Introduction

Form Approved
OMB No. 0902-XXXX
Exp.: XX/XX/XXXX

Thank you for your interest in fetal alcohol spectrum disorders (FASD). We would like to invite you to complete an evaluation survey on the FASD Toolkit. We appreciate your willingness to help us evaluate the effectiveness of the toolkit and its impact on your practice as you address the prevention, identification, and treatment of FASD.

This survey will take approximately 15 minutes to complete. Your responses will be kept secure and no individually identifying information will be included. Risks to participating in this survey are minimal and include the risk of your information becoming known to individuals outside the AAP.

Your participation in this survey is voluntary. You may decline to answer any question and you have the right to stop the survey at any time.

Please submit questions to the project partners at PEHDIC@aap.org.

FASD Toolkit User Survey

Part One: Scenarios

In this section, you will be asked to read four brief case scenarios. After each case scenario, you will be asked to use the toolkit to assist you in clinical decision-making related to a specific question. You will then be asked to rate the toolkit based on your experience. There is no right or wrong answer to any of the questions; we are interested in your honest feedback on the toolkit.

Please have the toolkit open in your browser window while you complete this section:
http://www.aap.org/fasd

FASD Toolkit User Survey

A. Identification of children at risk for FASD

Early identification of children at risk for FASD has many potential benefits, including: earlier diagnosis, early access to information regarding intervention and support for parents; earlier access to targeted interventions; and earlier identification of comorbid medical, developmental, and psychiatric conditions.

Initial Symptoms

Ann is an 8-year 7-month-old white girl who was brought to your office for a well-child visit by her adoptive mother. This is their first visit to your clinic since they moved from another state owing to a work transfer.

Medical History

Ann was born preterm at 29 weeks and stayed in the birth hospital for a total of 6 weeks, initially for respiratory support and then to support feeding and growth.

Weight: 2 lb (<3rd percentile)
Length: 39 cm (5th percentile)
Head circumference: 27.5 cm (<3rd percentile)

The biological mother denied the use of drugs but admitted to drinking alcohol at least weekly throughout the pregnancy. Owing to Child Protective Services involvement with a previous child, Ann was discharged to therapeutic foster parents, who subsequently adopted her. There were no disruptions in her home environment.

Developmental history revealed delays in gross motor, fine motor, self-care, and language skills.

Ann learned the alphabet early, but had difficulty with reading comprehension and mathematics in the first and second grades. However, Ann tests within the low average range and has met requirements to be promoted with her classmates, but only with intense support from the family members, which is causing a strain within the family.

Her mother said that she struggles in all academic areas. Ann is starting to have difficulty with peers owing to her academic challenges and immaturity.

Physical examination

Weight: 38 lb (<3rd percentile)
Height: 44 in (<3rd percentile)
Head circumference: 49.5 cm (<3rd percentile)

There were bilateral epicanthal folds and hypertelorism. She had short palpebral fissures, with a smooth philtrum and a thin upper lip (rank 4 on the Washington University Lip-Philtrum Guides). She had a grade 3/6 holosystolic murmur.

Neurological examination

Examination revealed generalized hypotonia. She was friendly and generally cooperative, although needed frequent redirection. She was shy but became appropriately socially engaged after she warmed up to you.

Please take a few minutes to navigate the toolkit contents with the purpose of helping you to determine whether or not this patient should be referred for diagnosis and then rate your experience using the toolkit by completing the questions below.

Rate the following statements about the toolkit content on **identification of children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The content is complete, offering comprehensive coverage.	○	○	○	○	○
The content is credible and trustworthy.	○	○	○	○	○
The topics covered are relevant to my work.	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in other online resources (e.g., database, website, etc.).	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in print resources (e.g., books, journals, etc.).	○	○	○	○	○

Rate the following statements about whether the toolkit has affected your knowledge about **identifying children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
It reinforced and validated what I already knew.	○	○	○	○	○
It provided me with information that was new to me and useful for my work.	○	○	○	○	○
I have already seen the information in a different resource.	○	○	○	○	○

Rate the following statements about whether the toolkit has affected (positively or negatively) your views and ideas about **identifying children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
It provided me with information that changed my views, opinions, or beliefs.	○	○	○	○	○
It provided me with a new idea or way of thinking.	○	○	○	○	○

FASD Toolkit User Survey

B. Diagnosis of children who have or who may have FASD

<u>Case Scenario #2</u>

Lily is a 7 y 10 month old Caucasian female who was adopted from Ukraine at 17 months of age and who presented with growth deficits, facial abnormalities, microcephaly, developmental delay and an MRI abnormality. She has frequent ear infections related to small ear canals. She also has ophthalmologic and orthopedic problems. She has urinary incontinence. She is an ex-32 weeker with birth weight of 2 lbs12 oz. Developmental history reviewed that Lily stood by herself at 19 mos and walked at 36 months. She can use a spoon, fork and regular cup and dress herself with assistance. She can scribble but has trouble drawing a circle/cross. She has a few words and 30-40 signs. She is receiving ECE services in a self-contained classroom. She receives speech language therapy and occupational therapy services.

• Family history: Unknown
• Social history: Adopted at 17 mos from Ukraine.

Physical examination showed height to be in the 7th %ile, weight at 3rd %ile and head circumference at 3rd percentile. She had very short palpebral fissures at 2.2 cm ®, smooth to flat philtrum and very thin upper lip. She had microcephaly, telecanthus, small, less developed ear with narrow canals, micrognathia, bilateral hockey stick creases, and shallow sacral dimple. Neurological examination showed a friendly, cooperative and attentive child with hypotonia in the upper extremities, increased tone on the ankles, poor tandem gait, and hyperreflexia in lower extremities. Psychological evaluation (DP-III) showed cognitive skills at 16 months age equivalent, and adaptive skills at 14 months age equivalent. Speech-language evaluation showed receptive language at 2 yrs 1 month and expressive language at 1 year 1 month (PLS-IV) and therefore had a severe receptive-expressive language impairment.

Please take a few minutes to navigate the toolkit contents with the purpose of helping you to diagnose this patient for an FASD condition and then rate your experience using the toolkit by completing the questions below.

Rate the following statements about the toolkit content on **diagnosing children who have or who may have FASD**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The content is complete, offering comprehensive coverage.	○	○	○	○	○
The content is credible and trustworthy.	○	○	○	○	○
The topics covered are relevant to my work.	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in other online resources (e.g., database, website, etc.).	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in print resources (e.g., books, journals, etc.).	○	○	○	○	○

Rate the following statements about whether the toolkit has affected your knowledge about **diagnosing children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
It reinforced and validated what I already knew.	○	○	○	○	○
It provided me with information that was new to me and useful for my work.	○	○	○	○	○
I have already seen the information in a different resource.	○	○	○	○	○

Rate the following statements about whether the toolkit has affected (positively or negatively) your views and ideas about **diagnosing children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
It provided me with information that changed my views, opinions, or beliefs.	○	○	○	○	○
It provided me with a new idea or way of thinking.	○	○	○	○	○

FASD Toolkit User Survey

C. Referring Children who have or who may have FASD

Case Scenario #3

Robert is a 14-year-old Caucasian male who was brought to your clinic by his adoptive mother because she was researching his symptoms online and was concerned that her son may have fetal alcohol syndrome. She knew all along that his 21-year-old biological mother drank alcohol (mixed drinks and wine, about 4-5 drinks, 2-3 nights a week) during her first 3 months of pregnancy. Beyond that, biological mother denied family history of any developmental disorders or psychiatric conditions. Biological mother finished at least 2 years of college. Robert is failing academically. He has significant behavioral problems in school. He has trouble following multi-step directions. He is extremely impulsive and has a lot of meltdowns and aggressive behavior. He was placed in emotional/behavioral disorder (EBD) classes, which his mother felt made some of the behaviors worse as he tended to go with the wrong crowd in these particular classes. He has always been naïve and suggestible and would do anything for a friend. Despite repeated instruction, he still has not mastered good self-care or grooming skills.

Robert was born at term though the pregnancy was complicated by intrauterine growth retardation. Birth weight and length were both at the 50th percentile. Head circumference was at 25th percentile. Previous psychoeducational testing done showed an IQ score of 80 but on academic achievement testing, his reading, mathematics and written expression standard scores were in the low 60s. He had good expressive language scores but his receptive language was in the borderline range and closer to a 10 year old level. He is currently on medications for ADHD but this has not significantly improved distractibility and impulsivity. His psychiatrist also gave him neuroleptic medications on the basis of extreme meltdowns and aggressive behavior. On physical examination, weight was at the 50th percentile while height was at the 25th percentile. Head circumference was at the 25th percentile. He had no dysmorphic facial features except for somewhat wide inner canthal distance (space between the eyes). He was charming and sociable but was unusually impulsive and distractible. He had difficulty staying focused on tasks and although he talked a lot, much of the conversation was circuitous and immature, closer to a 7-8 year-old child than that of a 14-year-old.

Please take a few minutes to navigate the toolkit contents with the purpose of helping you to refer this patient for support and intervention services related to FASD and then rate your experience using the toolkit by completing the questions below.

Rate the following statements about the toolkit content on **referring children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The content is complete, offering comprehensive coverage.	○	○	○	○	○
The content is credible and trustworthy.	○	○	○	○	○
The topics covered are relevant to my work.	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in other online resources (e.g., database, website, etc.).	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in print resources (e.g., books, journals, etc.).	○	○	○	○	○

Rate the following statements about whether your knowledge about **referring children who have or who may have FASD** has been affected by the toolkit.

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
It reinforced and validated what I already knew.	○	○	○	○	○
It provided me with information that was new to me and useful for my work.	○	○	○	○	○
I have already seen the information in a different resource.	○	○	○	○	○

Rate the following statements about whether the toolkit has affected (positively or negatively) your views and ideas about **referring children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
It provided me with information that changed my views, opinions, or beliefs.	○	○	○	○	○
It provided me with a new idea or way of thinking.	○	○	○	○	○

FASD Toolkit User Survey

D. Treatment Planning and Monitoring of children who have or who may have FASD

Case Scenario #4

Initial Symptoms
Ben is a 5-year-old African American boy who was brought by his grandmother to your office for hyperactive and impulsive behaviors. He does not follow directions unless they are stated repeatedly. His behaviors have been causing problems in the school and home settings.

Medical History

Ben was born at 40 weeks' gestation by vaginal delivery to an 18-year-old gravida 1 para 0 (G1P0) mother who drank 4 to 6 drinks per week (wine or beer), with some mixed drinks and liquor during weekends and some weekdays, in all 3 trimesters of the pregnancy. The mother denied drug and tobacco use. This information was obtained from the paternal grandmother, as disclosed by the biological mother.

Weight: 4 lb 3 oz (<5th percentile)
Length: 17 in (<5th percentile)
Head circumference: 30.5 cm (<5th percentile)

• Tested with Bayley Scales for Infant Development-II (BSID-II) resulting in a developmental quotient (DQ) of 85 in preschool.
• Previous magnetic resonance imaging showed significant microcephaly and a smaller corpus callosum.
• History of frequent ear infections, but a recent hearing test was normal.
• Normal vision, but poor eye tracking.
• Small ventricular septal defect evident at birth that subsequently closed.
• Both siblings have developmental delay.

Physical and Neurological Examination Findings

Physical examination
Normal vital signs

Weight: 30 lb (<5th percentile)
Height: 38 in (<5th percentile)
Head circumference: 48.5 cm (3rd percentile)

Epicanthal folds and palpebral fissures	Short and small palpebral fissures (2.3 cm, bilaterally), with an inner canthal distance of 3 cm (orbital hypertelorism)
Philtrum and upper lip	Smooth and thin (rank 4 on the University Washington Lip-Philtrum Guides)
Facial features	Normal ears set, flattened mid-face, and a narrow palate
Auscultation of lungs	Clear
Heart murmur	No
Abdominal examination	Benign
Skin examination	Normal
Extremities	Bilateral fifth finger clinodactyly

Neurological examination
• Hyperactive, impulsive, and highly distractible
• Had trouble following simple directions
• Cranial nerves were intact
• Had normal muscle strength and reflexes
• Displayed no ataxia, nystagmus, or tremor

Please take a few minutes to navigate the toolkit contents with the purpose of treatment planning and monitoring for this patient and then rate your experience using the toolkit by completing the questions below.

Rate the following statements about the toolkit content on **treatment planning and monitoring for children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The content is complete, offering comprehensive coverage.	○	○	○	○	○
The content is credible and trustworthy.	○	○	○	○	○
The topics covered are relevant to my work.	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in other online resources (e.g., database, website, etc.).	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in print resources (e.g., books, journals, etc.).	○	○	○	○	○

Rate the following statements about whether the toolkit has affected your knowledge about **treatment planning and monitoring for children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
It reinforced and validated what I already knew.	○	○	○	○	○
It provided me with information that was new to me and useful for my work.	○	○	○	○	○
I have already seen the information in a different resource.	○	○	○	○	○

Rate the following statements about whether the toolkit has affected (positively or negatively) your views and ideas about **treatment planning and monitoring for children who have or who may have FASD.**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
It provided me with information that changed my views, opinions, or beliefs.	○	○	○	○	○
It provided me with a new idea or way of thinking.	○	○	○	○	○

FASD Toolkit User Survey

Part Two: General Feedback

Please rate the following statements about the toolkit:

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The home page makes me want to explore it further.	○	○	○	○	○
The layout and design is clear and visually appealing.	○	○	○	○	○
It is easy to navigate through the different sections.	○	○	○	○	○
I am able to find the information I am looking for.	○	○	○	○	○
Screens/pages have too much information.	○	○	○	○	○
Screens/pages have too little information.	○	○	○	○	○
It is as easy or easier to find the information I am lookingfor, compared to finding the same information in other online resources (e.g., websites, databases, etc.).	○	○	○	○	○
It is as easy or easier to find the information I am looking for, compared to finding the same information in print resources (e.g., books, journals, etc.).	○	○	○	○	○

Please rate the following statements about the toolkit content overall:

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The content is complete, offering comprehensive coverage.	○	○	○	○	○
The content is credible and trustworthy.	○	○	○	○	○
The topics covered are relevant to my work.	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in other online resources (e.g., database, website, etc.).	○	○	○	○	○
The information is of equal or higher quality than information on this topic I can find in print resources (e.g., books, journals, etc.).	○	○	○	○	○

What kinds of information in the toolkit would you use regularly? (check all that apply)

- [ ] National Task force on FAS and FAE "Guidelines for Referral and Diagnosis"
- [ ] A Practical Clinical Approach to Diagnosis of Fetal Alcohol Spectrum Disorders: Clarification of the 1996 Institute of Medicine Criteria
- [ ] Algorithm for Evaluation
- [ ] Diagnosis and Assessment of FASD
- [ ] How to Use the Lip Philtrum Guide
- [ ] Online Course: FASD 4-Digit Diagnostic Code
- [ ] Medical Home Principles
- [ ] Sample Care Plan
- [ ] I would not use any of the information in the toolkit regularly

Other (please specify)

[   ]

Please give a specific example of how the toolkit has increased or validated your knowledge.

[   ]

To what extent would you feel confident using the knowledge validated or gained from the toolkit in your work?

- ( ) Not at all confident
- ( ) Not very confident
- ( ) Undecided
- ( ) Confident
- ( ) Very confident

Please give a specific example of how the toolkit changed your views or gave you new ideas (e.g., favorable or unfavorable).

[   ]

FASD Toolkit User Survey

Please indicate whether or not you plan on using information from the toolkit for the following purposes, using the scale below.

	Definitely not	Unlikely	Not Sure	Probably	Definitely
To inform decision-making (e.g., clinical, personal, or other)	○	○	○	○	○
To improve practice guidelines, programs, projects, or strategies	○	○	○	○	○
To improve training, education, or research	○	○	○	○	○
To inform public health policies and/or advocacy	○	○	○	○	○
To write reports/articles	○	○	○	○	○
To develop proposals	○	○	○	○	○
To guide a research agenda or methods	○	○	○	○	○
To put research findings into practice	○	○	○	○	○
To promote best practices	○	○	○	○	○
To increase public awareness	○	○	○	○	○
To increase my own knowledge	○	○	○	○	○

Please give an example of how you might use specific information from the toolkit in your work.

Please rate the following statements about performance areas that you expect to be affected as a result of using the toolkit:

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
Based on something I have learned from the toolkit, I expect to change the way I perform my job.	◯	◯	◯	◯	◯
I expect to use information from it to improve my skills related to caring for patients who have or who may have FASD.	◯	◯	◯	◯	◯
I expect it to help me to be more competent at working with patients and families who have or FASD.	◯	◯	◯	◯	◯
I expect it to help me to be more effective at working with patients and families who have or FASD.	◯	◯	◯	◯	◯
I expect it to help me to perform my job more efficiently (e.g., connecting children with FASD to community or national resources more efficiently, etc.).	◯	◯	◯	◯	◯
I expect my some of my patients will experience health benefits as a result of my applying the toolkit information.	◯	◯	◯	◯	◯
I expect my communication with families around FASD and related issues to improve.	◯	◯	◯	◯	◯
I expect it will improve the appropriateness of referrals for children in my care who have or who may have FASD.	◯	◯	◯	◯	◯
I expect it will improve the performance of my clinic with respect to identification of children with FASD.	◯	◯	◯	◯	◯
I expect it will improve the performance of my clinic with respect to diagnosing of children with FASD related conditions.	◯	◯	◯	◯	◯
I expect it will improve the performance of my clinic with respect to the treatment and monitoring of children with FASD related conditions.	◯	◯	◯	◯	◯

Please give a specific example of how you expect the toolkit might improve your own performance or your clinic's performance.

How likely are you to recommend the toolkit or its resources to a colleague or co-worker?

◯ Not at all likely

◯ A little likely

◯ Not sure

◯ Likely

◯ Very likely

Please give a specific example of how and what you might share with your colleagues or co-workers.

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How might you adapt the toolkit information for your own use? (check all that apply)

☐ I would adapt information to better fit the context I work in.

☐ I would adapt information to make it simpler to use

☐ I would translate information from English into another language.

☐ I would not adapt the toolkit information at this time.

Other (please specify)

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Please give an example of how you might adapt specific information from the toolkit to use in your work.

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FASD Toolkit User Survey

Part Three: Background Information

Please select the category that best describes your role. (Select all that apply)

☐ Primary Care Pediatrician

☐ Pediatric specialist

☐ Nurse practitioner

☐ Parent of a child with FASD

☐ School professional

☐ Educator/Trainer

Other (please specify)

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Please rate the following statements about where you currently work:

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
I have access to research findings where I work.	○	○	○	○	○
I have access to research findings on my floor.	○	○	○	○	○
I have time to read about research while I am on duty.	○	○	○	○	○
I base my practice on research.	○	○	○	○	○
I do not use research in my day-to-day practice.	○	○	○	○	○
Using research helps me meet my professional goals.	○	○	○	○	○
I would change my practice based on research findings.	○	○	○	○	○

FASD Toolkit User Survey

Closing

Thank you very much for your time and valuable feedback. Your feedback will be used to guide the development, management, and improvement of the toolkit in the future.

Please feel free to contact the manager for Screening and Public Health Prevention Programs at pehdic@aap.org anytime if you have any concerns or questions.

If you could make one significant change to the toolkit, what would it be?

Do you have any additional comments?

May we follow-up with you in the future to find out more about your opinions on the toolkit? If yes, please provide contact info email/phone: