## Fetal Alcohol Spectrum Disorders: Collaboration of National, State and Community Groups in Lifespan Prevention and Interventions

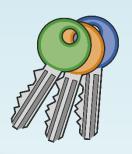
ANN CARRELLAS, LMSW, MA, MA

MICHIGAN DEVELOPMENTAL DISABILITIES INSTITUTE
WAYNE STATE UNIVERSITY
DETROIT, MI
CHILD WELFARE LEAGUE OF AMERICA
2016 NATIONAL CONFERENCE

**AUGUST 1, 2016** 

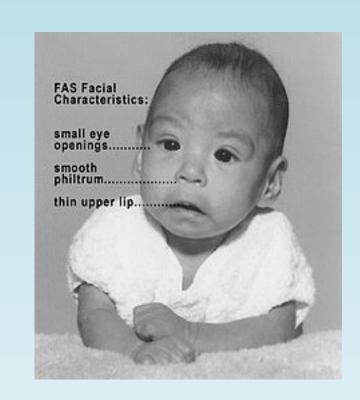
# **Key Objectives for Today**

- Describe the different organizations involved in FASD efforts
- Identify the programs and services offered by the State of Michigan related to FASD identification, prevention, and intervention
- Understand the role of the Michigan FASD Task Force in state and national prevention and intervention efforts
- Review the strategic planning processes and progress
- Explain the collaborations that exist across advocates, professionals, and local, state and national spheres



# What are Fetal Alcohol Spectrum Disorders (CDC, 2016)

- □FASDs are not a diagnosis but describes the effects of prenatal alcohol exposure which may include a range of disorders.
- □FASDs are caused by drinking alcohol while pregnant.
- □ Alcohol is teratogen—it interferes with the typical development of the fetus causing birth defects.



## Cause of FASDs

The sole cause of FASDs is the fetus being exposed to alcohol during the pregnancy.

"Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."

—IOM Report to Congress, 1996

## **Important Facts**

- FASDs are 100% preventable!
- All alcoholic beverages are harmful to a developing fetus.
- Binge drinking is particularly damaging to a developing fetus. For women, binge drinking means 4 or more drinks within about a 2 hour period of time (CDC, 2013).
- Any drinking during pregnancy is potentially harmful!



## **Causes of FASD**

- Fetal alcohol spectrum disorders are the leading preventable cause of intellectual disability in the United States (The Arc, 2013).
- FASDs are more prevalent than Down Syndrome (Shin et al., 2009; SAMHSA, 2013) and Autism Spectrum Disorders in children (The Autism Society, 2015).
- FASD is 100% preventable when women abstain from alcohol during pregnancy

## **Facts About FASDs**

- The effects of FASDs last a lifetime.
- People with an FASD *can* grow, improve, and function well in life with proper support.

• FASDs are 100% preventable.

# Things You Can Do to Support Someone who Has an FASD

- Assume that the individual is doing the best they can and can do better with the right support
- Remember that FASDs are a brain based disorder and that individuals are not intentionally trying to be oppositional or defiant
- Often what appears to be oppositional behavior is a result of being overwhelmed by requests for information, realized they made a mistake, don't want to be blamed or made to look stupid or are afraid
- Behaviors that create difficulties are often the result of memory, learning, communication, sensory, and communication problems **due to the brain damage**

# Factors Associated With Reduced Life Complications (Streissguth et al, 2004)

- Stable home
- Early diagnosis
- No violence against oneself
- More than 2.8
   years in each
   living situation

- Recognized disabilities
- Diagnosis of FAS
- Good quality home from ages 8 to 12



## **Some Context**



- Estimated that 70% of children in foster care have been prenatally exposed to alcohol (Astley et al., 2002)
- Rate of FASD in elementary school aged children in the general US population is 2.4% to 4.8% (May et al., 2014)
- \$2 to \$2.9 million is estimated costs over a lifetime for one individual with FAS (Lupton et al., 2004)
- The United States is estimated to spend up to \$4 billion a year in relation to the impact of FASD (Lupton et al., 2004)

## Cost to individuals, families, & communities

- Lifetime disability
- Lower intellectual ability
- Difficulties in academic achievement
- Problems with adaptive and executive functioning

## Which leads to:

- o Problems with the law
- Difficulties forming social relationships
- Struggles in managing daily living activities





## CHILDREN'S DEFINITION Michigan Mental Health Code

• If applied to a minor from birth to age five, a substantial developmental delay or specific congenital or acquired condition with a high probability of resulting in developmental disability as defined below.

Michigan Compiled Laws 330.1100a (21)





## Michigan Mental Health Code

Developmental Disability means either of the following:



- 1. If applied to **an individual older than five years**, a severe, chronic condition that meets all of the following requirements:
  - o Is attributed to mental or physical impairment or a combination of mental and physical impairments.
  - Is manifested before the individual is 22 years old.
  - Is likely to continue indefinitely



# Michigan Mental Health Code(cont)

 Results in substantial functional limitation in three or more of the following areas of major life activities:



- Self-care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency
- Reflects the individual's need for a combination and sequence of special, interdisciplinary, or other services that are of lifelong or extended duration and are individually planned and coordinated.



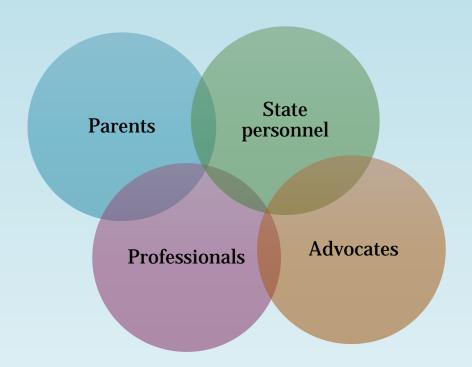




## Michigan FASD Task Force

# Michigan FASD Task Force

- History of the Task Force
- Role of MI-DDI
- Recent accomplishments



# Members of the Michigan FASD Task Force

- Parents
- Individuals who have FASD
- MCFARES (Michigan Coalition for Fetal Alcohol Resources, Education & Support, Michigan's NOFAS (National Organization on Fetal Alcohol Syndrome) affiliate
- Representatives from state departments-maternal and child health, behavioral services and developmental disabilities, juvenile justice, child welfare, substance use
- Professionals from different fields-health, social work, substance abuse, mental health and disability providers
- Arcs and advocates



## Brief History of the Task Force

### Initiatives before the task force

- First baby in the US to be diagnosed with Fetal Alcohol Syndrome came from Michigan and was diagnosed by Dr. Kenneth Jones in 1976.
- 1988-1995- Multiple conferences to educate professionals and communities about the impact of prenatal alcohol exposure
- 1999-State of Michigan designated \$200,000 for 5 FAS diagnostic teams to be trained at the University of Washington
- 2002-SAMHSA funds Town Hall Meeting, Conference for and by teens and adults with FASD held

## History

- 2004-Michigan FASD Task Force formed
- 2006-1st Michigan FASD Task Force Strategic Plan is created (2006 to 2011) with technical assistance from the FASD Center for Excellence
- 2011-2<sup>nd</sup> Strategic Plan is created (2012-2015)
- 2013-Our Journey of 40 Years and Beyond: Living and Learning with FASD
- 2015-3<sup>rd</sup> Strategic Plan is created (2016-2018)



## Michigan Developmental Disabilities Institute

- Is a University Center for Excellence in Developmental Disabilities (UCEDD)
- UCEDDS exist in every state and receive core funding from the Administration on Intellectual and Developmental Disabilities
- Authorized by the Developmental Disabilities and Bill of Rights Act of 2000 preceded by the first DD act signed by President Kennedy
- Part of a national network for full inclusion of individuals with disabilities in their communities
- Our values include cultural respect, empowerment, and self-determination
- We collaborate with families, individuals with disabilities, organizations, state departments, and local communities across Michigan

## Core Functions of MI-DDI

- Community Support and Services
- Training and Education
- Research and Evaluation
- Information Dissemination



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About Us

**DDI News** 

Community Support

Research & Evaluation

Training Calendar

Publications & Reports

Possibilities Video Series

S3 Learning Community

Graduate Certificate Program

Links

**AUCD** 







Section 508 Compliant

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## AN ALCOHOL-FREE PREGNANCY IS THE BEST CHOICE FOR YOUR BABY

When a pregnant woman drinks alcohol, so does her baby. Why take the risk?

Welcome to the Fetal Alcohol Spectrum Disorders (FASD) Task Force!

The FASD Task Force is a collection of self-advocates, advocates, family members, disability researchers and policy makers who's charge is to address issues facing individuals with FASD and spread information regarding FASD in order to educate the public. The vision of the Task Force is to come together to address Fetal Alcohol Spectrum Disorders through awareness, prevention and greater access to services.

### Mission of the FASD Taskforce:

The mission of the Michigan Fetal Alcohol Spectrum Disorders (FASD) Task Force is to advocate for statewide prevention and treatment. The Task Force brings together affected individuals, families and multidisciplinary professionals committed to increasing awareness of FASD, improving service delivery systems, decreasing these preventable disorders and enhancing quality of life for affected individuals and their families.

### Michigan FASD Task Force- 2016 Meeting Dates

Dates: February 17, May 18, August 17, November 16 | Time: 10:00am- 1:00pm

Location: Michigan Primary Care Association, Lansing. Click Here For Driving Directions.

### THE MICHIGAN FASD TASK FORCE PRESENTS:

### Our Journey of 40 Years and Beyond: Living and Learning with FASD

### September 12, 2013

7:30-8:00am	Registration, Continental Breakfast
7.30 0.00aiii	nceistration, continental breaklast

8:00-8:30am Welcome, Anniversary Explanation, Introduction of Kenneth Lyons Jones, MD

Wolverine Ballroom B,C,D,E

8:30-9:30am Keynote Address:

Looking Back, Looking Forward: Kenneth L. Jones, MD

9:30-10:30am Using the Intersection of Genetics, Toxic Traumatic Stress, and Prenatal Drug

and Alcohol Exposure to Transform Primary Healthcare: Mark Sloane, MD

10:30-10:45am BREAK

10:45-11:45am Workshop Sessions

Arbor Room 1. Parents and Youth Panel on Community Programs: Charisse Cossu-Kowalski,

Joshua Kowalski, Carol Cole, William Range, and Janet Maracle

Huron Room 2. Transition: Planning for Beyond High School: Sandee Koski, MA and Charlyss

Ray, OTR-L

Wolverine Ballroom A 3. Fundamentals of FASD: The Top Ten Things You'll Want to Know:

Sandra Kuhn, LMSW

Wolverine Ballroom B 4. Estate Planning and Amenities Trusts: Joshua Fink, Attorney

11:45am-12:30pm LUNCH

Wolverine Ballroom B,C,D,E

12:30-1:30pm Behavior is Communication! Sally Burton-Hoyle, Ed.D

1:30-2:30pm Workshop Sessions

Huron Room 1. Looking at the Whole Picture: Spectrum Health's Clinical Data Points: The

Way to a Clearer Vision: Helga Toriello, Ph.D and Barbara Wybrecht, RN, BSN

Arbor Room 2. Diagnosing Teens and Young Adults: Kenneth Lyons Jones, MD

Wolverine Ballroom A 3. Self Determination: Getting a Good Life! Michigan Partners for Freedom:

Pam Rathbun and Pat Carver

Wolverine Ballroom B

4. FASD State Coordinator Update & Innovative Community-Based Programs to Address Prevention and Intervention: Debra Kimball, MSN, RN

2:30-2:45nm RREAK

### THE MICHIGAN FASD TASK FORCE PRESENTS:

# Our Journey of 40 Years and Beyond: Living and Learning with FASD September 12, 2013

## THANK YOU TO OUR SPONSORS:

Ann Arbor FASD Parent Support Group

CARE of Southeastern Michigan

Developmental Disabilities Institute, Wayne State University

Great Lakes FASD Regional Training Center

Michigan Coalition for Fetal Alcohol Resources, Education & Support (MCFARES)

Merrill Palmer Skillman Institute, Wayne State University

Michigan Department of Community Health

Michigan Department of Education

Michigan Department of Human Services

Stonecastle Dentistry

West Michigan FASD Parent Support Group

Please click on your county for local resources for families and individuals with Fetal Alcohol Spectrum Disorders.



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# Save The Date

## "Into Action!"

Featuring: Adrienne Bashista

Director of Families Affected by Fetal Alcohol Spectrum Disorder

Supporting Individuals with

Fetal Alcohol Spectrum Disorder (FASD)

Through a Strength & Brain Based Approach

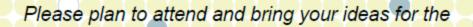
October 15 -16, 2015 Thursday & Friday

Wayne State University
Oakland Center
33737 West Twelve Mile Rd.
Farmington Hills, MI 48331

Hosted By:
The Developmental
Disabilities Institute &
Michigan FASD
Task Force

## Other accomplishments

- Presentations to schools, universities, social workers, probation officers, teachers on supporting individuals who have FASD to succeed
- Individual support and advocacy to families struggling to ensure the well being of their family members
- Resources and information dissemination
- Michigan's NOFAS affiliation agency is on the task force and sent a member to meet with legislators in Washington
- Continual strategic planning and monitoring progress



Michigan Fetal Alcohol Spectrum Disorders (FASD) Task Force

## Strategic Planning Day

When:

Thursday

November 19, 2015

9:30 am - 3:00 pm

Location:

Capital Area District Library

(Downtown Lansing)

401 South Capitol

Lansing, MI

## Leigh Tenkku Lepper, PhD

University of Missouri

will facilitate our day's work to create our roadmap for the next 3 years. Leigh is a social worker and professor of public health. She is a member of the NOFAS Affiliates Committee. She has published extensively and provides training about prevention and interventions related to FASD.

Lunch will be provided

Please **RSVP** to Ann Carrellas by November 13<sup>th</sup> by email at

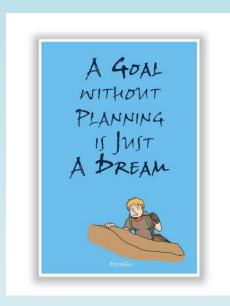
# Current MI FASD Task Force Strategic Plan 2016-2018

### Goal #1

• Make MCFARES as the NOFAS affiliate the clearinghouse for FASD information in Michigan and accumulate information regarding services and resources available for parents and professionals.

### Goal #2

• Educate all who come into contact with individuals who have an FASD for the purpose of improving lifelong outcomes by increasing access to information, to resources, referrals, screening tools, and intervention strategies.



### Goal #3

• Empower adults with FASD through screening, diagnosis, treatment and interventions, and support.

## Goal Group #1 Action Plan

Goal #1: Make MCFARES as the NOFAS affiliate the clearinghouse for FASD information in Michigan and accumulate information regarding services and resources available for parents and professionals.

1.Enhance the MCFARES website by adding information so that it becomes the hub of information and resources related to FASD in the state and nationally.

### 1.1.a

What: Populate website with categories of information and resources and continually monitor, making additions and deletions as needed to keep the website up to date.

## Action plan

## Categories of information include:

- History of MCFARES (including mission, vison statements and goals
- Resources: Library, yahoo group, Facebook page, twitter, diagnostic centers, support group list, NOFAS Calendar: Upcoming event
- Fundraising: Amazon (register with them), GoodSearch, Kroger, other stores (need to find them and register with them), link to direct-donate
- Information: Links to prevention; what is FASD, diagnostic information, interventions (schools, services, needs across lifespan), local and national groups: State Task Force, Michigan workgroup, NOFAS

## Action plan

Who's responsible: Charisse Cossu-Kowalski and other goal group members and others as needed and interested.

When: Initial upgrade to be done by April 2016

Ongoing: Keep updated throughout the plan's timeframe.

# Action plan

1.2c

What: Come up with talking points to present to legislators in Washington, DC as part of the NOFAS legislative advocacy and in local state meetings with legislators

When: Before June 20th, June 1st phone conference is planned

Ongoing: Individual Task Force members will contact their legislators using the talking points about FASD.

• Resources: Talking Points, References, Resources developed by Goal Group #1.



### Fetal Alcohol Spectrum Disorders Talking Points

### Fetal alcohol spectrum disorders

- Prenatal alcohol exposure causes the most serious neurobehavioral disabilities of all substances<sup>1</sup>
- The non-diagnostic term "FASD" includes the diagnoses of fetal alcohol syndrome (FAS), alcohol related neurodevelopmental disorders (ARND), and alcohol related birth defects (ARBD).
- Severity and types of disabilities can vary from mild to severe within each of the specific diagnostic categories
- Includes a range of physical, behavioral, social, emotional, and learning disabilities
- FASD-related challenges last the lifespan of the affected individual.<sup>2</sup>
- Recent studies show that 2% to 5% of elementary school children have been prenatally exposed to alcohol<sup>3</sup>
- Up to 70% of children in foster care have a FASD<sup>3,4</sup>
- Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) is in the DSM-V Appendix

#### Societal Impact

- Supporting one person with a FASD costs \$2.0 to \$2.9 million over a lifetime<sup>5</sup>
- U.S. spends 5.4 billion a year on expenses related to FAS alone (more if all disorders on the spectrum are considered)<sup>6</sup>
- Estimated that up to 45% of the US corrections population has a FASD<sup>7,8</sup>

#### Services Needed

- Families and individuals need cost-effective, accessible, appropriate and constructive lifespan supports
  and services in their communities such as respite care, therapies (PT, OT, speech), education, and inhome supports based on the individual and family needs
- Professionals working with children and adults who have a FASD need specific FASD-related training (teachers, social workers, physicians, allied health professionals, first responders, judges, etc.)
- Evidence-based programs such as Families Moving Forward<sup>9</sup> and the Social Skills Training for Children with FASD<sup>10</sup> should be funded widely as early intervention programs to prevent the development of secondary disabilities related to FASDs

#### NOFAS and MCFARES

- MCFARES (Michigan Coalition for Fetal Alcohol Resources Education and Support) is the Michigan NOFAS (National Organization on Fetal Alcohol Syndrome) Affiliate
- MCFARES/NOFAS Michigan and the Michigan FASD Task Force work together to educate, empower

# Goal Group #2

2.1. Increase knowledge of FASD of personnel in these different priority areas to facilitate appropriate screening, accommodations, and partnerships with families and caregivers.

## Priority areas include:

- Justice System Personnel
- Education Personnel including all involved with students in general and special education, media specialists, the students themselves
- Nurses and Physicians in OBGYN, Pediatrics, Family Practice

## **Action Plan**

What: Develop web based materials that can be posted to DDI and MCFARES websites to refer individuals for general information and information specific to their area.

- Develop a general information packet about FASD
- Develop specific information packets for justice system personnel, education staff, and health care workers such as nurses and physicians
- Develop a letter to go out to advertise the above information

## Action plan

Who: Ann will develop a short letter to go out with the links to the websites and information.

Who: DDI, MCFARES and task force members will disseminate the letter and information to their contacts.

When: For review at next Task Force Meeting, August 17, 2016.

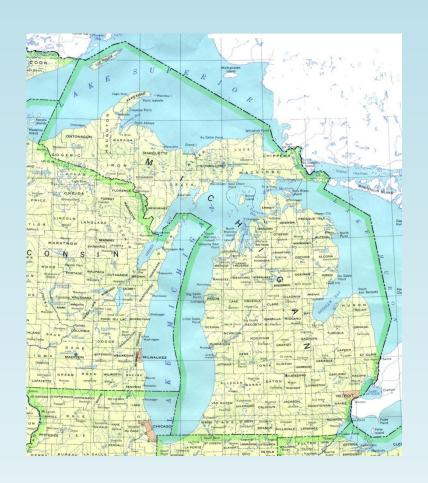
When: Letter and Information to be sent out week before and after September 9<sup>th</sup> which is the National FASD Awareness Day asking that personnel share the information via their newsletters and other ways.



State of Michigan FASD Programs and Services

## State of Michigan Policies and Programs

- Foster care
- Substance abuse
- Maternal and child



nealth & numan services Adult & Children's Safety & Injury Prevention Keeping Michigan Healthy Doing Business with MDHHS **Assistance Programs** Inside MDHHS Services Adult & Children's Services MDHHS / ADULT & CHILDREN'S SERVICES / CHILDREN & FAMILIES HEALTHY CHILDREN & HEALTHY FAMILIES Abuse & Neglect Adoption **Fetal Alcohol Spectrum Disorders** Adults & Seniors

What are Fetal Alcohol Spectrum Disorders (FASD)

Fetal Alcohol Spectrum Disorders (FASD) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical problems as well as problems with behavior and learning. Often, a person with an FASD has a mix of these problems. Fetal Alcohol Syndrome (FAS) is the most severe of these disorders.

According to the Centers for Disease Control and Prevention (CDC), "to prevent FASDs, a woman should not drink alcohol while she is pregnant, or when she might get pregnant. This is because a woman could get pregnant and not know for up to 4 to 6 weeks. In the United States, nearly half of pregnancies are unplanned. If a woman is drinking alcohol during pregnancy, it is never too late to stop drinking. Because brain growth takes place throughout pregnancy, the sooner a woman stops drinking the safer it will be for her and her baby."



Get on board with an alcohol-free pregnancy.



Child Fatality Registry

Child Support

Children & Families

Developmental Delays? Early On

Early Hearing Detection and Intervention

Healthy Children & Healthy Families

Hereditary Disorders

Immunization Info for Families & Providers

Lead Poisoning

Maternal & Child Health Epidemiology

Pregnancy Risk Assessment Monitoring

Trauma & Toxic Stress

Foster Care

Hope For A Home

Informed Consent for

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

March of Dimes

The Arc of the United States

U.S. Surgeon General: Advisory on Alcohol Use in Pregnancy

#### Resources in Michigan

FASD Community-Based Projects Overview

SAMHSA Treatment Locator

Michigan's Home Visiting System

Michigan Department of Education Office of Great Start

Michigan Alliance For Families

Women's Specialty Services, Office of Recovery Oriented Systems of Care

Healthy Michigan Plan

Michigan Affiliate of NOFAS - MCFARES 2016 Newsletter

Michigan Behavioral Health and Developmental Disabilities

#### Michigan Governor's FASD Proclamations

2015 Michigan Governor's FASD Proclamation

2014 Michigan Governor's FASD Proclamation

2013 Michigan Governor's FASD Proclamation

2012 Michigan Governor's FASD Proclamation

2011 Michigan Governor's FASD Proclamation

2010 Michigan Governor's FASD Proclamation

#### Michigan FASD Diagnostic Centers of Excellence

2016 FASD Diagnostic Centers of Excellence Contact Roster

#### Michigan FASD Strategic Plans

MI FASD Five Year Strategic Plan, 2015-2020, entitled: Preventing Prenatal Alcohol

Exposure and Supporting Individuals Affected by Fetal Alcohol Spectrum Disorders

MI FASD Maternal and Child Interagency Strategic Plan 2012-2014 Phase 1

MI FASD Task Force Youth In Transition and Adults 2012-2014 Phase 2

MI FASD Task Force Strategic Plan 2006-2011

#### Michigan FASD Training and Education

FASD - The Basics Webcast



#### Michigan FASD Diagnostic Centers of Excellence Contact Roster Michigan Department of Health and Human Services

FASD Diagnostic Clinic	FASD Clinic Director	FASD Clinic Coordinator	FASD Clinic Contact
ANN ARBOR University of Michigan Fetal Alcohol Spectrum Disorders Diagnostic Clinic Taubman Center, Room 1924, 1500 East Medical Center Drive Ann Arbor, MI 48109 <a href="http://www.med.umich.edw/pediatrics/fetalalcohol/index.htm">http://www.med.umich.edw/pediatrics/fetalalcohol/index.htm</a>	Prachi Shah, MD Assistant Professor, Pediatrics prachis@med.umich.edu	Tedi Milgrom, MPH Administrative Assistant fas-clinic@med.umich.edu Phone: (734) 232-1530 Fax: (734) 936-6897	Tedi Milgrom, MPH Administrative Assistant fas-clinic@med.umich.edu Phone: (734) 232-1530 Fax: (734) 936-6897
DETROIT Children's Hospital of Michigan Pediatric Specialty Center Division of Genetic and Metabolic Disorders 3950 Beaubien St. Detroit, MI 48201 http://www.childrensdmc.org/?id=703&sid=1	David Stockton, MD Chief, Division of Clinical Genetics dstockton@med.wayne.edu	Emily Vandenboon, MS, CGC Lead Genetic Counselor Phone: (313) 832-9330 evandenboon@dmc.org	Amonda Golida Patient Services Clerk agolida@dmc.org Phone: (313) 832-9330 extension 2 Fax: (313) 993-8685
FLINT Mott Children's Health Center 806 Tuuri Pl. Flint, MI 48503 www.mottchc.org	Dr. Lawrence Reynolds, MD Medical Director reynolds@mottchc.org	Janeen Williams, BSW Case Manager (810) 767-5750 x5309 janeenw@mottchc.org	Mary Jacisin Administrative Assistant woosterm@mottchc.org Phone: (810) 767-5750 extension 5299
GRAND RAPIDS Spectrum Health Medical Genetics 25 Michigan St., N.E., Suite 2000 Grand Rapids, MI 49503 <a href="http://www.helendevoschildrens.org/Genetics">http://www.helendevoschildrens.org/Genetics</a>	Helga Toriello, PhD FASD Clinic Director helga.toriello@spectrumheatlh.org  Paul Mark, MD Director Genetic Services paul.mark@spectrumhealth.org	Melissa Zuteck, MS, Genetic Counselor Phone: 616-391-2319 melissa.zuteck@spectrumhealth.org	Austin Georgacakes Administrative Assistant austin.georgacakes@spectrumhealth.org Phone: (616) 391-2700 Fax: (616) 391-3114
KALAMAZOO Southwest Michigan Children's Trauma Assessment Center (CTAC) Western Michigan University 1000 Oakland Drive Kalamazoo, MI 49008 www.wmich.edu/traumacenter	Mark Sloane, DO Medical Director mark.sloane@wmich.edu	Connie Black-Pond, LMSW Clinical Director Phone: 269-387-7053 connie.black-pond@wmich.edu	Donna Anson Office Administration ctac@wmich.edu Phone: (269) 387-7073 Fax: (269) 387-7050
MARQUETTE  Marquette Hospital Specialty Clinic – A Duke Lifepoint Hospital 580 West College Marquette, MI 49855 <a href="http://ww4.mgh.org/wcc/SitePages/Speciality%20Clinics.aspx">http://ww4.mgh.org/wcc/SitePages/Speciality%20Clinics.aspx</a>	G. Michael Nidiffer, MD Specialty Clinic Medical Director g.michael.nidiffer@mghs.org	Elaine Taylor, RN Clinic Manager Phone: (906) 225-3141 elaine.taylor@mghs.org	Rosemary Larson, LPN Clinic Nurse rosemary.larson@mghs.org Phone: (906) 225-7706 Fax: (906) 225-4830



Used with permission from State of Mississippi Department of Mental Health

#### What are Fetal Alcohol Spectrum Disorders (FASD)?

Answer: Fetal Alcohol Spectrum Disorders (FASD) is a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. They can include physical problems as well as problems with behavior and learning. Often, a person with FASD has a mix of these problems. Fetal Alcohol Syndrome (FAS) is the most severe of these disorders.

## What resources does the state of Michigan have to help pregnant women who may need help or support to stop drinking?

Answer: Michigan Department of Health and Human Services Office of Recovery Oriented Systems of Care and Women's Specialty Services provides information to help women looking for information, support and treatment. Pregnant women are given priority for treatment.

Women can find support and treatment in Michigan at:

- MDHHS Office of Recovery Oriented Systems of Care
- SAMHSA Treatment Locator

Learn more about FASD and evidence based resources available at:

- MDHHS FASD Website
- CDC FASD Alcohol Use in Pregnancy
- March of Dimes
- FASD Website State Capacity
- National Organization on Fetal Alcohol Syndrome (NOFAS)

### thinking about becoming pregnant approach alcohol?

<u>Answer</u>: No amount of alcohol can be considered safe during pregnancy. Alcohol can damage a baby at any time during pregnancy. It can cause birth defects and lifelong learning and behavior disorders.



#### What tips do you have for women to have a healthy pregnancy?

<u>Answer</u>: FASD is 100% preventable if a woman does not drink alcohol during pregnancy or when she is trying to become pregnant.

Learn more about resources for healthy mothers, healthy babies and healthy families available in Michigan:

- Maternal Infant Health Program
- Michigan's Home Visiting System
- MI Healthy Baby Website
- Healthy Hints for Pregnant Women

For more information talk with your health care provider.

The Michigan Infant Mortality website also has information and tips for healthy babies, healthy mothers and healthy families.

Listen to the interview with MDHHS Bureau of Family, Maternal and Child Health Director, Rashmi Travis

https://www.voutube.com/watch?v=i5I\_D4maVkvl\_l&fe

## Other Michigan activities

- FASD prevention focused public service announcements broad cast via Pandora, Twitter, and Facebook in the lower and upper peninsulas.
- Governor Snyder has done FASD Proclamations on FASD Awareness Day September 9<sup>th</sup> for the last 6 years.
- Lac Vieux Desert, Lake Superior Band of Chippewa worked with the Intertribal Council of Michigan to produce a DVD about the importance of integrated health services for individuals with FASD. The DVD is being distributed at many venues.
- State and community project staff participated in a national webinar sponsored by the Arc and the National Association of City and County Officials.
- Deb Kimball, FASD State Coordinator, participated in a national webinar on building state capacity sponsored by SAMHSA.

## 8 mini-grant funded community based projects

- Improve the functioning of children with FASD and their families
- Prevention of alcohol exposed pregnancies through Choices program to increase use of contraception and decrease alcohol use during pregnancy
- Pre-screen infants and children at risk for prenatal alcohol exposure and refer for diagnosis and services
- Collaborations among different agencies and government programs such as hospitals, WIC, Maternal Child Health, Family Planning
- Populations that are involved are all women of child bearing age, and culturally specific programs for Native American and Latina women

**Assistance Programs Keeping Michigan Doing Business with** Adult & Children's Safety & Injury Inside MDHHS Services Prevention Healthy **MDHHS** Keeping Michigan Healthy Related Content KEEPING MICHIGAN HEALTHY BEHAVIORAL HEALTH & DEVELOPMENTAL DISABILITY / BH RECOVERY & SUBSTANCE USE Peer Recovery Behavioral Health & Services and Developmental Supports Disability Women's Specialty Services Substance Use Behavioral and Physical OROSC Home Treatment Home To view page in large print, click A+ above. Assessments and Health Care Integration Classes BH Recovery & ROSC TSC Substance Use Self-Help Groups Gambling Disorder Welcome to the state of Michigan webpage for Michigan Addiction women in need of substance use disorder Project Integrated Treatment for treatment and those who provide women's · Providers of Co-occurring Disorders specialty services. Here you will find information Assessments and Mental Health about women's substance use disorder Classes Mental Health First Aid treatment, including state policies and Managing Reporting Requirements advisories, and links to resources that include opportunities for training and Confidentiality of enrichment. Patient Records Stakeholder 298 Workgroup 2016 Chronic Diseases Women's Treatment: Women's Specialty Services (WSS), and Fetal Alcohol Spectrum Disorders (FASD) Communicable & prevention services, are available at all levels of care, including residential, Chronic Diseases intensive outpatient, and outpatient treatment, and recovery supports. If you are a Health Statistics & woman in need of treatment for a substance use disorder, please click on the Get Reports Help Now link below. Primary Care & Public To meet the specific needs of women, programs must take into account the Health emotional growth of women and their reliance on the relationships in their lives. The majority of research done on treatment practices has been based on the emotional growth and development of men, and programming was developed based on this

research. With the research of women gaining recognition, programming has evolved to acknowledge women have different pathways to alcohol/drug use, consequences of use, treatment needs, and recovery support needs than do men.

#### SUBSTANCE ABUSE TREATMENT POLICY # 11

SUBJECT: Fetal Alcohol Spectrum Disorders

ISSUED: August 24, 2009 EFFECTIVE: October 1, 2009

**PURPOSE:** 

The purpose of this policy is to establish the process and expectations for the screening and referral of children for Fetal Alcohol Spectrum Disorder (FASD) and the inclusion of FASD prevention in treatment programs that serve women.

#### SCOPE

This policy impacts coordinating agencies (CAs) and their provider network of treatment programs that serve women and are funded by Michigan Department of Community Health, Bureau of Substance Abuse and Addiction Services.

#### BACKGROUND

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related neurodevelopment disorder (ARND), and alcohol-related birth defects (ARBD).

Each year, as many as 40,000 babies are born with a FASD, costing the nation about \$4 billion. The cost to care for an individual with one of the conditions averages \$860,000 per year according to Harwood et al, 2003. Some individuals' care exceeds \$4.2 million dollars.

Between fiscal year 2000 and 2004, 50% of Michigan women in treatment reported alcohol as their primary, secondary or tertiary substance of choice. In a recent match of those with a substance use disorder treatment admission and those giving birth in Wayne County; it was found that the average number of days clients were using in the thirty days before entering treatment was 10.33 days. It was also found that there were 2,144 births occurring to the 1,680 women who had a substance use disorder treatment admission. Of these women 48% listed alcohol as their primary substance of choice. When looking at the 2,144 births, 562 of these births were reported to the Michigan Birth Defects Registry with eight having the diagnostic code for FAS (3.7 – 7.8 per 1000 births).

#### REQUIREMENTS

Fetal Alcohol Syndrome (FAS) is a birth defect caused by alcohol use during pregnancy. FAS is a medical diagnosis. This form is not intended to take the place of a diagnostic evaluation.

Any previous diagnosis:



				FACIAL	FEATURES
Last Name:	I	First Name:		Sex: Male	Female
Address:	·			Race:	
City, State, ZIP code:				Birthdate:	
Parent/Caregiver Name(s):				Home Phone:	
Child is: Biological	☐ Foster	☐ Adopted	☐ Other	Work Phone/Cell	:
If 2 or more of the identifier	rs listed below are	noted, the indivi	dual should be i	referred for a full FA	S Diagnostic Evaluation.
IDENTIFIERS CI		CHECK	HECK OR EXPLAIN IF A CONCERN EXISTS		
1. Height and weight seem	small for age				
2. Facial features (see diagram above)					
3. Size of head seems smal	l for age				
4. Behavioral concerns: (any one of these qualifies as an identifier)  • Sleeping/eating problem  • Mental retardation or IQ below familial expectations  • Attention problem/impulsive/restless  • Learning disability  • Speech and/or language delays  • Problem with reasoning and judgment  • Acts younger than children the same age					
5. Maternal alcohol use dur	ring pregnancy				

FOM 802	10 of 11	DEVELOPMENTAL NEEDS OF FOSTER
		CHILDREN

- Respite care.
- Supports coordination.

All services provided to the child must be documented in the child's DHS-221, Medical Passport.

5-1-2015

#### FETAL ALCOHOL SPECTRUM DISORDER

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral and/or learning disabilities with possible lifelong implications. FASD is not a diagnostic term.

#### Caseworker Role in FASD

Caseworkers are expected to consider the possibility of FASD in children who present with behavioral or other types of problems that impact daily functioning. Conventional treatment for some behavioral problems may be ineffective for children with FASD. Without proper intervention, birth families and other caregiving families may struggle to maintain these children in their homes.

The caseworker may conduct an FASD pre-screening by observing the child and reviewing the child's medical history. If the results of a pre-screening for fetal alcohol syndrome contain two or more of the five identifiers listed below (and are not associated with another known syndrome), the child **must** be referred for a full FASD diagnostic evaluation.

The FASD identifiers include:

- Small head circumference (noted in the first three years).
- Height and weight for age below the 10th percentile.
- Behavioral markers (intellectual disabilities, eating/sleeping problems, attention problems/impulsive/restless, learning

CHILDREN 5-1-2015

Maternal alcohol use.

Full FASD diagnostic screenings are available at one of the five Michigan Fetal Alcohol Syndrome assessment centers. The assessment centers are located in Ann Arbor, Detroit, Grand Rapids, Kalamazoo, and Marquette; see <a href="http://michigan.gov/documents/mdch/FASD">http://michigan.gov/documents/mdch/FASD</a> Prescreen form Feb-10 314457 7.pdf for assessment center contact information.

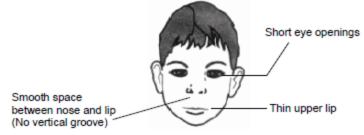
In addition, results of the FASD pre-screen must be included when requesting a pre-10 waiver for placement of children less than 10 years old in residential or other institutional settings.



## Collaboration

#### Michigan Department of Community Health Fetal Alcohol Spectrum Disorders Program FETAL ALCOHOL SYNDROME (FAS) PRE-SCREEN

FAS is a birth defect caused by alcohol use during pregnancy. FAS is a medical diagnosis. This form is not intended to take the place of a diagnostic evaluation.



#### FACIAL FEATURES

Last Name:	First Name:		Sex: Male	☐ Female	
Address:			Race:		
City/State/Zip code:			Birthdate:		
Parent/Caregiver Name/s:			Home Phone:		
☐ Bio ☐ Foster ☐ Adopted	□Other		Work Phone/Cell:		
If 2 or more of the identifiers listed below are noted, the individual should be referred for a full FAS Diagnostic Evaluation.					
IDENTIFIERS Chec		Check or	or explain if a concern exists		
Height and weight seem small for age					
2. Facial features (See diagram above)					
3. Size of head seems small for age					
Behavioral concerns: (any one of these qualifies as an identifier)					
Sleeping/eating problem     Mental retardation or IQ below familial expectations     Attention problem/impulsive/restless     Learning disability     Speech and/or language delays     Problem with reasoning and judgment     Acts younger than children the same age					
Maternal alcohol use during pregnancy					

Any previous diagnosis:

# REPORT ON EFFORTS TO PREVENT AND COMBAT FETAL ALCOHOL SYNDROME AS WELL AS DEFICIENCIES IN EFFORTS TO REDUCE THE INCIDENCE OF FETAL ALCOHOL SYNDROME

(FY2014 Appropriation Bill - Public Act 59 of 2013)

**April 1, 2014** 

**Section 502:** The department shall explore developing an outreach program on fetal alcohol syndrome services. The department shall report to the senate and house subcommittees on community health by April 1 of the current fiscal year on efforts to prevent and combat fetal alcohol syndrome as well as deficiencies in efforts to reduce the incidence of fetal alcohol syndrome.



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#### and Supporting Individuals Affected by Fetal Alcohol Spectrum Disorders

Michigan Five Year Plan 2015 - 2020



Population Health and Community Services Administration Susan Moran, Senior Deputy Director

> Behavioral Health and Developmental Disabilities Administration Lynda Zeller, Deputy Director

## Michigan's 5 year plan

#### **Broadly:**

- 1. Reduce prevalence through health promotion and prevention efforts enhancing efforts of women's health care systems in supporting women to avoid alcohol during pregnancy and other crucial times
- 2. Systems level approach to include health care, behavioral health care, social services, education, economic and criminal justice systems to provide access to appropriate interventions



## National Resources







#### Fetal Alcohol Spectrum Disorders (FASD)

Under the previously funded FASD Center for Excellence, SAMHSA developed a number of publications and resources that continue to be available. The following are intended to assist people affected by FASD and their families, state and local agency administrators, and service providers:

- Tools for Success: Working with Youth with Fetal Alcohol Spectrum Disorders (FASD) in the Juvenile Justice System 2014 is a self-paced educational program. It is based on Carlson and Holl's Tools for Success: Working with Youth with Fetal Alcohol Syndrome and Effects in the Juvenile Justice System Resource Guide — 2001. The program has been updated to emphasize more recent published literature and terminology.
- Curriculum for Addiction Professionals (CAP): Level 1 2007 provides guidance on encouraging women in treatment not to consume alcohol during pregnancy. It also helps professionals work with adult and adolescent clients affected by FASD, as well as clients with children affected by FASD. Parents, caregivers, and other family members can also benefit from this information. CAP Level 1 is organized into six competencies with content that includes:
  - An historical overview of alcohol use by pregnant women
  - · Identification and diagnosis of FASD
  - Prevention strategies to address FASD
  - Treatment strategies to address FASD
  - Continuing care for families affected by FASD
  - Legal issues affecting pregnant women and people affected by FASD
- Treatment Improvement Protocol (TIP) 58: Addressing Fetal Alcohol Spectrum Disorders (FASD) 2013 reviews alcohol screening tools and interventions for use with pregnant women and women of childbearing age to prevent FASD. It also outlines methods for identifying people affected by FASD and modifying treatment accordingly.

This page will be updated as additional resources are moved into the SAMHSA Store.

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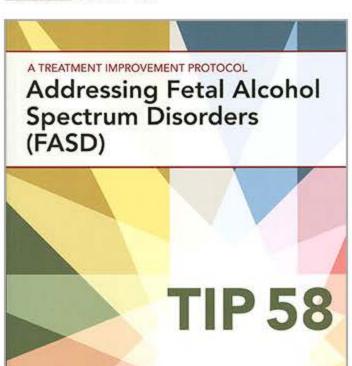
E-MAIL UPDATES







Add To Favorites



#### TIP 58: Addressing Fetal Alcohol Spectrum Disorders (FASD)

Average Rating: 5 out of 2 ratings.



Rate!

Comments

Price: FREE (shipping charges may apply)

Reviews alcohol screening tools and interventions for use with pregnant women and women of childbearing age to prevent fetal alcohol spectrum disorders (FASD). Also, outlines methods for identifying individuals with FASD and modifying treatment accordingly.





Pub id: SMA13-4803 Publication Date: 12/2013 Last Reviewed: 04/02/2014

Popularity: 112

Format: Guidelines or Manual

Audience: Public Health Professionals, Prevention Professionals, Professional Care Providers, Program

Planners, Administrators, & Project Managers

Series: TIP Series - Treatment Improvement Protocols (TIPS)

Population Group: Pregnant Women



Tags: Fetal Alcohol Spectrum Disorders Treatment Improvement Patient Assessment Brief Intervention Screening Tool Referral to Treatment Practice Guidelines Training & Continuing Education





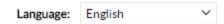
#### Fetal Alcohol Spectrum Disorders (FASDs)











Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. FASDs are completely preventable if a woman does not drink alcohol during pregnancy.

#### **BASICS**

Facts, causes, signs, diagnosis, and treatments.

#### **EDUCATION & TRAINING**

Tools, training centers, & educational resources.

#### FASD What's New

02/04 - Vital Signs: Alcohol and Pregnancy



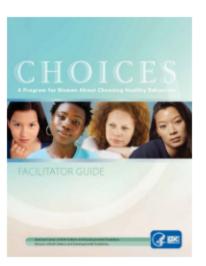


An Alcohol-Free Pregnancy is the Best Choice for Your Baby (woman looking down)

Poster:

This 11"x17" poster describes the risks of drinking alcohol during pregnancy, including fetal alcohol spectrum disorders. It shows a smiling White pregnant woman looking down.

Available in English 🔁



#### CHOICES Curriculum—CD Package

CHOICES: A Program for Women About Choosing Healthy Behaviors is an intervention for nonpregnant women of childbearing age and is designed to prevent alcohol-exposed pregnancies by addressing risky drinking and ineffective or no use of contraception. The CHOICES Curriculum includes CD-ROMs for each of the following: Facilitator guide, counselor manual, client workbook, and a training DVD with videos demonstrating components of the intervention. The training DVD now contains both English and Spanish sub-titles. These materials are designed for use by professionals trained in behavioral health counseling who will be conducting the CHOICES program. The counselor manual provides background information and guidance on conducting each of the four CHOICES counseling sessions and the client workbook provides materials to be shared with women participating in the program. The facilitator guide is designed for use by trainers providing instruction on how to conduct the intervention and includes presentation slides.

Please download and preview the materials to see if they are appropriate for your purposes before ordering.



HOME

FASD

RESOURCES

NOFAS

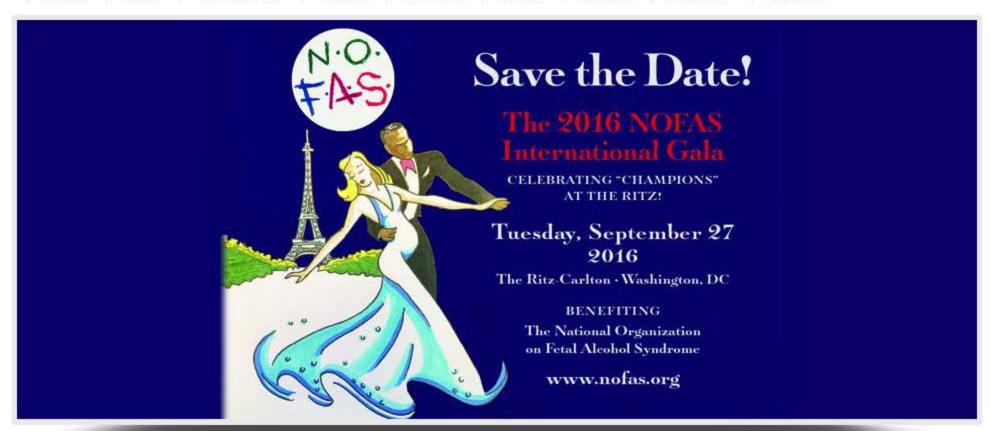
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Play it Smart. Alcohol and Pregnancy Don't Mix!











**Resource Directory** 

to recent remains of persons and an armoner

#### FASD: What the Foster Care System Should Know

The majority of children with Fetal Alcohol Spectrum Disorders (FASD) are not raised by their birth parents.

- It is reported that approximately 80% of children with FASD do not stay with their birth families due to the high needs of parents and children (Barth, Child Welfare, 2001).
- Studies suggest that a rise in alcohol and drug use by women has resulted in 60% more children coming into state care since 1986 (Stratton, Howe, & Battaglia, Institute of Medicine, 1996).

The incidence rate of FASD is unusually high among the U.S. foster care population.

- Children in foster care are 10-15 times more likely to be affected by prenatal alcohol exposure than other children.
- Children from substance abusing households are more likely to spend longer periods of time in foster care than other children (median of 11 months versus 5 months for others in foster care) (Foster Care Today, Casey Family Programs, 2001).

Many children with FASD go unidentified or are misdiagnosed. Often, behavioral problems caused by brain damage due to prenatal alcohol exposure are mistakenly thought to be solely a result of difficulties in the child's previous home environment.

Secondary behavioral disorders associated with FASD can further complicate a child's transition into and out of foster care homes.

Children with FASD often have difficulty:

Children with FASD can be easily frustrated and require a stable, structured home and school environment. Adjusting to a new home, a new family, and a new school can be particularly difficult.

Children with FASD can benefit from:

- · Consistent routines;
- · Limited stimulation;
- Concrete language and examples;
- Multi-sensory learning (visual, auditory and tactile);
- Realistic expectations;
- · Supportive environments; and
- Supervision.



The foster care system can help prepare for children with FASD by:

- Providing training to foster care/adoption personnel to help recognize the disorder's characteristics in order to seek diagnoses for suspected cases and ensure appropriate placements;
- Providing education to parents entering the foster care system, as well as for families who already have foster children, in order to help recognize the disorder's characteristics, seek a diagnosis, and appropriately respond to the unique needs of the child; and

## Collaborations between the Task Force, State, and SAMHSA

- SAMHSA paid for our strategic planner for several rounds. In Michigan DDI was able to pick up the costs for the planning as part of our core functions.
- State FASD coordinators are still planning on meeting even without SAMHSA funding to look at how they can create nation wide efforts in FASD prevention and intervention.
- Michigan's FASD coordinator is a member of the task force and supports the efforts of the task force. Maternal and child health paid for the printing of the 40<sup>th</sup> anniversary printing of conference material. Our FASD coordinator comes to our meetings to update us on the state's programs and invite us to take part in their planning efforts such as described above.
- We are involved in a web of local, state, and federal programs, services, information and resources related to FASD.

## **Future Directions**

- We would like to collaborate and get more aligned with the substance use services programs.
- We need to make a connection with someone from the Department of Education who can join us and help us get information to teachers.
- We would like to see all children who come into child welfare systems be screened for FASD.
- We would like to see children's and adult services expanded as this is a lifelong disability.

## **QUESTIONS?**

Feel free to contact me with questions for information, resources, and training

www.nofas.org

www.ddi.wayne.edu/fasd.php

www.Michigan.gov/fasd

www.cdc.gov

www.samhsa.gov

## **Contact Information**

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