NOFAS Affiliate Network Diagnostic Capacity Workgroup
Activity Report
September 2020

Objective: To identify existing FASD screening tools and promote their consistent, broad application in diverse settings including health care, child welfare, education, justice, and other systems.

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The Workgroup developed a survey to collect checklists, algorithms, and other tools to screen for fetal alcohol spectrum disorders. The survey received 17 responses summarized below.

Also described in section 2 of the report are publications and other FASD screening research, criteria, instruments, and other information identified by the workgroup.

The next workgroup steps are to organize screening tool information and forms in a concise, usable format for affiliates and the FASD community.

SECTION 1:
FASD Screening Tools Collection Form Results

Describe Yourself
Social Worker - 4
Caregiver to an individual with an FASD - 3
FASD Advocate - 3
Nurse Practitioner - 2
Child Welfare system Paraprofessional - 1
Medical Assistant - 1
Researcher - 1
Medical Paraprofessional – 1
Education System Paraprofessional - 1

Have you or your colleagues used one or more tools to screen an individual for a possible FASD?
Yes – 7 No - 10

What screening tool or tools have you used?

1. I am aware of work currently being done by Dr. Ira Chasnoff in Chicago. He is validating screening questions for children ages 2-5 in the areas of Regulation, Cognitive Function, Adaptive Living, & Sensory issues. I heard him do a recent webinar in which he noted that only 10% of children with PAE/substance exposure screened positive on typical developmental screens like Ages & Stages Q. He had indicated that his data collection process would be done by end of 2020.
2. None. However, I have a list of indicators I have developed in my FASD awareness work and training material.
3. I do not screen for FASD in my clients, but rather refer them to other professionals who are trained to do so. I review the diagnostic reports frequently.
4. 4 digit code - University of Washington; Hoyme.
5. I also think that Dan Dubovsky is validating his tool (Life History Screen- can't recall exact name) in varied settings including younger children in Minnesota area, behavioral health treatment settings in New England & TX. I spoke w him last over a year ago so he may have new information now that is helpful...
6. Alaska Screening Tool (AST)--I have been searching online, and this is the only screening tool I can find. (I am a volunteer FASD advocate) I am a member of the CO Governor's Behavioral Health Task Force Safety Net committee. I have learned that the Colorado Dept. of Behavioral Health has targeted these screening tools: UCLA Screen for Child/Adolescent Trauma and PTSD, the Vanderbilt for ADHD, ASQ for suicide, Columbia for suicide, PRIME for psychosis, and MDQ-A for bipolar (among others) to go with the Bright Futures Pediatric schedule, which as far as I can tell does not address FASD. None of these screens for FASD.
7. Only reading the findings, not administering the tools.

Do you believe existing FASD screening tools are adequate?

Yes – 0 No - 17

Why do you believe existing FASD screening tools are not adequate? (Check all that apply)

- o Not for use with all ages - 15
- o Not for use in all settings - 12
- o Lack of validation - 10
- o Difficult to use without training - 9
- o Poor sensitivity/true positive rate - 6
- o Poor positive predictive value - 3
- o Poor sensitivity/true positive rate - 2
- o Other:
- o Lack of widespread use, availability, lack of awareness of tools existence or importance
- o Complexity of FASD clinical presentation & lack of transfer of alcohol history information from prenatal history a problem
- o Do not exist or very hard to find.
- o Poor specificity/true negative rate

Why do you believe screening for FASD has not been broadly implemented? (Check all that apply)

- o No universal FASD screening tool/don't know what tool to use - 14
- o Screening tools are not adequate - 13
- o Lack of knowledge of what to do with clients that screen positive - 12
- o Limited overall knowledge of FASD - 11
- o Lack of training to use screening tools - 11
- o Limited awareness of existing tools - 10
- o Screening for FASD is not reimbursable -9
- o Screening is too difficult to integrate into practice - 8
- o Other:
  No simple FASD screening tool
  Stigma

Is there anything else you would like to share about FASD screening that is not reflected in your answers above?

1. Stigma, professionals fear of alienating patients/clients accidentally, no resources for FASD so they see it as risking alienation for no good reason, and child welfare has a real reputation here for treating FASD as a taboo subject because of their belief it will be harder to place children for adoption if they are diagnosed.
2. SO excited NOFAS is doing this search/survey!
3. Personally, I could create an FASD red flag/screening list/tool, as could many involved with FASD. I support NOFAS creating an FASD screening tool, to be used in conjunction with existing screening tools for behavioral health issues! I have looked at the AAP and CDC FASD websites, and they just generically refer to screening for FASD. I don't think they are going to step up to create the FASD screening tool we need. Plenty of research exists, but what we need is a good screening tool. That's why I'd love to see NOFAS create one. I am happy to share my list and talk with you further about this. As a member of the CO Behavioral Health Task Force (and one of the few members with lived experience (my adult son has FAS), I have been advocating for screening for FASD for all those entering the juvenile justice system in CO (and young adults first arrested). But it is hard to advocate this when I can't recommend a screening tool. Thanks for all you do. I was happy that Illuminate Colorado told me about your survey. I am a member of their FASD ID Work Group. Good luck.
4. It seems that there are more services, supports and funding for children who are diagnosed with Autism as opposed to FASD. Because FASD is harder to diagnose and has many symptoms in common with Autism, it seems that some clinicians default to an Autism diagnosis.

SECTION 2

FASD Screening Resources

The following links include proposed or validated FASD screening strategies, criteria, or tools.

The workgroup notes that screening is not a substitute for full assessment and diagnosis, and screening tools are not precise and can only predict the risk for FASD. Using screening tools to diagnose can stigmatize individuals and families. Screening should not be done where there is no access to diagnostic services or in areas where there is a lack of diagnostic capacity.

Screening in treatment programs for Fetal Alcohol Spectrum Disorders that could affect therapeutic progress
Note: The research reported here supports a brief interview protocol, the Life History Screen (LHS), that screens clients unobtrusively for adverse life-course outcomes typically found in FASD, so as to guide follow-up assessments and treatment planning.

Neurodevelopmental profile of fetal alcohol spectrum disorder: A systematic review
Note: A description and review of The Child Behavior Checklist and the Behavior Rating Inventory of Executive Function that have been used to identify a neurodevelopmental profile characteristic of FASD.

FASD: A Guide for Pediatricians and Mental Health Providers
Note: An explanation and guide for using the FAS Screen Form and The ARND Behavioral Checklist developed by Larry Burd. PhD.

A decision Tree to Identify Children Affected by Prenatal alcohol exposure
Note: A hierarchical decision tree model, combining neurobehavioral and physical measures, for identification of children affected by prenatal alcohol exposure even when facial dysmorphology is not present developed by Sarah Mattson, PhD and colleagues.

Recommended Assessment Tools for Children and Adults with Confirmed or suspected FASD
Note: Dated but still relevant cognitive tests and other tools for FASD assessment.

Flow Diagram for Medical Home Evaluation of FASD
Note: The Flow Diagram was devised to facilitate greater clinical recognition of children with fetal alcohol spectrum disorders (FASD) while acknowledging that FASD could and should be recognized in individuals of any age. It was developed by the American Academy of Pediatrics in conjunction with the Centers for Disease Control and Prevention.

Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan
Note: The guideline includes a proposed algorithm for the identification of FASD.

FASD 4-Digit Diagnostic Code
Note: FAS Diagnostic & Prevention Network

Children's Healthcare Canada's National Screening Toolkit for Children and Youth Identified and Potentially Affected by FASD
Note: Development of the National Screening Tool Kit for Children and Youth Identified and

Potentially Affected by Fetal Alcohol Spectrum Disorder (FASD) involved nearly one hundred experts and providers from Canada and the United States.

Australian Guide to the Diagnosis of FASD
Note: Includes FASD Diagnostic Assessment Forms.

A Treatment Improvement Protocol: Addressing Fetal Alcohol Spectrum Disorders (FASD)
Note: Published by the Substance Abuse and Mental Health Services Administration (SAMHSA), the TIP includes a checklist and assessment questions to identify the presence of an FASD, beginning on page 17.

Addressing Fetal Alcohol Spectrum Disorders (FASD): A Review of the Literature
Note: A review of the science on screening and/or diagnosis, beginning on page 1-38.

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure
Note: Neurocognitive, self-regulation, and adapt domains for assessing developmental traits associated with prenatal alcohol exposure.