## Local and State Action to Prevent Fetal Alcohol Spectrum Disorders

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## Objectives

- Increase awareness of FASD prevention activities at local and state levels, specifically Ohio's Not a Single Drop initiative and Michigan's FASD Community Grants.
- Learn about strategies to support education and screening of pregnant women for exposure to alcohol.
- Learn how to engage communities in FASD prevention activities through partnerships at the local and state health departments.



## Presenters







## Presenters



Phil Petrosky
Ohio Department of Health,
WIC Program



## Presenters



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Mary Claire Massi-Lee
Public Health, Delta and
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## Overview of Fetal Alcohol Spectrum Disorders



## Fetal Alcohol Spectrum Disorders (FASD)

- Group of conditions that occur in a person whose mother drank alcohol during pregnancy
- Effects may include physical problems, behavioral problems, and difficulty with learning
- FASD is not a clinical diagnosis
- Effects can range from mild to severe



## Types of FASDs

Fetal Alcohol Syndrome (FAS)

Alcohol-Related Neurodevelopmental Disorder (ARND)

Alcohol-Related Birth Defect (ARBD)



# Signs, Difficulties and Disabilities by Age Level

Age Level	Signs, Difficulties, and Disabilities
INFANTS	Low birth weight; irritability; sensitivity to light, noises and touch; poor sucking; slow development; poor sleep-wake cycles; and increased ear infections.
TODDLERS	Poor memory capability; hyperactivity; lack of fear; no sense of boundaries; and a need for excessive physical contact.
GRADE- SCHOOL YEARS	Short attention span; poor coordination; and difficulty with both fine and gross motor skills.
OLDER CHILDREN	Trouble keeping up with school; and low self-esteem from recognizing that they are different from their peers.
TEENAGERS	Poor impulse control; cannot distinguish between public and private behaviors and must be reminded of concepts on a daily basis.
ADULTS	Need to deal with many daily obstacles, such as affordable and appropriate housing, transportation, employment and money handling.

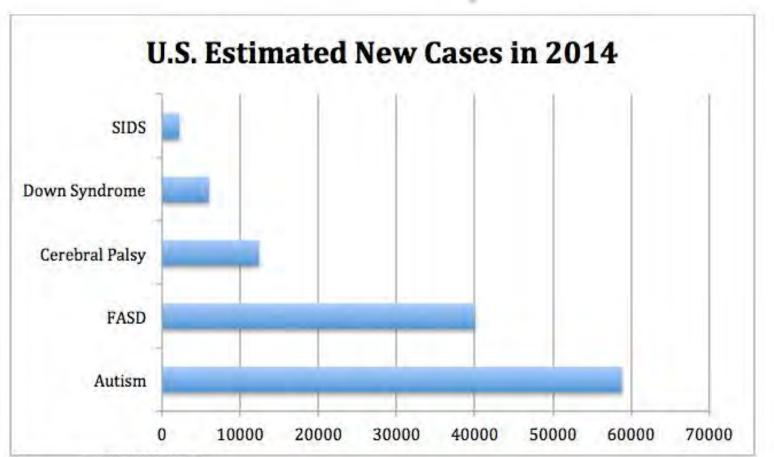
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## **FASD Facts**

- Scientists believe that there are at least 3 times the number of FASDs as FAS
- An estimated 0.2 1.5 cases of FAS occur for every 1,000 live births
- Each year 40,000 babies are born with an FASD
- FASDs are a leading preventable cause of intellectual disabilities



## FASD in Comparison



Source: CDC, SAMHSA



## Financial Impact of FASD



- FASDs cost about \$6 billion per year
- The lifetime cost of caring for one individual with FASD is estimated to be greater than \$2 million
- For a child with identified FAS, incurred health costs are 9 times higher than for children with an FASD



\*Defined as at least one drink of any alcoholic beverage in the past 30 days.

Source: CDC Behavioral Risk Factor Surveillance System (BRFSS), United States, 2006–2010.



• 1.4% of pregnant women and

15.0% of non-pregnant women reported binge drinking in the

Facts about

Alcohol Use

• 7.6% of pregnant women and

51.5% of non-pregnant women

reported drinking alcohol in the

past 30 days

past 30 days

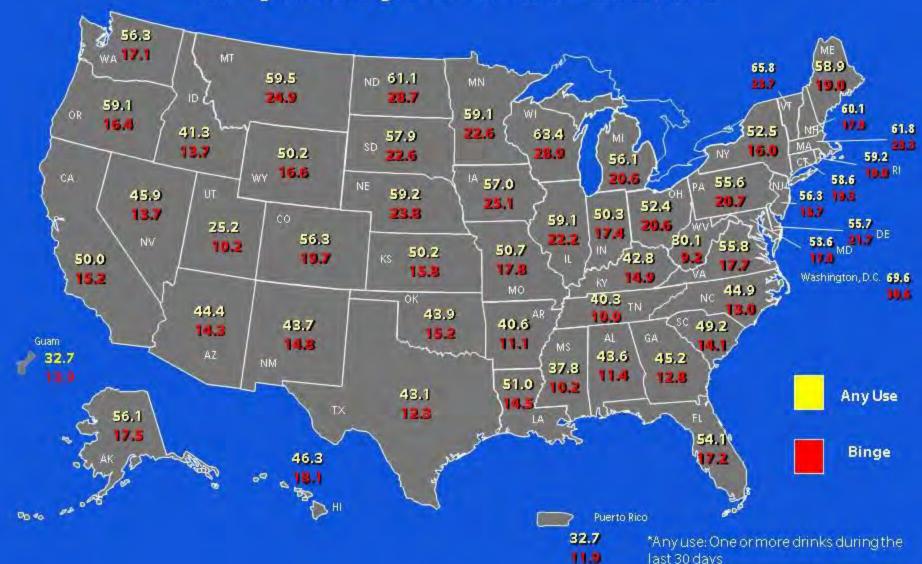
 The highest estimates of reported alcohol use among pregnant women were:

- Aged 35-44 years
- White
- College graduates
- Employed

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#### State-Specific Weighted Prevalence Estimates of Alcohol Use (Percentage of Any Use\*/Binge Drinking†) Among Women Aged 18 – 44 Years — BRFSS, 2012



Binge: Four or more drinks on any one

occasion during the last 30 days

## FASD Prevention & Reduction

#### Prevention begins with communication

- Ask all women of child-bearing age about alcohol use
- Talk about the effects of alcohol on an individual and on a fetus

#### Brief interventions

 Outreach, screening, referral, and other activities that promote the health of the mother and the fetus

#### Public Health Messaging

- No known safe amount of alcohol use during pregnancy or while trying to get pregnant
- FASDs are completely preventable if a woman does not drink alcohol during pregnancy



## FASD Resources

- The Arc
  - http://www.thearc.org/learn-about/fasd
- Centers for Disease Control and Prevention (CDC)
  - http://www.cdc.gov/ncbddd/fasd/index.html
- Substance Abuse and Mental Health Services (SAMSHA)
  - http://www.fasdcenter.samhsa.gov/



Phil Petrosky, Parent Network Ohio FASD Steering Committee

Ohio Department of Health Phil.Petrosky@odh.ohio.gov August 28, 2014





#### 2003 - Foundation

Mrs. Hope Taft, First Lady of Ohio (Emeritus), in partnership with members of the Ohio Family and Children First (OFCF) Cabinet Council, formed the Ohio FASD Steering Committee. Original committee included: nine state agencies, institutes of higher education, providers and parents.







#### **Ohio FASD Steering Committee State Agency Membership**

- Ohio Department of Aging
- Ohio Department of Alcohol and Drug Addiction Services merged into Ohio Department of Mental Health and Addiction Services (July 2013)
- Ohio Department of Education
- Ohio Department of Health
- Ohio Department of Job and Family Services
- Ohio Department of Medicaid (Launched July 2013)
- Ohio Department of Mental Health merged into Ohio Department of Mental Health and Addiction Services (July 2013)
- Ohio Department of Developmental Disabilities
- Ohio Department of Rehabilitation and Corrections
- Ohio Department of Youth Services





## Ohio FASD Steering Committee Advocacy Membership

- 7 Parents/Caregivers
- Ohio Center for Autism and Low Incidence
- Ohio Family and Children First Council
- Double ARC Toledo, Ohio
- Montgomery County ADAMHS Board
- Akron Children's Hospital Regional Genetics Center
- Lorain County General Health District
- First Step Home (Women's Center)
  - Cincinnati Children's Medical Center





- On Sept. 9, 2004, the FASD Steering Committee held a Town Hall Meeting to increase awareness of the challenges faced by Ohio's children and families.
- This testimony and a needs assessment conducted in 2005 with The Ohio State University's Center for Learning Excellence, using the Partnerships for Success Strategic Planning Process, led to a course of action based on key findings.







#### **Strategic Planning Findings**

- Many professionals who provide services to children and families in Ohio are ill-prepared to address FASD.
- Children are often diagnosed with several mental and physical health disorders that can lead to a variety of uncoordinated services. New and existing services should be designed and coordinated to screen for FASD.





#### Strategic Planning Findings

- With the exception of a few areas of the state, services available to individuals affected by FASD are inadequate.
- There are few services available for parents, foster parents and other caregivers, who play key roles in promoting the welfare of children affected by FASD.





#### **Strategic Planning Findings**

- Efforts should be undertaken to establish formal recognition of FASD. Policies should be developed and adopted that define how FASD is addressed in educational settings.
- Ohio-specific FASD prevalence data should be collected on a continuing basis.





#### **Steering Committee Mission**

To establish efficiency in state systems resource allocation, coordination of services and augmentation of available resources to address Fetal Alcohol Spectrum Disorders

(FASD)





#### The Strategic Plan Has Five Goals

- 1. Increase the availability of services for those already affected by FASD and for parents and other caregivers;
- 2. Increase awareness regarding the risks associated with alcohol use during pregnancy;
- 3. Provide FASD-specific education and training for agencies, organizations and professionals who provide services to children and families with or at risk of FASD;





#### The Strategic Plan Has Five Goals

- 4. Adopt appropriate FASD screening tools and protocols and increase access to screening; and
- 5. Create and implement a data tracking system to track FASD risk factors, prevalence, and incidence in Ohio, and measure progress toward reaching the other four goals.





#### **FASD Parent Network**

- The Ohio FASD Parent Network is a workgroup of the Steering Committee. Their mission is to increase FASD awareness and provide information and resources to families and caregivers as well as organizations serving individuals affected by FASD.
- The parent network has held meetings in five Ohio regions for input from families about their experiences with FASD. Feedback is provided to the Steering Committee to help shape Ohio goals and priorities
- Three parent network families participated in an FASD training video for educators entitled: In Their Own Words





On August 16, 2005, the 1<sup>st</sup> Ohio FASD Conference was held with expert featured speakers: Dr. Larry Burd, Dr. Susan Astley, Ira Chasnoff, and Kathleen Mitchell.

 About 350 families, health & human service professionals, & teachers participated







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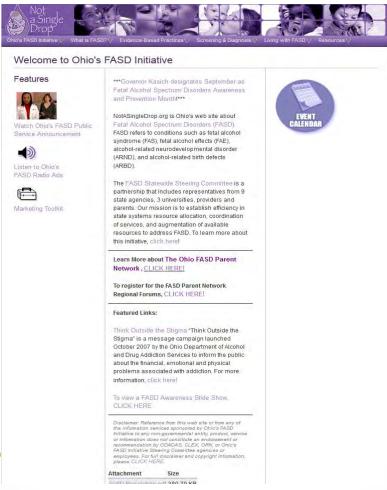
#### Ohio's FASD Web Site

https://notasingledrop.mh.state.oh.us/

Launched in April 2006, the site includes featured links for: definition of FASD, information on Ohio's FASD initiative, evidenced-based practices, screening and diagnosis, living with FASD, and resources including Ohio's Marketing Toolkit and FASD Generalist Training Power Point









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#### April 2006 - FASD Awareness

The Ohio FASD universal marketing campaign kicked off with public service announcements airing on WBNS 10TV, Ohio News Network, Mix 97.1FM and Ohio News Network Radio.

Advertisements also ran in Columbus Parent magazine and its sister publications throughout the state.





September is FASD Awareness Month in Ohio

In **2011**, the Governor's Resolution on *FASD Prevention* and *Awareness Month* was presented at an FASD celebration of accomplishments in the Ohio Statehouse Atrium in Columbus.

First Lady of Ohio, Karen Kasich, presented the Governor's Resolution to the Ohio FASD Steering Committee.





#### September is FASD Awareness Month in Ohio

A letter for Maternal and Child Health Care programs is provided with information to assist with FASD awareness month efforts; the letter includes attachments such as:

- ✓ Governor's FASD Month Designation
- ✓ FASD Awareness Day Suggestions Sheet
- ✓ FASD Fill-in Press Release
- ✓ FASD Fill-in Letter to Elected Officials
- ✓ Ohio FASD Facts Sheet





#### Ohio FASD Fast Facts Sheet



#### Ohio's Fetal Alcohol inge Spectrum Disorders Initiative

#### Did You Know...

- 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 lifelong implications.
- Prenatal exposure to alcohol is the leading cause of preventable birth defects in the country.
- ♠ Each year, as many as 40,000 babies are born with an FASD, costing the nation about \$4 billion. (Source: FASD Center for Excellence)
- ♦ FASD is an irreversible, lifelong condition that affects every aspect of a child's life and the lives of the child's family - there is no cure for FASD.
- According to the Centers for Disease Control and Prevention and the US Surgeon General, there is no known safe amount or safe time to drink alcohol during pregnancy.
- It has been estimated, the cost of FASD to Ohio taxpayers for providing special services for education, juvenile justice, medical and mental health services, foster care and unemployment is nearly \$300 million every year. (Source: Ohio Department of Health)
- Raising a child with FASD is 100 times more expensive than preventing FASD in a child.
- Due to a combination of factors, most go undiagnosed. In fact, of the estimated 114,000 Ohioans living with FASD, only 300 have been clinically diagnosed. (Source: Ohio Department of Health)
- Early diagnosis and treatment for FASD can help children reach their fullest potential, lessen secondary disabilities and problems, and help families better understand and cope.
- Although the various effects of FASD are permanent conditions, specific symptoms may be treatable or manageable. People with FASD can grow, improve and function in life with proper support.
- It's hard to determine lost potential such as educational achievement and other ways that alcohol affects children that go unnoticed.
- FASD is a 100 percent preventable birth defect. All women of child-bearing age need to know Not a
- September 9 is set aside annually as International Fetal Alcohol Syndrome Awareness Day.

#### **Primary Disabilities:**

Possible facial features associated with FAS/ARND include:

- Short palpebral fissures (small eye slits).
- Short upturned nose
- Low nasal bridge
- Flat philtrum (vertical groove between the upper lip and nose)

#### Other possible physical defects include:

- Eve and ear defects

- Thin upper lip
- Flat midface.
- Small chin
- Simply formed, low set ears

- Respiratory (lung) problems
- · Limb reduction
- Low birth weight
- Hutchinson's teeth

The following primary cognitive disabilities associated with FAS/ARND are caused by brain damage. Many overlap with diagnoses for other disabilities. Therefore, many children will be misdiagnosed or underdiagnosed with Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), Obsessive Compulsive Disorder (OCD), Sensory Integration Disorder (SID), and Learning Disabilities (LD), among others,

- Developmental delays often acts younger than his or her age.
- Inconsistent performance seems to "get it" one day and lose it the next.
- Hyperactivity constantly in motion.
- Impulsivity says and does whatever comes to mind without thinking about consequences.
- ♦ Attention deficits, distractibility at times their lack of ability to stay focused on a task for very long is due to attention deficits; may also be easily distracted.
- Disorganization messy, can't find things, unprepared for school or work.
- ♦ Poor social skills has problems making and keeping friends, does not understand social cues or body language.
- Literal thinking doesn't understand subtle jokes or statements that have double meanings. For example, don't say, "Hit the road" when you mean "Leave" or "Cut it out" when you mean "Stop".
- Difficulty with abstractions struggles with abstract concepts such as math, money management. time, ownership, and consequences.
- Difficulty with transitions needs help when switching from one activity to another. May become very involved in current activity and will have difficulty changing to a new one especially if it is felt that the current activity is incomplete.
- Memory problems difficulty storing and retrieving information.
- Processing deficits may think more slowly, may only understand every third word of normally paced conversation
- Ability to repeat instructions, but inability to put them into action.
- Inability to predict outcomes or understand consequences and cause/effect poor judgment.
- ♠ Difficulty generalizing from one situation to another a lesson learned in one situation does not carry over to a new situation.

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#### **Ohio FASD Awareness Activities**

In 2010, provided FASD Training for Parents and Providers in NW and SW Ohio Regions, & FASD Generalist Training in NE Region

In 2013, provided FASD

Diagnostic Capacity Training

for health care practitioners in

SE & Central Ohio Regions





#### Additional Ohio FASD Prevention Efforts

ASBI stands for Alcohol Screening Brief Intervention.

- It is a process modeled after California Women, Infants, and Children's program (WIC), which screens all pregnant WIC participants for alcohol use, provides brief interventions to all who screen positive, follows those receiving brief interventions during pregnancy, and refers them to treatment services.
- The goal is to educate pregnant women about the dangers of drinking alcohol while pregnant and, in turn, positively influence their decision about reducing or completely ceasing drinking.





#### Additional Ohio FASD Prevention Efforts

Results from Montgomery County, Ohio WIC pilot ASBI project indicated that:

- five percent of the pregnant women screened positive,
- 97 percent abstained from further alcohol use after an initial brief intervention, and
- 99 percent abstained after two brief interventions.





#### Additional Ohio FASD Prevention Efforts

Ohio WIC and the Montgomery County WIC program developed four Alcohol Screening and Brief Intervention training modules for Ohio WIC projects and other programs' use.

Modules are on the *OhioTrain* website: Course number 1044743

ASBI process materials are available on the Ohio WIC website at: <a href="http://www.odh.ohio.gov/en/odhprograms/ns/wicn/wic1.aspx">http://www.odh.ohio.gov/en/odhprograms/ns/wicn/wic1.aspx</a> Click on ASBI and scroll down to links for:

- ASBI Screening and Scoring Tools
- WIC Project CARE Health and Behavior Workbook
- ASBI Follow-up Visit Questions
- What is a Standard Drink



Not a Single Drop

#### Additional Ohio FASD Prevention Efforts

As of April 7, 2014

- 650 Ohio WIC employees had been trained on the ASBI process.
- There were 5,160 Ohio WIC participants that had been screened, and
- 564 brief interventions were given.





#### Additional Ohio FASD Prevention Efforts

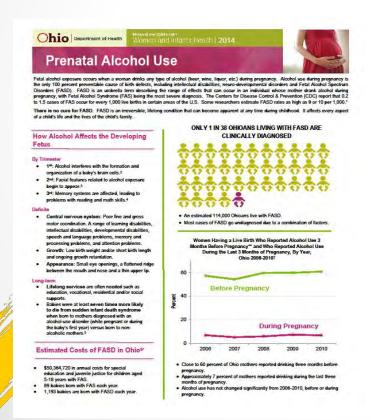
NCADD Alcohol and Drug-Related Birth Defects Awareness Week May 2013 & 2014





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# Additional Ohio FASD Prevention Efforts Prenatal Alcohol Use Fact Sheet - MCH Grant





There is no safe amount and no safe time to drink alcohol during pregnancy.



# Questions??



# Michigan Fetal Alcohol Disorders Program

Rose Mary Asman, RN, MPA

Michigan Department of Community Health





#### Michigan Health and Wellness Dashboard

#### Performance Key:

Performance improving

= Performance staying about the same

Performance declining

Click on the links in the table below for more detail.

Access to Health Care			
Uninsured adults	12.7%	Current 11.7% (2013)	Progress
Primary care physicians (per 100,000 population)	117.4 (2012)	119.4 (2013)	<b>5</b>
Veterans using Veterans Administration health care services	20.9% (FY 2012)	22.2% (FY 2013)	<b>6</b>

Health Indicators	_	_	_
	Prior	Current	Progress
Life expectancy at birth - Leading causes of death	78.1 (2011)	78.0 (2012)	<b>8</b> 7
Preventable hospital stays (per 1000 Medicare enrollees)	69.8 (2012)	70.3 (2013)	.2
Infant mortality (per 1,000 births)	7.4 (2012)	7.3 (2013)	•
Attempted suicide and self- inflicted injury	5,380 (2011	4,881 (2012)	3

	Prior	Current	Progress
Schools not selling unhealthy food and beverages	26.7% (2010)	28.5% (2012)	<u>.</u>
Food stamp sales at Michigan's farmers markets	\$1,530,319 (2012)	9 \$1,701,926 (2013)	· <u>~</u>



Health Behaviors				
	Prior	Current	Progress	
Obesity in the population (adult)	31.3% (2011)	31.1% (2012)	<b>☆</b>	
Obesity in the population (high schoolers)	12.1% (2011)	13.0% (2013)	<b>8</b> 2	
Adult physical activity*	n/a	19.7% (2011)	n/a	
Adequate daily consumption of fruits and vegetables*	n/a	17.8% (2011)	n/a	
Routine checkups in past year	66.5% (2011)	66.5% (2012)	=	
Recent dental visits*	n/a	68.0% (2012)	n/a	
Childhood immunizations	92.9% (2011)	87.0% (2012)	82	
Teen birth rate (births per 1000 women ages 15-19)	30.1 (2012)	27.8 (2013)		
Adult cigarette smokers	23.3% (2011)	23.3% (2012)		
Excessive alcohol consumption	7.0% (2011)	6.1% (2012)	<b>.</b> △	
Sexually transmitted disease - chlamydia (per 100,000 population)	507 (2011)	493 (2012)	<b>△</b>	



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# Michigan Governor's Dashboard of Priorities what is the relevance to FASD?

#### Researchers identified:

- Prenatal alcohol exposure and fetal death association more than 20 years ago.
- Fetal mortality was found to be 77 percent higher when alcohol was consumed during pregnancy.
- Prenatal alcohol exposure is associated with a higher rate of infant death.
- Likelihood of miscarriage increased directly with alcohol consumption.
- Risk was twice as high in women consuming 1 ounce of absolute alcohol as infrequently as twice a week.

Curriculum for Addiction Professionals (CAP); Level 1 <a href="http://fasdcenter.samhsa.gov/educationTraining/courses/CapCurriculum/">http://fasdcenter.samhsa.gov/educationTraining/courses/CapCurriculum/</a>

Accessed 10/28/2011





## FASD Interagency Strategic Plan

#### 2012-2014

- Goal 1: Prevention of Prenatal Alcohol Exposure Among Women of Reproductive Age.
- Goal 2: Intervention for Affected Children Birth to 18 Years
- Goal 3: Resource Development for FASD

Currently working on Michigan's Strategic Plan for 2015-2020. Result of the Report to Senate & House Subcommittee on Community Health for FASD April 1, 2014.





## Target Populations

for FASD promotion, prevention, and intervention

- **General Populations**
- Women of Reproductive Age
- Children & Adolescents
- Youth in Transition
- Adults Affected by FASD DD Diagnosis
- Parents/Caretakers/Partners/Extended Family
- Native American Tribal Communities, Latino & African American Community-Based Projects
- **Workforce Training**





## Components of the Current Michigan FASD Program

#### Network OF 5 Diagnostic Clinics

- Diagnose Children, Birth to 18 years
- Provide Initial Plan of Care for the Child & Family

#### 8 Community-Based Projects

- Provide Local Community Prevention Initiatives
- Linkage & Referral to Local Community Services
- Family Support

#### Training and Education

- 16 CDC FASD Certified Trainers in Michigan
- FASD State Coordinator





### Statewide Alcohol Specific Screening for Medicaid Pregnant Women

- The Maternal Infant Health program (MIHP) is Michigan's Medicaid Fee for Service home visiting program.
- Largest home visitation program in the state and all counties have services.
- Provided by: Federally qualified health centers; Home Health Agencies; Hospital based clinics; Native American tribes; Private providers; Local and regional public health departments.
- Includes home visitation support and care coordination for pregnant women and infants.
- Uses evidence based, comprehensive Maternal and Infant Risk Identifiers that determines the maternal or infant risks based on an algorithm designed into the database plus professional observation.
- Consists of standardized training, forms, interventions and plan of





## MIHP Alcohol Specific Screening

- T-ACE embedded into the MIHP Risk Assessment that all pregnant women and mothers received at time of enrollment into program
- Approximately 27,000 women and another 25,000 mothers of infants screened yearly
- 130,821 pregnant women Risk Assessments since 2008
- 28,967 (22.1 percent) admitted to having consumed alcohol while pregnant, Most reported quitting after finding out they were pregnant
- www.michigan.gov/mihp





# Public Health, Delta & Menominee Counties

## FASD Reduction Project

http://www.phdm.org/









# Public Health, Delta & Menominee Counties

 Mission: To enhance the quality of life for the community by preventing disease, encouraging healthy lifestyles, and protecting the environment.

 Vision: To be a community leader in promoting, protecting, and providing for the public's health.







# Integration of FASD Community Project at PHDM

Benefits for women of reproductive age

- Multiple programs offered that connect to Medicaid beneficiaries and pregnant women
- Staff work in several programs:
  - MIHP
  - WIC
  - Family Planning
  - Early On
  - Substance Abuse Services

· It's a small community







- Staff educate about the risks of alcohol during pregnancy in all programs
  - Strong "in house" referrals
- MIHP home visiting program has the strongest opportunity for early interventions
  - T-ACE is built into the risk assessment







## T-ACE

- TOLERANCE: How many drinks does it take to make you feel high?
- Have people ANNOYED you by criticizing your drinking?
  - Have you ever felt you ought to CUT DOWN on your drinking?
- EYE OPENER: Have you ever had a drink the first thing in the morning to steady your nerves or get rid of a hangover?







# Alcohol-Specific Risk Screening during pregnancy & post-partum

PHDM education packet includes FASD information brochures to prevent alcohol exposed pregnancy (AEP)

**FASD Brochures:** 

Think Before You Drink (ARC & CDC)

I Never Thought I'd Get Pregnant (CDC)

Family Planning Information







#### Low Risk

## Basic Education on alcohol & other drugs FASD brochures/information

#### Moderate Risk

Potential effects of alcohol on fetal development
Advising access to services
FASD brochures/information

High Risk

Brief interventions & referral to treatment
Advising access to services/suggest alternatives
FASD brochures/information







## MIHP Postpartum Plan of Care

- Review Family Planning methods available
- Referrals to Family Planning or provider of choice
- On-going WIC involvement/dietician
- Availability to set up appointments for other on-site programs
- Early-On staff on site for infants eligible for both MIHP & Early-On
- Possibility of the same staff working with families in multiple



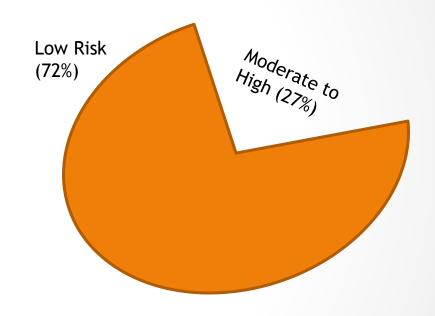






## FY Data Year to Date 2014

- 77 Women Screened
- 56 Low Risk
- 21 Moderate to High Risk









### Lessons Learned Since Involvement

- Initially we were targeting only those affected
- Moved to a true prevention based model
   Universal- messages/education
   Indicated- screening for alcohol use and family planning
   Selected-those at risk from screening
- Assume minimization with WIC program reporting







# Strengths

- Umbrella of services
- Appears to be a greater awareness of FASD
- Women reporting abstinence upon knowledge of pregnancy
- Committed NP's in Family Planning
- Good relationships with:
   Hospital Social Worker
   Women's Center
   Upper Peninsula Health Plan (UPHP)
- Knowledge of PHDM staff







# Questions??



# FASD Prevention Project

www.thearc.org/FASD-Prevention-Project

Thank You!



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