

# TRAINING NEEDS OF HEALTHCARE PROVIDERS RELATED TO CENTERS FOR DISEASE CONTROL AND PREVENTION CORE COMPETENCIES FOR FETAL ALCOHOL SPECTRUM DISORDERS

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## ABSTRACT

### Background

Fetal alcohol spectrum disorders (FASDs) are birth defects directly linked to consumption of alcohol during pregnancy and hence completely preventable. Many health and allied health professionals are in prime positions for primary prevention of FASDs through work with women of childbearing age and secondary prevention through work with affected individuals whose lives can be greatly improved via tailored intervention.

### Objectives

To develop educational guidelines for FASD prevention.

### Methods

Interviews were conducted with 26 individuals representing eight health or allied health professions. Participants were asked about professional groups with which they had sufficient experience to describe FASD-related competencies and educational needs for the given group(s). For each group, participants were asked for their perceptions of group members' FASD awareness, knowledge, and skills application as related to the seven core competencies for FASD practice developed by the Centers for Disease Control and Prevention (CDC).

### Results

Findings revealed that competence, especially when viewed separately in terms of knowledge versus capacity for application of information, in the area of FASDs is unevenly distributed among and throughout healthcare provider groups.

### Conclusion

Based on this information, recommendations are offered for optimal health and allied health education efforts to prevent and treat FASDs, framed along FASD core competencies recommended by the CDC.

**Key Words:** *Fetal alcohol spectrum disorders, FASD, fetal alcohol syndrome, FAS*

**F**etal alcohol spectrum disorders (FASDs), caused by maternal consumption of alcohol during pregnancy, are the leading known, entirely preventable birth defects in the USA. Prevalence estimates suggest between 0.5 and 2 per 1,000 individuals in the general population are born with full fetal alcohol syndrome (FAS) every year.<sup>1</sup> Other prenatal alcohol-related conditions (i.e., FASDs other than FAS) are estimated to occur at three times the national rate for FAS, for

approximately 4.5 per 1,000 live births.<sup>2</sup> The financial burden associated with the consequences of prenatal alcohol exposure are substantial, with an annual cost to the nation of \$2.8 billion and overall lifetime cost estimates as high as \$9.69 million per individual.<sup>3,4,5,6</sup>

Given these statistics and the negative outcomes for mother and child associated with prenatal alcohol exposure, health and allied health professionals must maintain adequate foundational

knowledge and skills related to FASD primary and secondary prevention, diagnosis, and treatment. FASD-related core competencies for healthcare practitioners have been published since 2004 by the Centers for Disease Control and Prevention (CDC)<sup>7,8</sup> and consist of seven areas of knowledge and related practice behaviors: 1) background and foundational FASD knowledge, 2) screening and brief interventions for women, 3) models of addiction, 4) biomedical basis of FASDs, 5) diagnosis and assessment of FAS, 6) life-long care and treatment strategies, and 7) ethical, legal, and policy issues.<sup>7</sup> The seven core competencies are viewed as crucial to the successful prevention, identification, diagnosis, and management of FASDs.

Professionals within various disciplines, including medicine, nursing, psychology, social work, occupational therapy, speech and language pathology, and substance abuse treatment, are in optimal positions to provide discipline-tailored FASD education, prevention, screening, referral, diagnosis, and treatment services based on CDC's FASD core competencies. Through increasing community awareness, educating individuals, advocating for vulnerable populations, and providing FASD-specific interventions, practitioners can greatly reduce the prevalence of FASDs and can provide effective diagnostic and treatment services that lead to improved long-term outcomes by reducing the occurrence of secondary disabilities. To date, little research has assessed health and allied health practitioners' FASD practice behaviors or FASD-related education and training needs. Studies conducted<sup>8,9,10</sup> have been narrow in focus and none have explicitly explored competencies and needs as related to CDC's seven FASD core competencies.

The purpose of this qualitative formative evaluation project was to develop educational approaches for FASD primary and secondary prevention based on an exploration of competency and educational needs of health and allied health professionals related to the seven CDC FASD core competencies. The project was carried out by a CDC FASD Regional Training Center, the Arctic Fetal Alcohol Spectrum Disorder Regional Training Center (Arctic FASD RTC) in Anchorage, Alaska, to guide development of culturally-appropriate and discipline-specific FASD training programs tailored to needs and

contexts of practicing medical and allied healthcare professionals. Findings are vital to the success of FASD education efforts nationwide that seek to increase knowledge and awareness of FASDs among health and allied health professionals.

## METHODS

### Participants

Interviews were conducted with 26 individuals representing eight health or allied health professions, namely, medicine, nursing, psychology, social work, occupational therapy, physical therapy, speech and language pathology, substance abuse treatment, and consumer advocacy. Participants included 23 women and three men with a mean age of 47 years (ranging from 27 to 67). Most (n=23) self-identified as Caucasian; one identified as Other; and two declined to provide this information. The majority had master's degrees (n=14); three had doctorates (two PhDs; one MD), six had bachelor's degrees, one had an associate's degree, and two did not provide this information. Participants had an average of 19.2 years of professional experience (range: 5 to 37 years) with an average of 17.6 of those years in Alaska (range: 2 to 37 years). Primary residence was in rural communities for eight individuals and urban communities for 18.

### Instrumentation

A semi-structured interview protocol was developed to elicit perceptions about FASD core competencies, educational needs, and training preferences, structured around the seven CDC-developed FASD domains.<sup>7</sup> Participants were asked about professional groups with which they had sufficient experience to describe FASD-related competencies and educational needs. For these groups, participants shared perceptions of competencies in the CDC domains, educational needs, and format preferences for training. Interviews took approximately one hour.

### Procedures

Prior to implementation, project design was reviewed and approved by the University of Alaska Anchorage Institutional Review Board. Utilizing Arctic FASD RTC advisors and experts, purposeful sampling was utilized to select expert key informants who could "purposefully inform

an understanding of the study or research problem".<sup>11</sup> Potential participants were contacted by telephone and asked if they would be willing to participate in a 40-to-60 minute interview about the competencies and educational needs of individuals who provide care in the realm of FASD. Interviews were conducted in person or by telephone, depending on respondents' place of residence. All interviews used the same procedures and were digitally recorded for transcription. Of 37 individuals who were contacted, 26 (70%) agreed to participate despite the fact that no incentive for participation was provided. Prior to the interview, informed consent documents were presented and reviewed. Only after participants had read, understood, signed, and returned the informed consent form, did interviewers start the interview and recording. After reviewing participants' background and experience relating to FASDs, interviewers asked participants to identify with which health and allied health groups they had worked. Once that was determined, interview questions were asked only for provider groups with whom participants had experience.

### Data Analysis

Digital audio recordings were transcribed in Microsoft Word and imported into NVivo software for qualitative data coding based on grounded theory.<sup>12,13</sup> Line-by-line open coding by two coders of six transcripts was used to create a list of potential free nodes (concepts). Nodes were discussed by two coders and two supervisors, examined for retention, and, if retained, explicitly defined. Coding was iterative to assure that all interviews were coded in the presence of the entire node list. In this process, six interviews were coded by both coders to establish inter-coder reliability. Once an interview was completed by both coders, they met to review both sets of coding for the entire interview, paragraph by paragraph. Based on these interviews, it was established that coders were coding with more than 90% agreement across interviews and paragraphs. Of the remaining 20 interviews, 16 were divided between the two coders and four were coded by both. The four double-coded interviews were compared in intervals to ensure maintenance of inter-coder reliability above 90% agreement. Careful review of the four double-

coded interviews revealed ongoing high inter-rater reliability and the absence of drift.

## RESULTS

Through the free coding of the 26 interviews, 42 individual nodes emerged from the data that were thematically sorted into five broad categories, described as FASD Knowledge, Skillful Application of FASD Knowledge, Provider FASD Educational Needs, Barriers to FASD Competency, and FASD Educator Roles and Methods.

### FASD Knowledge

*"[Providers in Alaska] know more about FASD than do people in other places in the country. That said, there is still a lot of misinformation."*

In general, providers from targeted disciplines were characterized as having rudimentary understanding of the foundations of FASDs as reflected in CDC Core Competency One. Respondents described providers as generally knowledgeable with regard to the biomedical basis of fetal alcohol syndrome. Although most providers were said to have basic awareness of clinical and epidemiological issues, a preponderance of this knowledge appeared concentrated in the area of FAS (the full syndrome). An understanding of the distinction between FAS and the spectrum of disorders appeared less prevalent in most provider groups.

Most providers across disciplines were described as uninformed about screening and brief interventions for alcohol use with pregnant women, CDC Core Competency Two. Some providers were noted as not understanding their responsibility in screening for alcohol use among women during pregnancy and not knowing how to make referrals to alcohol treatment. Participants indicated that providers typically failed to comprehend their role in screening for alcohol use in pregnant women, often assuming that *"somebody else is doing the job for them."* Even among providers who were thought to acknowledge their role in screening and brief intervention, few were said to be informed about risk factors, appropriate use of screening and assessment tools, and established brief intervention models. Knowledge of models of addiction, CDC Core Competency Three, was said

to be low for most providers across all disciplines, the notable exception being (predictably) substance abuse treatment providers. The latter group was viewed as having in-depth knowledge related to alcohol screening and brief interventions; models of alcohol use; stages of dependence, addiction, and change; and characteristics of alcohol-dependent family systems. However, even substance abuse treatment providers were perceived as having only spotty knowledge about how FASD prevention interfaces with addiction models and interventions. Pockets of relevant information related to Core Competency Three were noted in mental health and substance abuse treatment providers' awareness of coexisting psychiatric disorders related to alcohol use. The application of this knowledge to FASD prevention and intervention, however, remained unclear.

Knowledge of biological effects of alcohol on developing embryo and fetus, CDC Core Competency Four, was perceived as lacking among practitioners in all groups. Providers across all disciplines were seen as having incomplete awareness of the biomedical basis of FASD. Additionally, providers were perceived as being victim to myths, misconceptions, or outdated information that prevented them from becoming accurately informed. Chief among outdated dogmas was the notion that individuals with an FASD look different, with *"some clinicians who [still] think you can tell every FASD kid by the look of their face."* Few providers were viewed as able to grasp the full range of potential effects of prenatal alcohol exposure and the behavioral, cognitive, psychological, and physical sequelae of FASDs. For example, due to a lack of knowledge of the cognitive aspects of FASDs, a provider working with a client with an FASD on a physiological-motor issue may misattribute routine tardiness to willful behavior. Notable exceptions to providers' misinterpreting of behaviors were speech and language pathologists and developmental disability service providers, who were described as being able to recognize the presence of a neurobehavioral issue and its relationship to FASD diagnoses.

Related to CDC Competency Four, a number of respondents expressed frustration that pregnant women continue to be given false counsel

regarding harm from alcohol consumption during pregnancy. *"People really listen to their doctors, and if their doctor says it's okay to have a drink or two while you're pregnant, that is the fact."*

Many participants described instances of providers in professional and social contexts reporting misinformation about the teratogenic effects of alcohol on the developing embryo and fetus by discounting effects of alcohol, even recommending an occasional glass of alcohol during pregnancy.

Respondents viewed providers across the targeted disciplines as knowledgeable about screening, diagnosis, and assessment of FASDs as defined in CDC Core Competency Five. However, this knowledge was generally limited in breadth to providers' own disciplines, lacking in recognition of interactions across disciplines and symptom manifestations. Participants discussed several discipline-specific nuances to providers' understanding. For example, substance abuse treatment providers were perceived as knowledgeable about FASD risk assessment for adults but having little knowledge regarding screening for the presence of FASDs. Similarly, speech and language pathologists were seen to have expertise in screening for FASDs in children or adults with palate malformations, but less knowledgeable about mental health procedures typically used and necessary to screen individuals for FASD. These pockets of information (or pockets of lack of knowledge) were viewed as resulting in less than adequate assessment protocols and erroneous conclusions based on incomplete screening and assessment. They were also noted as highlighting the need for transdisciplinary collaboration.

Little knowledge was observed among providers across all targeted disciplines related to treatment for individuals with FASDs or supportive care for their families across the lifespan, CDC Core Competency Six. Few providers were said to understand the treatment process for adults with FASDs. Although most providers were described as wanting to know what works, they were also described as preferring *"cookie-cutter"* approaches and tending to rely on treatment approaches with which they were familiar as a default, even if they were less suitable for individuals with FASDs. A prominent example was the use of insight-oriented

therapies from which respondents concluded that providers still do not understand the needs of individuals with FASDs. For example, one interviewee gave the example that as long as providers think that children with FASDs need to learn to recognize their impact on others, they do not truly understand the cognitive challenges of their patients. Particularly keen knowledge of treatment strategies and family support needs for individuals experiencing FASDs and their families was attributed to developmental disability services providers and consumer advocates. Consumer advocates were said to have considerable knowledge about treatment strategies and daily living supports gained through their daily experience of living with children with FASDs. They and developmental disability service providers were viewed as more capable of assessing systems and their utility or lack of utility to children and families with FASDs.

Ethical, legal, and policy issues related to FASDs, CDC Core Competency Seven, raised less discussion than questions about other core competencies. Several participants acknowledged lack of familiarity with this competency and noted a need for further research and dissemination of knowledge by FASD experts in this area. Interviewees who did comment consistently noted lack of knowledge in this competency area among providers across all disciplines. Although some disciplines were deemed knowledgeable about ethics, policies, or laws *in general*, they were not thought to have adequate understanding of the issues as they pertain to FASDs. For example, social workers were described as well versed in legal policies and procedures, but perceived to be under-informed or uninformed regarding the interactions between FASDs and the law. Similarly, psychologists were viewed as well trained in ethics, but as having no experience with ethical practice guidelines in the context of treating individuals with FASDs.

### **Skillful Application of FASD Knowledge**

*“[The challenge is] translating and operationalizing ...core knowledge into ‘what do you do?’—If I walked into your office and I wanted to see whether or not you had a good understanding, what would I be looking at?”*

Respondents regularly spoke about the limited abilities of providers to turn knowledge about FASD

into successful prevention, intervention, and treatment. They asserted that provider proficiency in the application of FASD information must be carefully distinguished from FASD knowledge. Having information was viewed as necessary but not sufficient for successful clinical practice. Providers were perceived as somewhat successful applying knowledge in the context of assessment and diagnosis, especially for children. Assessment and diagnosis for adolescents and adults appeared to be challenging for most provider groups, an area in which knowledge was not seen as translating into practice. Even greater challenges were reported in the context of FASD treatment services, especially psychiatric and mental health treatment for all ages, as well as treatment in general for adults. Respondents described psychiatric and behavioral healthcare providers as lacking clinical treatment skills for FASDs, especially with children and adolescents displaying inattention, hyperactivity, impulsivity, emotion dysregulation, or maladaptive behavior associated with attention-deficit/hyperactivity disorder, bipolar disorder, oppositional defiant disorder, or conduct disorder. The most frequent examples of inappropriate care for FASDs emerged in the context of residential treatment and psychiatric medication. Respondents pointed out that most, if not all, residential care settings make use of contingency-based systems or points systems. Given that individuals with FASDs often have difficulties with abstract concepts, such systems are doomed to failure. Participants also criticized psychiatrists' predilection toward using mixes of psychotropic medications that may not be suitable for individuals who have organic brain damage. They asserted that such prescriptions are given even if the inappropriateness of psychotropics for people with FASDs is pointed out to the prescriber.

Application gaps were also noted about correctly understanding the meaning and importance of behaviors evidenced in treatment. For example, if, as mentioned above, tardiness is understood as willful defiance, as opposed to a manifestation of organic brain damage, providers select interventions that are less than successful. This application gap, occurring when providers who were trained and aware of FASDs failed to translate knowledge into clinical practice, was noted among most provider groups.

A few provider groups were said to possess skills that allowed them to deliver effective treatment services to (at least some) individuals experiencing FASDs without ever having received specific FASD education. Specifically, according to respondents, the nature of the occupational or physical therapy disciplines lend themselves to working in ways that are person-specific rather than illness-specific, so that diagnosis may not be the determining issue in treatment planning. Occupational and physical therapists were viewed as offering “a lot of practical intervention-based information—breaking things down to where somebody with a disability or a very severe functional or physical impairment is able to” improve and perform.

Substance abuse treatment providers were also seen as having a subset of effective skills despite not having received specific FASD training. Respondents viewed these professionals as skilled in evaluating drinking patterns, utilizing brief intervention strategies, and offering treatment referrals. This skill set was seen as particularly important to FASD prevention efforts. Unfortunately, and perhaps related to the lack of formal FASD training for these providers, application of these skills was perceived as incomplete. Substance abuse treatment providers’ intervention efforts, viewed as being based in substance abuse, misuse, and addictions frameworks, were described as failing to recognize the dangers of “social” drinking on a developing embryo and fetus. Thus, although participants perceived substance abuse providers as skilled in working with overtly alcohol-abusing women at risk for having a child with an FASD, they expressed reservations about these providers’ skillful application of treatments and intervention strategies for individuals not fitting into classic addictions schemas.

### **Providers’ FASD Educational Needs**

*“Practicum [for students in healthcare programs] should include working with somebody with FASD and working with members of a diagnostic team to better understand FASDs. We have psychiatrists, neurologists, pediatricians, and nurses on our diagnostic team. They could impart education [to practicum students] in a very meaningful way based on years of experience working with people with FASDs.”*

Although variation was revealed regarding training needs across disciplines, most of the discussions were not discipline specific. Instead, providers’ educational needs were assessed in terms of specific, objective lessons and general, dispositional changes to be instilled in providers. Respondents frequently alluded to the need for up-to-date training for providers and nascent practitioners in all disciplines, particularly given the rapid pace of research into FASDs. They noted that, “*the science of FASD is changing. We’re learning new things all the time, and we need to pass that information on to people who are on the front lines dealing with these families and these individuals.*” Respondents recommended that education for FASD providers incorporate experiential training with individuals with FASDs and their families. To help support consistent training of providers and students, a number of individuals discussed a desire for curriculum and licensure changes. Addition of FASD content to academic programs for all disciplines was deemed appropriate by many participants. A few also suggested exploring the addition of FASD training as a requirement for licensure and license maintenance.

Dispositional, approach-based changes advocated by participants included the need for increased intra- and interdisciplinary communication in a team approach to meet the needs of individuals with an FASD. Respondents asserted that FASD treatment cannot be successful outside the multidisciplinary context and without clear, open communication across providers from multiple backgrounds and perspectives. Relatedly, participants strongly endorsed family-centered approaches to treatment wherein families are recognized as experts on FASDs (at least as manifested within their context). Recognition of families as key players in treatments for individuals with FASDs was also seen as a reminder that families need to be part of defining what treatment success means for a given individual.

Mental healthcare providers were identified as a group most benefitting from learning to embrace outside-the-box approaches to adapting treatment to meet the needs of individuals with FASDs. Individuals with FASDs, perhaps more than any other client groups, were not perceived as well served by one-size-fits-all modalities. One individual shared representatively that “*many*

*mental health providers feel ill-prepared to work effectively with individuals who are suspected of having an FASD. Some have shared that... particularly in a supervisory role, they observe staff struggling with taking knowledge and transitioning it into day-to-day practice.”*

Social workers were identified as needing to know about legal, ethical, and policy considerations when working with families affected on multigenerational levels by prenatal exposure to alcohol. Respondents recommended that providers in all groups receive up-to-date training on these areas. A group that was described as particularly adept at understanding the intersection between FASDs and the legal system were parole officers from the Department of Juvenile Justice (about whom participants were not prompted to respond but who were brought up spontaneously by several). Respondents pointed to juvenile justice workers as examples of care providers with skills and motivation to assess children as a way of engaging in early intervention, “...helping children get into treatment before they become serious offenders.”

### **Barriers to FASD Competency**

*“It is as though some providers take an interest in FASDs or a light bulb comes on for them, and then they become passionate about understanding folks with FASDs; those are the providers who send us referrals and who get it when they’re working with these children. Others don’t really cue into it.”*

A number of barriers to competent practice were noted despite being unprompted by interview questions and are summarized in Figure 1. They ranged from individual issues, such as resistance to new learning or new practices, to agency level issues, such as inadequate transdisciplinary staffing, to systemic issues, such as laws that make third party payment for services inaccessible for individuals with FASDs. Related to the latter point, inflexible systems were discussed as creating barriers to competent practice. State requirements were seen as preventing providers from wanting to become adept at FASD practice. Specifically, providers were perceived as reluctant to label an individual with a FASD diagnosis as such a diagnosis does not link to adequate funding for treatment. Unlike what is true for other developmental disabilities (DD) diagnoses, individuals with FASDs do not automatically qualify for DD services. As such services are financially auspicious in that they can be provided at lower costs and are particularly useful to dealing with behavioral manifestations of FASDs, the absence of a clear qualifying process for individuals with FASDs is viewed as a grave disservice. Such a perceived lack of access to resources, including financial and geographic barriers, for both providers and patients in turn were viewed as barriers to identification, treatment, and ongoing care.

**FIG. 1**



Feared stigma and family reactions were also discussed as impeding assessment and diagnosis. Participants expressed concern that care providers failed to address the issue of FASDs for fear of offending or losing the patient. Regarding physicians who provide care for women of childbearing age bringing up drinking in the context of prenatal care, one individual representatively noted that, *“when you confront a patient about a behavior like that, you risk them going on to another physician or not going to a physician at all ... It is not a matter of irresponsibility so much as it is hard for doctors to know how to bring up the topic in a way that won't alienate the patient from getting medical care during pregnancy.”*

Similarly, provider resistance was discussed as a particular hurdle when trying to increase FASD education. Misconceptions, stereotypes, and misinformation were perceived as getting in the way of providers being able to hear prevention messages as relevant to their work. Some providers are perceived as rejecting FASD prevention messages, claiming non-applicability of the topic to their particular clientele. For example, it was noted that racial stereotyping among medical providers leads to claims such as, *“I don't deal with Native children, so this is not an issue [in my practice].”* Such misconceptions about FASDs were highlighted as barriers among healthcare providers across all disciplines, but particularly among physicians. In contrast, participants described consumer advocates as well informed, open to the FASD message, and skillful in applying knowledge practically. Advocates were perceived as underscoring the value of taking on a supportive parenting role with children who have an FASD, making sure that the stigma typically associated with this role does not get in the way of being an open, proactive, and engaged parent to these children. Thus, advocates were viewed as important partners in attempts to deal with stigma-related barriers to care and prevention. Respondents agreed that care providers need to learn to allow, *“Parents who have raised children to tell [them] what their experience is. ... to learn the real experts in the field are not [always] them.”*

### **FASD Educators' Roles and Methods**

*“Core knowledge around FASD [should be] expected to be embedded in all professional training programs ... and directly linked to the [CDC core] competencies.”*

Participants were asked about preferred methods of educational material distribution and offered a list of samples. All respondents discussed a preference for presentations about the topic, though the nature of presentations varied, with some preferring web-based presentations (webinars); some choosing DVDs, audiocassettes, or videos; and others favoring in-person lectures. Print presentations emerged as a preferred method for some, with some preferring hard copies and others preferring web-based materials. Unprompted categories of education that were mentioned included conferences, summits, interactive adult-learning based trainings, and social networking meetings. While talking about methods, respondents also veered into preferred contents, with the one consistent theme relating back to the application gap. Specifically, participants were particularly keen on education, regardless of type, that focused on translating information into action. They indicated that: *“we have a lot of [theoretical] information, but not necessarily the [practical] education on how to deal with FASDs”* once they are diagnosed.

Finally, participants discussed the role or roles that they would like the Arctic FASD Regional Training Center to fill in supporting their work in FASD prevention and intervention efforts in Alaska. Answers echoed responses to previous questions and emphasized the desire for a dynamic approach to training that is pragmatic, practical, and responsive to local and changing needs. Interestingly, respondents suggested that efforts should focus on educating two nearly diametrically opposed groups: care providers on the front lines to assure skillful direct services delivery to individuals with FASDs and individuals in positions of political and fiscal power to advocate for training requirements and licensure changes. This approach, in their perceptions, would help the regional training center not only educate important stakeholders but would also place it in a much-needed mediator role between these two groups.



## DISCUSSION

This project elucidated FASD-related training needs of professionals likely to encounter individuals with FASDs or women at risk for alcohol-exposed pregnancy, framed by the seven FASD core competencies defined by the CDC.<sup>7</sup> Findings revealed that FASD competence

(especially when viewed as capacity for application of information versus knowledge) is unevenly distributed (Figure 2), making it necessary to tailor and refine training efforts to assure that professionals learn the very skills needed to improve clinical practice related to FASD.

FIG. 2

	Knowledge	Skill	Knowledge	Skill	Knowledge	Skill	Knowledge	Skill	Knowledge	Skill	Knowledge	Skill	Knowledge	Skill
Mental Health	●	○	○	○	○	○	○	○	●	●	○	○	○	○
Psychiatric Care	●	○	○	○	○	○	○	○	●	●	○	○	○	○
Substance Abuse	●	○	○	○	○	○	○	○	●	○	○	○	○	○
Medical Care	●	○	○	○	○	○	○	○	●	●	○	○	○	○
Developmental Disability Services	●	○	○	○	○	○	○	○	●	●	●	●	○	○
Occupational & Physical Therapy	●	○	○	○	○	○	○	○	●	●	●	●	○	○
Speech Language Pathology	●	○	○	○	○	○	○	○	●	●	●	●	○	○
Consumer Advocacy	●	●	○	○	○	○	○	○	●	●	●	●	○	○
Social Work	●	○	○	○	○	○	○	○	○	○	○	○	○	○
	<i>C1 Foundations Of FAS</i>		<i>C2 Screening &amp; Brief Intervention</i>		<i>C3 Models Of Addiction</i>		<i>C4 Biomedical Effects</i>		<i>C5 Screening &amp; Diagnosis of FAS</i>		<i>C6 Lifespan Treatment</i>		<i>C7 Ethical, Legal, &amp; Policy Issues</i>	

### Existing Strength versus Needed Training in the Context of Core Competencies

*CDC Core Competency One*, concerned with foundations of FASDs, has been an educational area of emphasis in recent years that has paid dividends. Findings reveal that basic FASD information has reached most professionals who encounter individuals with FASDs or women at risk for alcohol-exposed pregnancies.<sup>14</sup> Professionals have basic knowledge about FASDs, with greatest level of knowledge about FAS. Perhaps due to systemic barriers (e.g.,

infrequent training, lack of licensure requirements for FASD, staff turnover), variations in foundational FASD knowledge and skills still exist within, more so than between, provider groups. Notable exceptions are consumer advocates who are cited as staying informed and up-to-date, perhaps related to more members of this group having children with FASDs.

*CDC Core Competency Two*, concerned with screening and intervening with women at risk for alcohol-exposed pregnancies, emerged as an ignored area. No professional discipline was

described as proficient in screening and intervention with pregnant women around alcohol use during or while planning pregnancy. The profession with the greatest strength in this core competency was that of substance abuse providers, who were equipped with skills to screen and intervene effectively in active alcohol abuse situations. Other groups were described as needing information on how to screen pregnant women without fear of offending or alienating.

*CDC Core Competency Three* focuses on models of addiction. Although no provider group was said to be completely proficient in all aspects of this competency as related to FASDs, mental health and substance abuse treatment provider groups were praised for their ability to understand the complexities of the coexistence of mental illness and substance abuse. They were seen as potential role models for other professionals for their openness to learning more about FASDs given their understanding of the importance of considering coexisting illnesses.

*CDC Core Competency Four*, concerned with the biomedical basis of FASDs, was described as inadequately understood across all groups, particularly due to misconceptions surrounding diverse manifestations of FASDs, etiology, and life-long effects. Although medical and psychiatric caregivers were viewed as having knowledge of biochemical and physiological effects of alcohol, they tended to lack the fuller perspective of how individuals with FASDs function on a daily basis. Groups regarded as more educated about the impact of biomedical effects on day-to-day functioning were speech and language pathologists and developmental disability service providers. Perhaps because they work with individuals who have been prenatally exposed to alcohol on basic speech and day-to-day living tasks, these professionals were seen as potential role models for medical and psychiatric care providers about the behavioral and functional aspects of alcohol's effect on the developing fetus.

*CDC Core Competency Five*, screening, diagnosis, and assessment of FAS, was consistently discussed as being strong for providers across all disciplines with regard to comfort and skill with screening for presence of FASD-related signs and symptoms within the purview of their own discipline, especially as related to screening children. Interdisciplinary

aspects of screening and diagnosis were viewed as in need of improvement as providers rarely were viewed as able to see beyond their own profession's screening. Lack of interdisciplinary efforts results in incomplete screening and deficient understanding of FASD complexity and treatment needs.

*CDC Core Competency Six* is concerned with treatment across the lifespan and was reported to be lacking for many provider groups, even groups who specialize in treatment modalities with great promise for individuals with FASDs. Developmental disability service providers, consumer advocates, and occupational/physical therapists were distinguished from other disciplines as being equipped with tools to work successfully with individuals with FASDs throughout the lifespan. Developmental disability service workers and consumer advocates were seen as understanding the permanence of the disability and the need to deal with FASDs via a support-based approach rather than a medical model of curing a disorder. Occupational/physical therapists, who were noted as having less knowledge of FASDs but superior treatment skills, may be finding success by working with *individuals* rather than a *diagnosis*. Utilizing person-based and adaptive functioning-focused (rather than illness-based and cure-focused) perspectives was viewed as inspiring providers to engage in "outside-the-box" thinking by throwing out "cookie-cutter" approaches that are less than effective in working with individuals with FASDs.

*CDC Core Competency Seven* relates ethical, legal, and policy issues to work with individuals with FASDs and emerged as an area of training not encountered by most providers. Many providers groups, especially social workers and mental health care providers, were perceived as highly knowledgeable about mental health law and ethics in general, but perceived as unclear about ethical, legal, and policy issues in the context of FASDs. Only one subgroup of professionals, juvenile justice workers, was praised as being familiar with the law as related to FASDs. This group was perceived as a resource for other professionals on how to use the legal system to affect positively the lives of individuals with prenatal alcohol exposure.

## **Suggestions for Training Delivery and Enhancement**

**Core Competency One** – Provide regular opportunity for training:

- a. to inform previously-trained providers about new developments
- b. to bring new professionals up to speed about the basics of FASD knowledge
- c. to address myths and misinformation that tend to remain entrenched among practitioners
- d. to incorporate cultural and contextual issues about FASD knowledge

**Core Competency Two** – Offer training modules that include skill development centered on how to communicate with women of childbearing age about issues related to FASDs:

- a. to assure that all women have access to information about the effects of alcohol on the embryo or fetus, especially from their medical care providers
- b. to overcome provider resistance centered on fear of offending or alienating their clientele and hence losing patients to other providers
- c. to give providers concrete communication skills that are easily applied in all health and allied healthcare settings (e.g., reflection skills, motivational interviewing skills, or related strategies of eliciting information and behavior change)

**Core Competency Three** – Create opportunities for exposure to models of addiction and their relevance to FASD prevention and risk screening:

- a. to give all providers a context within which to understand FASD risk among women of child-bearing age
- b. to increase sensitivity to issues of comorbidity and the interdisciplinary framework needed for successful intervention
- c. to draw upon the strength of substance abuse and mental healthcare providers and to share their insights with other professional groups

**Core Competency Four** – Develop training content that emphasizes practical and interdisciplinary application of information:

- a. to create prevention efforts based on the most recent literature about the effects of alcohol on the embryo and fetus
- b. to weigh and discuss the differences between public health versus patient-provider communications and messages related to alcohol use during pregnancy
- c. to give providers tips and hints about how to translate biomedical information into risk communication
- d. to assure that providers understand the long-term effects and behavioral or functional manifestations of the biomedical issues involved in FASDs

**Core Competency Five** – Offer case example-based training to demonstrate the central need for interdisciplinary and culturally competent screening and assessment to arrive at a diagnosis within the spectrum of FASDs:

- a. to assure providers clearly understand the inadequacy of partial screening or assessment
- b. to emphasize the essential nature of an interdisciplinary and culturally relevant understanding of an individual with an FASD
- c. to help providers build better networks that emphasize interdisciplinary collaboration for purposes of screening and assessment
- d. to develop interdisciplinary forums for information exchange
- e. to convey the many implications of the interaction of medical, psychological, behavioral, speech, occupational, physical and social aspects of functioning

**Core Competency Six** – Provide case examples and schemas for knowledge application related to FASD-tailored intervention approaches:

- a. to exemplify person-based and adaptive functioning-focused means of intervention that emphasize individually tailored treatment for individuals with FASDs and their families
- b. to assure comprehensive treatment approaches that wrap around an individual with an FASD to incorporate interventions that address the

- individual, the family, the community, and the environments in which they function
- c. to develop interdisciplinary treatment approaches that are culturally appropriate and tailored to draw on existing resources within the individual's and family's context
  - d. to use disciplines that have developed effective interventions as role models and mentors
  - e. to draw on advocates and families to contextualize information and give input on treatment plans

**Core Competency Seven** – Establish application of general professional ethics and mental health law in the context of FASDs:

- a. to support ethical and professional decision-making that is appropriate yet relevant
- b. to draw upon existing expertise in the community about the positive aspects of the law and legal issues for individuals with FASDs
- c. to help professionals translate ethical codes and legal strictures into clinical practice that considers the special social, economic, and behavioral context of FASDs

## CONCLUSIONS

Training for professionals who deal with individuals at risk for FASDs or alcohol-exposed pregnancies has seen decades of support and development. Given historic foci on breadth of information, it is becoming increasingly important to begin to tailor prevention and training approaches for depth to assure optimal utility and impact. The current work emphasizes that training structured along the seven FASD core competencies outlined by the CDC is crucial and needs to incorporate several important cautions that emerged from our key informants.

These cautions are related to:

- assuring adequate content coverage that is interdisciplinary, culturally competent, and free of myths and misinformation;
- drawing on existing strengths from within relevant provider groups to give access to role models, mentors, and consultants;

- sharing case examples to make information applied and practical to maximize the capacity of trainees to translate knowledge into action;
- framing all information and application in an interdisciplinary context that emphasizes the complexity of the behavioral and functional manifestations of the underlying biomedical issues inherent in FASDs; and
- supporting efforts that are person-centered and functionally focused (as opposed to being prescribed or “cookie-cutter”).

By utilizing lessons offered by current providers in the education process and embracing transdisciplinary team methods, training efforts can remain congruent with CDC's curriculum suggestions, while incorporating respectful and patient-centered perspectives that include advocates and families as experts on FASDs. Interviews suggest there is a niche to be filled by FASD Regional Training Centers as currently funded by the CDC and that the process of fulfilling the roles of provider, educator, advocate, and mediator begins and ends with trust in a regional training center to keep professionals well-informed, well-promoted, and well-supported.

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## Special Notes

1. All quotes in the manuscript were edited for grammatical accuracy as per editorial request.
2. A copy of the key informant interview can be obtained from the first author.

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