

TOWARD EFFECTIVE IDENTIFICATION OF FASD: A TOPICAL REVIEW OF CONSIDERATIONS FOR ENHANCING EVIDENCE-BASED SCREENING WITHIN AN IMPLEMENTATION SCIENCE FRAMEWORK

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ABSTRACT

The need to improve identification and understanding of individuals who have fetal alcohol spectrum disorder (FASD), including their strengths and challenges, is being increasingly recognized. Identification of FASD via screening is an important system-level intervention that may serve to improve early and accurate recognition of individuals who may have FASD, facilitate the provision of appropriately tailored support and interventions, and in doing so, foster healthy and positive outcomes for individuals and families. Effective and ethical implementation of FASD screening practices requires consideration of several factors for success, ensuring that resulting benefits outweigh potential harms. Using an implementation science framework, this topical review aims to provide an overview of these key considerations in order to guide further research and support practice and decision-making for service providers, organizations, and policy makers in the implementation of FASD identification and screening practices. These include prioritizing partnerships with stakeholders; taking a person-centered and ethical approach to FASD identification and screening; applying rigorous methodological research approaches to screening tool development, validation, and evaluation; increasing broader FASD awareness and response capacity at the system level; and advocating for continued policy reform and resources to enhance effective community-based support and interventions following identification.

Keywords: fetal alcohol spectrum disorder; identification; implementation science; screening

THE IMPORTANCE OF IDENTIFYING FETAL ALCOHOL SPECTRUM DISORDER

Fetal alcohol spectrum disorder (FASD) is a term used to characterize a common neurodevelopmental disability resulting from prenatal alcohol exposure (PAE).^{1,2} Although each person with FASD has their own unique strengths and abilities, the effects of PAE on fetal development are widespread and may impact cognitive, affect, and self-regulatory domains to varying degrees among

individuals.¹⁻⁴ Conservative estimates suggest that FASD may impact between 2% and 5% of the general population in North America at high social and economic costs.⁵⁻⁹ Early identification of FASD, followed by comprehensive assessment, intervention, and appropriate supports, help to foster healthy and positive outcomes.¹⁰⁻¹² However, rates of missed detection and misdiagnosis remain high due to multiple complex and intersecting factors, including substantial stigma related to alcohol use in

pregnancy and FASD more broadly, lack of FASD awareness among clinicians and service providers, and insufficient resources and capacity for identification, assessment, and diagnosis of FASD.^{13–18} Furthermore, a great majority of individuals with FASD do not present with outwardly visible physical characteristics. This, coupled with a clinically complex profile of requirements, overlapping presentation with other common neurodevelopmental and mental health disorders, and potentially masked deficits in the face of relative personal strengths, increases identification challenges.^{3,14,19,20} This may result in suboptimal understanding of needs, missed opportunities, and poor alignment of supports for individuals, caregivers, and families, ultimately contributing to increased difficulties across the life course.^{11,12,19–21}

Identification of FASD via screening has been proposed as an important system-level intervention that may improve early and accurate recognition, and in doing so, improve outcomes and reduce costs associated with misaligned services and later difficulties.^{8,10,22–26} To date, many FASD screening tools and practices have been developed with the overall goal of improving identification of FASD.^{24,25,27} This work has been led by both community agencies and researchers, highlighting the development of screening tools and processes as a priority for many stakeholders. In order to ensure that screening practices are successfully implemented and effective in achieving intended outcomes, a range of factors should be considered. In this topical review,²⁸ we provide a focused overview of the evolving research and clinical literature on identification and screening of FASD through an implementation lens. Drawing from our perspectives in clinical and developmental psychology, we aim to extend findings from recent comprehensive systematic reviews focused on the evidence supporting FASD screening tools,^{25,27} and provide an up-to-date and applied synthesis of factors relevant to the successful implementation of FASD identification and screening practices. Applying an implementation science framework²⁹ we review important considerations to

inform a pathway forward toward enhancing evidence-based approaches for identifying FASD, with guidance for the future research and practice.

IDENTIFICATION THROUGH SCREENING, ASSESSMENT, AND DIAGNOSIS

First, it is important to carefully define and differentiate key aspects of FASD identification, including screening, assessment, and diagnosis, as they pertain to different processes. *Identification* captures the broader task of recognizing characteristics of an individual that may be related to FASD, including evidence of possible prenatal alcohol exposure. Identification methods may range across a continuum, spanning from less formal interactions and inquiries, such as asking FASD-informed questions and having conversations about FASD with individuals and families, to more formal methods, including use of specific screening tools as well as comprehensive assessment and diagnosis of FASD using a range of guidelines.^{1,2,30–32} Further, identification of FASD in children, adolescents, and adults can be distinguished from the important and much-needed identification of alcohol use during pregnancy and associated screening and prevention practices.³³

The more specific process of *screening* involves the use of formal tools or instruments, processes, and/or indicators to identify individuals who may have FASD.^{22,30,34,35} Screening tools are designed to provide a helpful, accurate, and quick indication of whether someone may have a particular condition or disorder, such as FASD, and inform whether further assessment or intervention is appropriate.^{30,34,35} Screening may be completed at the population level or within specific groups and settings, and as a part of brief or routine clinical or professional interactions.^{22,36} Specific screening tools may differ in respect to their format, item content, and intended applications and goals.^{24,25,27,34,35} Importantly, screening tools, including those designed to identify individuals who may have FASD, do not constitute formal diagnostic assessment instruments and

cannot be used as such. Diagnostic assessment requires comprehensive evaluation by trained experts, where the nature of strengths and weaknesses are fulsomely characterized, diagnostic decisions are made, and specific recommendations for addressing presenting concerns are developed.^{1,2,10,31} That said, successfully implemented evidence-based screening practices have the potential to help practitioners and organizations more effectively understand and respond to the needs of individuals and families, allocate limited resources and streamline referral pathways for diagnostic services, bolster prevention efforts by identifying women and families who may benefit from additional supports, aid in estimating the potential prevalence of FASD in large-scale populations, and inform policies directing funding and resources.^{8,10,22,25,36,37}

ADOPTING AN IMPLEMENTATION SCIENCE FRAMEWORK

Implementation science provides a method of understanding how to put evidence-based interventions into practice and evaluate what makes them work in real-world contexts, with clear relevance to FASD interventions and screening.^{29,38–40} In order to support the successful implementation of FASD identification and screening practices, first steps include clearly defining and operationalizing intended outcomes and goals.²⁹ Participatory engagement across a range of stakeholders ensures that identified goals and outcomes are shared, and that tools and processes themselves are more likely seen as helpful and a good fit, resulting in improved buy-in and increased probability of achieving successful outcomes in everyday practice.²⁹ Identification and screening tools or practices must also have been shown to be effective for the intended population and settings, ideally via rigorous research approaches.²⁹

An implementation science approach emphasizes the importance of attending to both *intervention* (or program-level) processes and outcomes for individuals, organizations, and/or communities as well as *implementation* processes and outcomes, the

latter of which are often intricately related to the knowledge, skills, attitudes, perceptions, and behaviors of practitioners, staff, and other stakeholders.^{29,39} Both intervention and implementation processes and outcomes should also be measured and formally evaluated on an ongoing basis to ensure positive outcomes, and that benefits must outweigh any potential harms, particularly when attempting to shift interventions developed in research or laboratory settings to community-based settings.^{29,41–43} As such, evaluation represents an ongoing and evolutionary process, allowing for changes and adjustments to be made as more is learned throughout.⁴⁴ Many resources are available to support research teams and community-based practitioners and organizations in applying implementation science considerations, with relevance to FASD screening.^{29,39,40}

Identifying Screening Goals

Practitioners and organizations hoping to improve identification of FASD have considerations to review prior to implementing a specific screening tool or practice, including an overarching ethical imperative to ensure that the benefits outweigh any potential risks.^{22,45,46} The primary goals and intended outcomes associated with FASD identification and screening must be established early on to help orient organizations to any internal or external changes to policies, procedures, relationships, and/or resources that must first be undertaken to ensure meaningful outcomes of screening.⁴¹ Broader goals likely include improving identification of FASD and facilitating access to enhanced care, supports, and interventions, ultimately improving outcomes for individuals, families, and society.^{8,10,22} Organizational goals unique to the service or setting may also be considered, such as operational improvements via better allocation of resources and more effectively tailored service delivery, which may ultimately also result in cost-savings.^{10,23}

An important aim of FASD screening may be to identify individuals in need of referral for further FASD-specific assessment and diagnosis services, and may aid in serving to address referral criteria for some programs.⁴¹ At the same time, such intensive

and specific clinical services may not always be quickly accessible or feasible, given limited specialized FASD resources.^{10,15,21} Many FASD identification and screening tools and approaches can serve not only to flag a potential need for further diagnostic evaluation but can also screen for functional needs that may be addressed within and beyond the service at hand, such as accommodations to support learning requirements, and identification of needs related to mental health, housing, employment, and other areas.^{12,25,27,47} Therefore, when setting out to adopt FASD identification and screening practices, a range of more specific and immediate goals tailored to the individual's strengths, needs, age, and personal circumstances could also be considered. Specific goals may include coordinating targeted follow-up assessment (e.g., neuropsychological, psycho-educational, or medical evaluation), adapting program practices, implementing individualized accommodations based on identified needs and strengths, adjusting treatment goals, creating safety plans, making referrals to partner agencies and services, and connecting individuals and caregivers with peer support networks, thereby enhancing over-all networks of support.^{12,47-51}

Individuals undergoing screening and their care providers and families are important stakeholders who should be involved in the goal-setting process.^{22,45} It is possible that participating in FASD screening and any resulting follow-up assessments or diagnostic services may not align with an individual's personal goals. Indeed, dignity of the person and autonomy are key ethical considerations in developing and implementing FASD screening practices.^{22,45,46} In addition, care must go into planning for meaningful and ongoing informed consent procedures, given the additional support needs that may be present for people who may have FASD.^{22,46,48} This may include thoughtfully reviewing the purpose, process, and potential outcomes of FASD screening, using language aligned with an individual's capacities and needs, checking in on comprehension using active paraphrasing and other approaches,

or inviting a support person to be present during the consent process.^{22,48}

Selecting Evidence-Based Tools

Many FASD-specific screening tools have been developed. These include tools that are currently available for implementation, such as checklists, rating scales, questionnaires, and interviews, as well as emerging approaches, such as those using biomarkers.^{24,25,27} These tools also differ in respect to the populations (e.g., children, adolescents, or adults) and settings (e.g., schools, or correctional settings) for which they were developed and validated, item content (e.g., PAE-specific indicators vs. broad indicators of neurodevelopmental impairment or environmental adversity), and the extent to which items map onto specific FASD diagnostic systems.^{25,27} A range of broader FASD screening approaches may also hold promise in facilitating FASD identification, such as stepwise or phased approaches used in case ascertainment prevalence studies, and decision-trees using specialized test scores to guide clinical decision-making.^{6,9,52,53} There are also a wide range of screening tools designed to identify other developmental, cognitive, behavioral, and mental health concerns that are not specific to FASD but may nevertheless hold promise for FASD screening with tailored application.⁵⁴

Despite growing proliferation and interest in the development and implementation of FASD screening tools and practices, the evidence-base supporting the psychometric properties and effectiveness of many specific instruments remains limited.^{25,27} This gap emphasizes a strong need for additional, methodologically rigorous research to support effective implementation. A stronger evidence-base is required to maximize benefits and minimize harms to individuals with FASD and their families, guide service providers in selecting instruments appropriate for the population and context, and ensure proper implementation, so that objectives and goals are achieved.^{22,25,27,29,41} In particular, screening tools should be highly *sensitive* so

that as many cases as possible are accurately detected. Strong test sensitivity helps to minimize “missed cases” or false negatives, which if not addressed, may contribute to delayed or missed identification, and/or misdiagnosis, and ultimately a poor match between needs experienced and services received.^{14,24,25,41,55} Screening tools must also be appropriately *specific* to the condition they are intended to detect.^{41,55} Strong specificity minimizes incorrect positive screens, which pose high potential costs to individuals, families, and systems, in the context of comprehensive follow-up assessment and diagnostic services that are time-consuming and resource-intensive.^{12,25,46,55} False positive screens may also contribute to delays in the appropriate provision of resources for individuals in need of supports and interventions.^{41,55} With FASD screening in particular, there are additional important risks associated with false positives to consider, including the potential for unnecessary psychological harm (e.g., worry, guilt, or shame), damage to familial relationships, concern raised about biological family members, and stigma.^{22,45,46}

PRACTICAL CONSIDERATIONS FOR IMPLEMENTATION

A range of practical issues and perspectives should be also considered to ensure successful outcomes associated with FASD identification and screening practices. Organizations may first need to assess practitioner and organizational knowledge, policies, programs, and practices with respect to being FASD-informed and address gaps through training, and revision of policies or program requirements.^{47,48,51,56} Guides to support evaluation and practice change for organizations are available to help support this process.^{56,57} As mentioned, it is also important to ensure that careful thought goes into selecting a specific screening tool or approach that is aligned with intended goals and outcomes. This includes selecting the appropriate tool based on evidence, setting, and population, ensuring that

appropriate training and support is provided to staff engaged in the screening process, and practical considerations such as associated costs, administration time, and impacts to service delivery.^{25,41} For organizations and settings already conducting in-depth screening for other mental health and neurodevelopmental concerns, it may be possible to adapt current practices to incorporate FASD screening (and evaluate implementation processes and outcomes) rather than adopt a novel approach, particularly in the context of time and resource constraints.

Determining where and for whom screening will be completed is another principal consideration. Ideally, given appropriate and validated tools for such purposes, universal screening of young children, such as in educational and medical contexts, could lead to the highest rate of identification and provision of support as early as possible.^{8,10,22,24,25} More targeted screening in high-risk populations and settings where individuals with FASD are thought to be disproportionately represented, such as among siblings of those diagnosed with FASD, and within the child welfare and legal systems, may also lead to improved understanding, and tailored supports and interventions to support healthy trajectories.^{10,14,36,37,58,59} Further, screening for FASD at intake and through a range of programs and services supporting mental health, substance use, women’s health, and even vocational and housing supports, may result in more effective identification of unique client strengths and needs, and the application of FASD-informed approaches to improve service delivery and outcomes.^{1,10,47,51,60}

Care must also be taken to ensure that FASD surveillance and inquiry is applied objectively, in line with evidence, and without bias in light of structural racism and ongoing inaccurate and harmful stereotyping leading to assumptions about disproportionate risk for FASD in some communities and populations.^{61–64} FASD can affect all populations, regardless of factors such as socioeconomic status, ethnicity, or culture. Thus, screening only members of highly stigmatized groups may lead not

only to missed cases among less stigmatized groups but also an overrepresentation of these populations among those identified as having FASD, which may in turn perpetuate stigma among these groups.^{13,62–65}

Ensuring community-engagement and planning together with impacted stakeholders, including those with lived experience, provides a necessary foundation for informing procedures and approaches to ensure shared goals. These processes also work to ensure that screening practices are conducted in a manner that is FASD-informed, person-centered, culturally safe, and both gender- and trauma-informed.^{48,51,56,63,66–68} Planning for next steps along a care pathway that begins with the practitioner and/or organization completing the screening and extends to include other referral and support processes for individuals and families, including coordinating follow-up support for people identified as potentially having FASD across agencies and in their primary community is also important to ensure from the outset.^{22,41,47,48,56}

Potential barriers and challenges that may impact successful implementation of FASD identification practices should also be recognized and may occur at the client, practitioner, organizational, and policy levels.^{29,38,56} Examples may include practitioner workload and time constraints, the stigmatized and sensitive nature surrounding FASD, gaps in knowledge, comfort, and training around FASD among practitioners, insufficient resources, and concerns related to adversely impacting the patient-provider relationship, or involvement of child protection services.^{22,40,69–72} Put simply, choosing and implementing a screening tool, in the absence of these considerations, may not only fail to achieve desired positive outcomes, but may also result in harming individuals and families.

CONCLUSIONS

The need to better identify individuals who may have FASD, including their strengths and challenges, is being increasingly recognized.^{4,10,21} Identification of FASD is necessary not only for

informing evidence-based transition and care planning for improved outcomes but also for helping individuals with FASD to develop and maintain positive, ability-focused self-views, and achieve everyday successes.^{4,73} While screening instruments represent one important tool in the broader “tool-box” of resources needed to improve identification and understanding of FASD, it is neither the start nor the end of considerations for implementing meaningful FASD identification and response practices. It is critical that researchers, practitioners, and organizations engage with stakeholders to identify relevant, feasible, and meaningful goals and outcomes, continue to apply rigorous methodological approaches to screening tool development, validation, and evaluation, increase broader FASD awareness and response capacity at the system level, and advocate for continued policy reform and resources to enhance effective community-based supports and interventions following identification.

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