C.

Hoyme, H. E., Kalberg, W. O., Elliott, A. J., Blankenship, J., Buckley, D., Marais, A.-S., … May, P. A. (2016). Updated Clinical Guidelines for Diagnosing Fetal Alcohol Spectrum Disorders. *Pediatrics*, *138*(2). doi:10.1542/peds.2015-4256

Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders. (2011). *Consensus Statement on Recognizing Alcohol-Related Neurodevelopmental Disorder (ARND) in Primary Health Care of Children*.

Jirikowic, T., Gelo, J., & Astley, S. (2010). Children and youth with fetal alcohol spectrum disorders: Summary of intervention recommendations after clinical diagnosis. *Intellectual and Developmental Disabilities*, *48*(5), 330–344.

Kable, J. A., Coles, C. D., Strickland, D., & Taddeo, E. (2012). Comparing the Effectiveness of On-Line versus In-Person Caregiver Education and Training for Behavioral Regulation in Families of Children with FASD. *International Journal of Mental Health and Addiction*, *10*(6), 791–803.

Kodituwakku, P. W. (2010). A neurodevelopmental framework for the development of interventions for children with fetal alcohol spectrum disorders. *Alcohol, 44*(7-8), 717-728.

May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., … Hoyme, H. E. (2018). Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. *JAMA*, 319(5), 474-482.

Mitchell, A. M., King, D. K., Kameg, B., Hagle, H., Lindsay, D., Hanson, B. L., . . . Knapp, E. (2018). An Environmental Scan of the Role of Nurses in Preventing Fetal Alcohol Spectrum Disorders. *Issues in Mental Health Nursing*,39(2), 151-158. doi:10.1080/01612840.2017.1384873

Mukherjee, R. A. S., Hollins, S., & Turk, J. (2006). Fetal Alcohol Spectrum Disorder: An Overview. *Journal of the Royal Society of Medicine*, 99(6), 298–302.

National Organization on Fetal Alcohol Syndrome. (2014). FASD prevention. Retrieved from https://www.nofas.org/wp-content/uploads/2014/05/Facts-prevention.pdf

National Organization on Fetal Alcohol Syndrome. (n.d.). *FASD: What the Justice System Should Know About Affected Individuals*. Retrieved from https://www.nofas.org/wp-content/uploads/2014/05/Facts-for-justice-system.pdf

O'Brien, P. L. (2012). Ego-Dystonic Pregnancy and Prenatal Consumption of Alcohol Among First-Time Mothers. *Maternal and Child Health Journal,16*(7), 1431-1439. doi:10.1007/s10995-011-0907-5

O'Leary, C. M., & Bower, C. (2012). Guidelines for pregnancy: What's an acceptable risk, and how is the evidence (finally) shaping up? *Drug and Alcohol Review*, 31(2), 170-183.

Paley, B., & Auerbach, B. E. (2012). Children with Fetal Alcohol Spectrum Disorders in the Dependency Court System: Challenges and Recommendations. *The Journal of Psychiatry & Law, 38*(4), 507-558.

Peadon, E., & Elliot, E. J. (2010). Distinguishing between attention-deficit hyperactivity and fetal alcohol spectrum disorders in children: Clinical guidelines. *Neuropsychiatric Disease and Treatment,* 509.

Pomeroy, E. C., & Parrish, D. E. (2011). Prenatal Impact of Alcohol and Drugs on Young Children: Implications for Interventions with Children and Parents. *Children of Substance-Abusing Parents*.

Pomeroy, E. C., & Parrish, D. E. (2013). Online Training on Fetal Alcohol Spectrum Disorders for Court-Appointed Special Advocates Volunteers. *Health & Social Work, 38*(3), 159-165.

Rentner, T. L., Dixon, L. D., & Lengel, L. (2012). Critiquing Fetal Alcohol Syndrome Health Communication Campaigns Targeted to American Indians. *Journal of Health Communication,17*(1), 6-21. doi:10.1080/10810730.2011.585692

Riley, E. P., Infante, M. A., & Warren, K. R. (2011). Fetal Alcohol Spectrum Disorders: An Overview. *Neuropsychology Review*, 21(2), 73–80.

Roberts, S. C., Thomas, S., Treffers, R., & Drabble, L. (2017). Forty Years of State Alcohol and Pregnancy Policies in the USA: Best Practices for Public Health or Efforts to Restrict Women's Reproductive Rights? *Alcohol and Alcoholism*, 52(6), 715-721.

Russell, M. (1980). The impact of alcohol-related birth defects (ARBD) on New York State. *Neurobehavioral Toxicology*, *2*, 277–283.

Substance Abuse and Mental Health Services Administration (SAMHSA). (2014). *Addressing Fetal Alcohol Spectrum Disorders (FASD)*. Treatment Improvement Protocol (TIP) Series 58. HHS Publication No. (SMA) 13-4803. Rockville, MD. Retrieved from https://store.samhsa.gov/system/files/sma13-4803.pdf

Velasquez, M. M., von Sternberg, K. L., Floyd, R. L., Parrish, D., Kowalchuk, A., Stephens, N. S., … Mullen, P. D. (2017). Preventing Alcohol and Tobacco Exposed Pregnancies: CHOICES Plus in Primary Care. *American Journal of Preventive Medicine*, *53*(1), 85–95. doi:10.1016/j.amepre.2017.02.012

Waterman, E. H., Pruett, D., & Caughey, A. B. (2013). Reducing Fetal Alcohol Exposure in the United States. *Obstetrical & Gynecological Survey, 68*(5), 367-378.

Williams, J. F., & Smith, V.C. (2015). Fetal Alcohol Spectrum Disorders. *Pediatrics*, 136(5).

Zarnegar, Z., Hambrick, E. P., Perry, B. D., Azen, S. P., & Peterson, C. (2016). Clinical improvements in adopted children with fetal alcohol spectrum disorders through neurodevelopmentally informed clinical intervention: A pilot study. *Clinical Child Psychology and Psychiatry*, *21*(4), 551–567.

Appendix

TEP Meeting Agenda

September 12, 2019
8:30 a.m. - 4:15 p.m. EST

8:30 – 9:00	Welcome (ASPE)— Brenda Destro, Deputy Assistant Secretary for Planning and Evaluation, HSP Arne W. Owens, Deputy Assistant Secretary, DALTCP
9:00 – 9:30	Meeting Purpose & TEP Member Introductions (RTI)—Carol Council
9:30 – 9:50	Environmental Scan: Major Themes (RTI)—Julie Seibert
9:50 – 10:05	Break
	Presentations: State Approaches to FASD—Carol Council
10:05 – 10:50	Minnesota (Susan Carlson & Christopher Boys)
10:50 – 11:10	Washington (Heather Olson)
	Activity 1: Policy Considerations–Barriers *Three breakout groups discuss barriers to:* *(1) prevention of FASD* *(2) identification of FASD* *(3) intervention with affected individuals*
11:15 – 11:20	Purpose (RTI)—Julie Seibert
11:20 – 12:00	Group Discussions—3 groups identify a leader
12:00 – 12:15	Report Out to Full TEP—Leader from each group reports on identified barriers, Julie Seibert, facilitator
12:15 – 1:15	Lunch (HHS cafeteria)
1:15 – 1:30	**Activity 1 Follow-up: Policy Considerations–Prioritization of Barriers—Julie Seibert** *TEP attendees vote to prioritize barriers in preparation for Activity 2.*
	Activity 2: Identification of Solutions *Three breakout groups discuss potential solutions to top-priority barriers.*
1:30 – 1:35	Purpose (RTI)—Julie Seibert
1:35 – 2:20	Group Discussions
2:20 – 2:35	Report Out to Full TEP—Carol Council, facilitator
2:35 – 2:45	Break
2:45 – 3:45	Policy Research Gaps—Carol Council, facilitator *TEP discussion focused on findings from environmental scan and 2 activity sessions.*

3:35 – 4:00	Parking Lot (things we did not discuss that are important)—Julie Seibert
4:15	Conclusions and Thanks—Kristina West/Mir Ali