# Preventing Prenatal Alcohol Exposure and Supporting Individuals Affected by Fetal Alcohol Spectrum Disorders

Michigan Five Year Plan 2015 - 2020



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# Preventing Prenatal Alcohol Exposure and Supporting Individuals Affected by Fetal Alcohol Spectrum Disorders

### **Executive Summary**

This five year plan documents the Michigan Department of Health and Human Services (MDHHS) comprehensive approach to address Fetal Alcohol Spectrum Disorders (FASD) by reducing the prevalence via prevention and to address the needs of individuals affected by FASD supporting their development to their full potential. This plan addresses three of the department's FY 2015 Strategic Priorities<sup>1</sup>:

- Promote and protect health, wellness, and safety implement the recommendations of the Mental Health and Wellness Commission; reduce disparities in health outcomes;
- Improve outcomes for children reduce substance use disorders with children and youth; enhance
  efforts to identify and improve early intervention mental health services; support increasing the number
  of infants who survive and thrive; implement cross-system collaborative strategies to improve health
  outcomes from preconception through adolescence;
- Transform the healthcare system strengthen mental health, substance abuse, and physical health integration; support an integrated multidisciplinary delivery system with a focus on inter-professional, person-centered care.

Prenatal alcohol exposure has been identified as the most preventable cause of birth defects and developmental disabilities. The Institute of Medicine Report to the U.S. Congress (1996) stated: "Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus." Alcohol can damage a fetus at any stage of pregnancy and damage to the developing brain can occur in the earliest weeks of pregnancy, even before a woman knows she is pregnant. However, Fetal Alcohol Spectrum Disorders are one hundred percent preventable if a woman does not consume alcohol during pregnancy. The United States Surgeon General has issued two public health warning advisories (1987 and 2005) urging women not to consume *any* alcohol during pregnancy or when considering to become pregnant. The neurological, cognitive, behavioral and developmental disabilities that can result from prenatal alcohol exposure are complex, last a lifetime and is very costly. Fetal Alcohol Syndrome (FAS), the most severe form of FASD, is estimated to cost at least \$2 million for the life time of an individual affected by FAS.

Michigan's FASD reduction plan promotes comprehensive tactics with three approaches: 1) health promotion, 2) health prevention and 3) interventions designated to targeted population groups to address prevention of FASD, and to address the complexities of the needs created by the impact of FASD. This five year plan outlines goals, objectives, activities and recommendations to prevent FASD, promote awareness in targeted population groups: women of child bearing age; their health care providers before, during and after pregnancy; women's families and the general population. Expanded awareness and education of FASD for other key groups is a major emphasis. These key groups are: the general population, families and care providers of individuals affected by FASD, and workers in the areas of health care, behavioral health care, education, social services, and juvenile and criminal justice.

The plan builds upon existing resources and interventions currently in place and calls for enhancements, particularly for more competent and consistent screening, expanding capacity for diagnosis, implementing and expanding evidence-based and promising interventions. There is also a call for developing needed interventions and support systems that are not available at this time but are paramount for each individual affected by FASD to develop into an adult living up to his or her full potential. The plan includes addressing the social determinates of health as necessary to improve each life stage with culturally relevant and effective approaches for all, especially for populations of color to achieve health equity.

This work is a collaborative effort of Public Health and Behavioral Health and Developmental Disabilities Administrations of MDHHS coordinating for an efficient use of resources and implementation evidence-based programs that will enhance existing systems of care, improve outcomes, significantly lower costs over the life span and improve user's satisfaction at the community and state levels.

# Michigan's Five Year Plan for Preventing and Supporting Individuals Affected by FASD

### Introduction

Alcohol is a culturally acceptable substance, widely consumed within many social circles. When consumed any time during pregnancy, alcohol can disturb normal human embryo and fetal development causing birth defects and altering growth and development. Alcohol can produce an array of birth defects, growth deficiencies and brain-based defects known under a group of disorders called Fetal Alcohol Spectrum Disorders (FASD). FASD is the leading cause of preventable birth defects and lifelong disorders and disabilities that include physical and functional disabilities, behavioral health disorders, intellectual and other cognitive and learning disabilities. Alcohol is one of the most dangerous substances causing permanent impairments to the developing baby. The Institute of Medicine Report to the U.S. Congress (1996) stated: "Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."<sup>2</sup>

FASD is one hundred percent preventable if a woman does not consume alcohol during pregnancy. Preventing prenatal alcohol exposure to the fetus and reducing the impact across the life course for individuals affected by Fetal Alcohol Spectrum Disorders is a critical public health charge. All of the following conditions are included in the spectrum of disorders known as FASD: Alcohol Related Neurodevelopmental Disorders, Alcohol Related Birth Defects, Partial Fetal Alcohol Syndrome, and Fetal Alcohol Syndrome (FAS).<sup>4, 5,16</sup>

Fetal Alcohol Syndrome (FAS) is the most severe form of FASD. FAS is a medical diagnosis and the only disorder for which diagnostic guidelines have been published. FAS is characterized by three diagnostic features: 1) abnormal distinct facial features, 2) growth delays at or below the 10th percentile which may occur in utero prior to birth, and 3) central nervous system difficulties due to structural and neurological changes of the brain.<sup>4</sup>

The call for a reduction of the incidence to combat fetal alcohol syndrome comes from the Michigan Public Act 59 of 2013, Section 502 of the FY 2014 Michigan Department of Health and Human Services Appropriation Bill:

"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 [2014] on efforts to prevent and combat fetal alcohol syndrome as well as deficiencies in efforts to reduce the incidence of fetal alcohol syndrome."

The April 1, 2014 report called for the development of a plan. The Fetal Alcohol Spectrum Disorders Michigan Department of Health and Human Services Boilerplate Report and this work plan are collaborations of the Public Health and Behavioral Health and Developmental Disabilities Administrations within the department, working to meet the charges set forth by the Michigan Legislature:

The objectives of this plan are to:

- A. Increase public awareness and knowledge among the general population living in Michigan especially among women of reproductive age, 15–44 years, and their families that no amount of alcohol is safe during pregnancy.
- B. Implement prevention strategies targeted to women of child bearing age before, during and between pregnancies, women's health care providers, and the general population.
- C. Develop and implement early screening, diagnosis, assessment, interventions and support services across the life cycle for those individuals who are affected by FASD.
- D. Increase readiness of the work force to prevent alcohol exposure during pregnancy and to identify, implement and provide effective, efficient and lifelong support services for individuals affected by FASD in the key support and service systems: health care, behavioral health care, education, social services and criminal justice.

# History, Problem and Prevalence

Alcohol consumption has a place in social, cultural and medicinal history since early times. It was not until 1973 that FAS was first described in the United States as a clinical diagnosis for the debilitating effects of alcohol on human development. Before this realization alcohol was even used as an analgesic for the pains of long labor. It has been in relatively recent history, in 2004, the Centers for Disease Control and Prevention set forth guidelines for diagnosis of FAS.<sup>4,17,19</sup>

Prevention of FASD is a recent effort to make everyone aware, especially women of child bearing age typically considered 15-44 years old, to avoid alcohol intake any time during pregnancy and during times she has the potential of becoming pregnant. No consumption of alcohol during these crucial periods is the only prevention available but it is highly effective. This presents a troubling conundrum of the frequency of alcohol consumption rates of child bearing women, the rate of unintended pregnancies and the lack of using reliable, effective contraception while sexually active.

In 2012, according to Michigan's Behavioral Risk Factor Survey, 56.1 percent of women of child-bearing age drink and 20.6% of these women binge drink (consuming four or more drinks per occasion). Younger women tend to binge drink more, 34 percent of women 18-25 years old as compared to 10 percent of women 26 years old and older. Nationally, approximately 11.8 percent of all age groups of pregnant women (15-44) admit to drinking some alcohol during the previous month.<sup>6</sup> Michigan is able to report on the admission of alcohol consumption while pregnant of a subgroup of pregnant women by using the collective data from the Medicaid home visiting program, Maternal Infant Health Program (MIHP). This subgroup of Medicaid beneficiaries report a similar rate of drinking during pregnancy as compared to the national rate. Of the 130,821 prenatal screens entered into the Medicaid data base from 2008 to July 2014 of pregnant women screened for alcohol consumption, 28,967 (22.1 percent) admitted to having

consumed alcohol while pregnant. Most reported quitting once they found out they were pregnant, but this means their early fetus was exposed to the risk. As many as 2,153 (1.6 percent) admit to continuing alcohol consumption during their pregnancy at the time of their screen.

According to 2008 Michigan Pregnancy Risk Assessment Monitoring System (PRAMS) 42.9 percent of women's pregnancies were unintended.<sup>7</sup> The unintended rate is higher within the younger age ranges. The younger women, who have the largest percentage of the births in any year, have a higher percent of unintended pregnancy rates: 77.3, 56.2, and 36.9 percent respectively for the age groups 18-19, 20-24, and 25-29 years old. Note that the younger two age groups who have the larger percentage of all births and the largest percentage of unintended pregnancies, also binge drink significantly more. This is a troubling combination.

Prevalence is the proportion of a population found to have a condition, disease or risk factor. Defining the prevalence of FASD has been difficult because of the lack of awareness of its existence and impact, the lack of screening and limited diagnosis of the conditions that make up the spectrum, and the poor/underreporting of alcohol consumption during the prenatal period. However, using United States Department of Health and Human Services, Office of Substance Abuse and Mental Health Services Administration's FAS prevalence data, the worst of the spectrum conditions, range between .5 and 2 per 1,000 births and for the entire spectrum (FASD) the prevalence is estimated at 10 per 1,000 births. Applying these prevalence rates to Michigan's approximately 115,000 births in a calendar year, 58 to 230 babies could be affected by FAS and 1,150 infants affected by FASD annually. In Michigan, Fetal Alcohol Spectrum Disorders (FASD) are identified as birth defects and reportable to the Michigan Birth Defects Registry (MBDR).

The FASD rate is greater than our state's infant mortality rate at 6.4 per 1,000 births (2012) which has been highlighted as a public health crisis and is one of the Governor's and this department's measure of the state's health status. Of approximately 115,000 births annually (2013), 800 babies do not survive their first year of life compared to approximately 1,500 babies may have brain-damage and disruptions of their neurological system because their mother consumed alcohol during their nine months of development in the uterus.

### **Financial Impact**

The costs for individuals who are affected comprise expenditures related to an inability to grow and develop appropriately. Individuals who are affected require additional support in education as they tend to perform poorly in school and have a number of behavioral problems due to poor neurologic development. In addition, those who are affected are often involved in the juvenile and criminal justice systems as they age into adulthood. Recent studies confirm children affected with FASD have significantly more co-occurring psychiatric disorders and this fact is under recognized. This makes becoming a contributing member of society difficult.

The cost estimate to support a person affected by the most devastating of the conditions within the spectrum, FAS, is \$2 million.<sup>4</sup> This cost is so great because the needs stretch across multiple service systems: health, education, social service, and juvenile and criminal justice. The

cost savings of preventing FAS is substantial and does not take into account the benefit to the individual who does not have to live with a lifetime of disabilities. The costs associated with treating FASD include time in the high level care hospital unit, Neonatal Intensive Care Unit, at birth; therapeutic interventions throughout life; special education services; extenuating health care and behavioral healthcare services; and residential placement for individuals over age 21. These costs do not include a caregiver's lost wages or the costs of incarceration when that is often a result. 4,8,14

# **Consequences of Fetal Alcohol Spectrum Disorders**

Consequences of Fetal Alcohol Spectrum Disorders are many and varied. The neurological, cognitive, behavioral and developmental disabilities that can result from prenatal alcohol exposure are complex, last a lifetime, and often involve co-occurring mental health and substance use problems. According to research publications by the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the results from neuropsychological studies show that "generally, heavy prenatal alcohol exposure is associated with deficits in a wide range of areas of function, including both cognitive functioning (for example, general intellectual functioning, learning of new verbal information, and performance on visual-spatial tasks) and fine-and grossmotor performance."22 Additionally, deficits in executive functions both in children with fetal alcohol syndrome and in children with less severe impairments were identified. Individuals who are affected with FASD often do not understand global concepts and/or have the intellectual ability to associate their behaviors with outcomes. Both groups of children also exhibit problem behaviors, such as alcohol and drug use, hyperactivity, impulsivity, and poor socialization and communication skills. Brain imaging studies have identified structural changes in various brain regions of these children. Research studies concluded the "extent and severity of a child's condition depends on several factors, such as how much alcohol the pregnant mother consumed and how often and at what point during her pregnancy she drank."8

Some infants affected by FASD may have the following symptoms, although they are not exclusive to FASD:

Low birth weight Poor sucking

Irritability Increased ear infections
Sensitivity to light, noises, and touch Poor sleep-wake cycles
Physical features (skeletal features Auditory and hearing deficits

of the face, nose, and size of the head) Slow development

Unfortunately, the effects of FASD make it difficult to soothe an infant, and subsequently difficult to form the important maternal-infant bond. This can lead to poor maternal child attachment, impacting baby's behavior and development negatively in addition to the symptoms of FASD.

While early diagnosis is paramount to improving chances of achieving developmental potential, there is no one test to diagnose FASD or a way to tell how an infant will be affected or not affected prior to birth, or what the long term impacts on an individual will be until their development has progressed and they can be fully evaluated. Many babies do not display any of the physical features or abnormalities of FAS, and as a result, do not receive appropriate services for behavioral or cognitive disorders in a timely manner due to misdiagnosis.<sup>9</sup>

Toddlers living with FASD may have the following symptoms, although they are not exclusive to FASD:

- Poor memory capability
- Hyperactivity
- Lack of fear
- No sense of boundaries
- Need for excessive physical contact

Not every woman's consumption of alcohol during pregnancy will result in a child born with a fetal alcohol birth defect. The use of alcohol during pregnancy may result in no visible signs of facial features, brain damage or neurological disorders. Additionally, there is no one test to diagnose FASD. Thus, accurate medical diagnosis associated with fetal alcohol exposure requires specialized training as well as diagnostic evaluations by a multidisciplinary team of specialists such as the teams at the six Michigan FASD Diagnostic Centers located throughout the state (Marquette, Grand Rapids, Kalamazoo, Flint, Ann Arbor and Detroit). Because of limited identification or diagnoses, infant and toddlers may be adopted without the adoptive family ever being told that their new child may have some form of FASD.

School age children may have the following symptoms, although they are not exclusive to FASD:

- Toddler symptoms noted above and
- Slowly developed fine and gross motor skills
- Low self-esteem

Usually by grade school, a parent or caregiver is aware that a child has challenges or difficulties in the form of a short attention span or poor coordination and difficulty with fine and gross motor skills. However, misdiagnosis is still prevalent in this age group with the focus on alleviating the symptoms instead of identifying the cause. Older children will experience difficulty keeping up in school, may be socially behind, and suffer from low self-esteem due to recognizing that they are different from their peers. In addition, their peer group may also recognize that the child is different.

Teenagers living with FASD may have the following symptoms, although they are not exclusive to FASD:

- Poor impulse control,
- Difficulty distinguishing between public and private behaviors
- Must be reminded of behavioral concepts on a daily basis

These symptoms can lead to theft, criminal sexual conduct charges, poor relations with peer groups, juvenile detention/incarceration, and an inability to keep on task or keep up with assignments. While most parents and caregivers would be preparing teens for independence,

attempts to do so with a teen affected by FASD are frustrating and rarely successful. Many of these teens are unable to master the necessary skills and are easily frustrated by the repetition, without additional support.

Adults living with FASD may experience the following symptoms, although they are not exclusive to FASD:

- All the previously identified symptoms of their developmental years
- Mental health disorders depression and suicidal ideation
- Inappropriate sexual behavior and involvement in the sex trade
- Addictions

Results of these difficulties are: disrupted school and employment, trouble with the law, and other deviate social behaviors and experiences. In addition they need to deal with many daily living activities, such as obtaining affordable and appropriate housing, transportation, employment and money handling skills but have great difficulties due to poor executive functioning and judgment related to their neurological disorder. If they have never been diagnosed or have been misdiagnosed, they may not be receiving services that can help alleviate some of their symptoms and the resulting difficulties. Adults with FASD frequently have a substance use and/or other co-occurring disorders that need treatment. However, traditional interventions and treatment strategies are not compatible with the learning needs of individuals affected by FASD who need structure and frequent prompts.<sup>18</sup>

### Enhancements in Health Promotion, Prevention, Intervention, and Service Systems

The Michigan plan to reduce prevalence and to provide support to individuals affected by FASD and their family takes a multifaceted approach to assure that the many components of the complex conditions that make up FASD are appropriately addressed. The foremost effort must be to prevent newly affected babies by assuring the population is aware of FASD and the only preventive measure, as called for twice by the U. S. Surgeon General is for "...women not to consume any alcohol during pregnancy or when considering to become pregnant." The plan that follows in this document targets health promotion efforts for the entire population, women of child bearing age, and providers of care in health, behavioral and mental health and social service systems. The plan also calls for the women's care systems to be enhanced to routinely, without regard to social economic or racial considerations, provide education, screening, referral and support for women to avoid alcohol during these crucial periods.

The second level of the plan takes a systems perspective and includes health care, behavioral health care, social services, education, economic and criminal justice systems. After the identification of pregnant women who are currently drinking and individuals who were exposed in utero, assuring that they receive the appropriate assessment and referral for interventions and services is paramount. To do so, there must be capacity at diagnostic clinics and treatment centers to identify those who are FASD affected. Another needed enhancement to the current diagnostic service is linking families to assistance to assure access to interventions and/or behavioral management services.

The need to educate pertinent professionals and service providers to improve their awareness and informed recognition of symptoms, and the need for screening and assessing for FASD symptoms cannot be overemphasized. Physicians/primary care providers, teachers, behavioral health clinicians, case workers, educators/special education teachers, community health workers, nurses, social workers, care providers, are targeted for the education to assure the awareness of FASD and how it can be prevented, and the need and skills to provide interventions and support.

Individuals affected by FASD require a wraparound, comprehensive service system. Michigan does not currently provide services and supports specifically addressing the needs of those affected with FASD. New evidence-based and promising interventions have been and are being uncovered and developed. Implementing promising interventions will help the target population accomplish developing to their potential.<sup>20,21</sup>

Complete wraparound services include addressing the "social determinates of health refer to social, economic, and environmental factors that contribute to the overall health of individuals and communities. *Social factors* include, for example, racial and ethnic discrimination; political influence; and social connectedness. *Economic factors* include income, education, employment, and wealth. *Environmental factors* include living and working conditions, transportation, and air and water quality. A focus on health equity in Michigan calls for more targeted efforts to address these and other social determinants of health in order to optimize health promotion and disease prevention efforts."<sup>11</sup>

While being noted last in this description of service delivery enhancements for addressing FASD, this next item is not to be discounted. Problems in the country's care system identified by the prestigious Institute of Medicine of the National Academy of Sciences and highlighted by others as well are inequities of care to populations of color<sup>9,10</sup> and care for mental health or substance use problems.<sup>11</sup> As we propose to address the needs of individuals affected by FASD, we must take purposeful steps and monitor our efforts to assure we exclude the ingrained institutional bias in care and services for populations of color. Our plan includes activities targeting interventions that are intended to be culturally relevant to members of minority groups of our state's population. As we implement the plan we must remember equal is not equity, meaning the same interventions with the same intensity may not be appropriate or may be insufficient to produce a similar level of improvement in quality results for minority populations.

### Michigan's Five Year Plan for Reducing FASD

The Michigan FASD reduction plan promotes a comprehensive tactic with three approaches: health promotion, health prevention and interventions designated to prevent FASD and target population groups to address the complexities of the needs created by the impacts of FASD. The plan also intends to build upon existing resources and interventions in place calling for enhancements and development of needed interventions and support systems that are not available but are paramount for each individual affected by FASD to develop into an adult living

up to his or her full potential. The plan includes addressing the social determinates of health as necessary to improve each life stage and culturally relevant and effective approaches for populations of color.

The three approaches are defined as follows:

**Health promotion** - educating the general public or a whole population group that has not been identified on the basis of individual risk.

**Prevention** – providing activities/programs that are effective in addressing attitudes and behavior among individuals or subgroups at risk due to certain social, environmental or biological factors. The target audience is individuals without identification of unrecognized disease or signs of symptoms, including individuals with pre-symptomatic disease who are apparently in good health.

**Intervention** - providing treatment and support to individuals who are identified as having a diagnosed condition.

FASD prevention requires action prior to and during pregnancy. FASD is a lifelong, incurable condition requiring ongoing interventions and support as infants grow through each life stage into adulthood, affecting not only the individuals who have the disorder but also those that work with, care for and interact with them. <sup>13,17,19</sup>

The approaches target key population groups are defined as:

- General population (all persons in Michigan regardless of age, sex or race)
- Women of reproductive age (15-44 years), women intending to become pregnant and those who are pregnant
- Children and adolescents (age 0-17 years old in the general population and those affected by FASD)
- Youth affected by FASD in transition (age 16-26 years old and in school)
- Adults affected by FASD (age 18 years and older and out of school)
- Parents, partners, families and caregivers of individuals affected by FASD
- Populations of color (African American, Arab/Chaldean American, Asian American, American/Pacific Islander, Latino/Hispanic and American Indian/Alaska Native)
- Workforce (medical and dental providers, educators, juvenile and criminal justice, behavioral/mental health/substance use providers, human service agency providers, diagnostic centers and health centers, and care providers)

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# **HEALTH PROMOTION**

Educating the general public or a whole population group that has not been identified on the basis of individual risk.

# A. General Population

### Objective:

Within two years of implementation start date, a sustainable infrastructure will be developed for the general population that educates and increases awareness that alcohol consumption is known to be dangerous to the brain and body development of a baby during pregnancy.

### Activities:

- 1. Determine a sustainable funding strategy
- Work with Michigan Department of Health and Human Services Communications to develop a media plans
- Adopt the use of "None for Nine" icon developed by Mississippi with credit given to their state
- Develop media outreach each September to accompany the governor's proclamation of Fetal Alcohol Spectrum Disorder Awareness Day and Substance Abuse Recovery Month activities
- Develop infrastructure for the annual Fetal Alcohol Spectrum Disorder media, marketing and awareness campaign
  - Incorporate a broad spectrum of activities to include social media, radio, and print materials.
  - Promote the Substance Abuse and Mental Health Services Administration s treatment locator for substance abuse
  - Review other states and national organizations outreach material for ideas
  - Revise and update the State FASD website.
- Promote public/private partners and hospitals to include Fetal Alcohol Spectrum Disorder prevention and early intervention resources through their websites
- Incorporate Fetal Alcohol Spectrum Disorder promotion activities in Fetal Alcohol Spectrum Disorder community projects and diagnostic clinic contact's required activities
- 8. Develop fact sheets on Fetal Alcohol Spectrum Disorder
  - Consequences
  - What to do if suspected
  - Evaluation locations
  - Follow-up after diagnosis



# B. Women of Reproductive Age

### Objective:

Within two years of implementation start date, develop infrastructure for health care providers, family planning clinics and home visiting programs to provide education to women of reproductive age that alcohol consumption is known to be dangerous to the brain and body development of a developing baby during pregnancy.

### Activities:

- Review prevention messages available and identify messages that Michigan could adapt for use
- 2. Identify methods to promote chosen message(s)



### C. Children and Adolescents

### Objective:

Within two years of implementation start date, Fetal Alcohol Spectrum Disorder information will be incorporated into the Michigan Model for Health.

### Activities:

- 1. Work with appropriate departments and stakeholders
- 2. Develop appropriate materials/information for students
- 3. Provide resources for parents and educators



# D. Youth Affected by FASD in Transition

### Objective:

Within three years of implementation start date, develop and distribute in pilot sites, transition information packets for youth affected with Fetal Alcohol Spectrum Disorder, their families and professionals.

### Activities:

- 1. Obtain agreement from pilot sites
- 2. Develop pilot requirements and initiate activity
- 3. Develop informational packets and social media plan
- 4. Evaluate impact of pilot



# E. Adults Affected by Fetal Alcohol Spectrum Disorder

### Objective:

Within five years of implementation start date, increase by 20% adults seeking Fetal Alcohol Spectrum Disorder diagnostic evaluation.

### Activities:

Determine base line number of adults seeking diagnostic evaluation

- Determine capacity of diagnostic clinics and methods of reimbursement for adult evaluation
- Develop and conduct awareness campaign on adults affected by FASD



# F. Parents, Partners, Family and Caregivers

### Objective:

Within two years of implementation start date, develop fact sheets and informational messages that can assist a parent, caretaker or family member to know if additional evaluation is necessary to determine whether their child/adult child has Fetal Alcohol Spectrum Disorder.

### Activities:

1. Develop a targeted awareness and education campaign



# G. Populations of Color

# Objective:

Within two years of implementation start date, develop core message(s) and an awareness campaign for populations of color.

- Develop infrastructure for on-going media that includes populations of color (i.e., African American, Hispanic/Latino, Arabic, Vietnamese, Native American)
- Develop a targeted educational awareness campaign
- Research for appropriateness of Public Service
   Announcements and educational materials currently in use for populations of color
- 4. Identify promotional materials for special populations developed by national and international entities
- Obtain input from identified population representatives regarding appropriate messages

- 6. Conduct focus groups representing populations of color to test and review materials for appropriateness
- 7. Develop messages/materials appropriate to populations
- Distribute materials to targeted population clinics, centers, agencies, etc.
- Enlist targeted population advocates to assist with promotion awareness
- Determine services targeting populations of color that can provide education and promote zero-use of alcohol during pregnancy
- Post materials on state web site, distribute to health care providers, human service organizations, educational institutions, and social service organizations



# H. Workforce

### Objective:

Within two years of implementation start date, develop education, media and professional campaigns for MI workforce on effects of alcohol during pregnancy.

- 1. Develop education and awareness plans
- Develop a marketing/media plan for dissemination of zerouse message to providers, educators, and organizations if a woman is pregnant
- 3. Review materials currently available for use by workforce
- Engage workforce groups in development, review and training of their respective professions
- Develop consistent messages for all workforce participants to understand the priority of addressing prenatal alcohol exposure



- Develop education and training materials for workforce training
- Work with education, human services and criminal justice on specific messages and education for their workers
- 8. Review educational material currently used in schools
- 9. Compile and develop necessary materials for distribution
- Enlist higher education (colleges, universities, trade schools) to promote message on Fetal Alcohol Spectrum Disorder prevention and alcohol use
- Begin making partnerships with other stakeholders to provide zero use message if a woman is pregnant
- Provide speaker on Fetal Alcohol Spectrum Disorder to workforce conferences and their professional organizations
- 13. Develop educational webcast



### **PREVENTION**

Activities/programs that are effective in addressing attitudes and behavior among individual or subgroups at risk due to certain social, environmental or biological factors.

Identification of unrecognized disease in individuals without signs of symptoms, including individuals with presymptomatic disease who are apparently in good health.

# A. General Population

### Objectives:

Within one year of implementation start date, initiate discussions on reimbursement of screening tool with payers and develop a sustainable funding strategy.

Within two years of implementation start date, identify the proportion of the general population who use the September Substance Abuse and Mental Health Services Administration screening tool and expresses awareness of their personal risk level of alcohol use.

Within five years of implementation start date, increase by 10% proportion of general population who expresses awareness of their personal risk level of alcohol use by use of screening tools.

Within two years of implementation start date, measure the saturation and proportion of general population who expresses awareness that Fetal Alcohol Spectrum Disorder is 100% preventable and early childhood intervention can help prevent or ameliorate Fetal Alcohol Spectrum Disorder secondary disabilities.

Within five years of implementation start date, increase by 10% proportion of general population who expresses awareness that Fetal Alcohol Spectrum Disorder is 100% preventable and early childhood intervention can help prevent or ameliorate Fetal Alcohol Spectrum Disorder secondary disabilities.



### Activities:

- Determine baseline measure
- Obtain funding for Behavioral Risk Factor Services and Surveillance and measure change over time in (5 years)
- Discuss with Medicaid/other providers possible reimbursement for screening
- Design, implement and find financial support for annual media outreach
- Promote mass media use of the Substance Abuse and Mental Health Services Administration's Self-Screening Tool statewide and provide web links throughout all public health programs

- Promote public/private partners to include Fetal Alcohol Spectrum Disorder prevention and early intervention resources throughout partnership websites statewide
- Develop an education tool for the indicated (population) who score high risk

# B. Women of Reproductive Age

### Objectives:

Within one year of implementation start date, meet with Medicaid and other third party payers regarding Screening, Brief Intervention, and Referral to Treatment Michigan billing codes for reimbursement.

Within one year of implementation start date, meet with and explore feasibility of including Fetal Alcohol Spectrum Disorder prevention and intervention resources into a single point of contact into the 211 community system statewide.

Within two years of implementation start date, explore the feasibility with Family Planning/Title X regarding implementation of Project Choices statewide at local health departments.

Within three years of implementation start date, identity the proportion of home visiting clients who have been screened and provided education re: their personal risk levels of alcohol use and Fetal Alcohol Spectrum Disorder prevention.

Within four years of implementation start date, measure the proportion of women of reproductive age who expresses awareness that Fetal Alcohol Spectrum Disorder is 100% preventable and early childhood intervention can help prevent Fetal Alcohol Spectrum Disorder secondary disabilities.



### Activities:

- Obtain Michigan Behavioral Risk Factor Surveillance System data and disseminate throughout public programs statewide
- 2. Distribute Recovering Hope DVD
- Promote online "Alcohol Free Baby and Me" training and continuing education for providers statewide
- 4. Provide education on Project Choices for Family Planning/Title X

### C. Children and Adolescent

### Objectives:

Within two years of implementation start date, develop a targeted training for select groups working with children and adolescents.

Within two years of implementation start date, increase referrals to Diagnostic clinics for evaluation, diagnosis and follow-up.



### Activities:

- Evaluate capacity of diagnostic clinics and current levels of service
- Determine funding strategy to support adequate capacity at diagnostic clinics
- Work with pediatricians, primary care providers, and their professional organizations to utilize the American Academy of Pediatrics Fetal Alcohol Spectrum Disorder toolkit to screen children and adolescents
- Track referrals from pediatricians and primary care providers to diagnostic clinics
- Provide community training for select groups (Department of Human Services, Public Safety Officers, juvenile justice system, substance abuse treatment centers and Community Mental Health staff) who work with children and adolescents
- Pilot a "Baby Court" for children with Fetal Alcohol Spectrum Disorder
- Develop and implement a peer led presentation program on children and adolescents who have Fetal Alcohol Spectrum Disorder for high school students

# D. Youth Affected by FASD in Transition

# Objective:

Within four years of implementation start date, develop two collaborative community pilots that focus on transition planning for youth age 16 to 24 years with Fetal Alcohol Spectrum Disorder in two counties.

### Activities:

- 1. Develop requirements for pilots
- Involve community stakeholders (Department of Human Services, Community Mental Health, Intermediate School District, and court systems as needed)
- Develop transition process for post-secondary or person centered employment; housing options and identification of family and peer mentors
- 4. Evaluate effectiveness of pilot

# E. Adults Affected by Fetal Alcohol Spectrum Disorder

### Objectives:

Within five years of implementation start date, working with medical provider's organizations such as Michigan State Medical Society, Michigan State Osteopathic Association, MINP etc., initiate a training program to assist the medical providers in recognizing and providing care to adults with Fetal Alcohol Spectrum Disorder.

### Activities:

- 1. Partner with health care providers organizations on training
- 2. Develop training and resources for providers
- Partner with a local Community Mental Health, Department of Human Services, and Developmental Disabilities Institute/University Center of Excellence at Wayne State, to develop an outreach program to identify adults who are suspected to have brain damage due to Fetal Alcohol Spectrum Disorder

# F. Parents, Partners, Family and Caregivers

### Objective:

Within two years of implementation start date, develop a targeted effort to increase awareness of parents, caretakers, partners/extended families on the life-long effects of alcohol affected individual.

- Develop and distribute an Fetal Alcohol Spectrum Disorder Fact Sheet available for use by families through primary care offices, schools, Department of Human Services, juvenile justice system, community mental health system by October 2016
- Develop prevention messages for partners and extended family



# G. Populations of Color

### Objectives:

Within two years of implementation start date, develop sustainable screening initiatives with targeted message for populations of color.



### Activities:

- Identify federal, state, local and international screening tools and curricula for populations of color
- Obtain input on screening and education tools from special population representatives
- 3. Develop and provide education material for pregnant women in populations of color
- Focus groups representing populations of color to test and review materials for culture appropriateness
- Post screening tools, educational materials and videos on state web site and distribute to health care providers, human service agencies, populations of color centers and leaders
- Disseminate to stakeholders the Lac Vieux Desert MI Native American Fetal Alcohol Spectrum Disorder DVD Digital Story developed by National Healthy Start
- Develop training web casts/modules to focus on screening and brief intervention for health care providers, human services agencies serving populations of color
- 8. Provide "Train the Trainer" sessions to increase number of touch points for screening and interventions

# H. Workforce

### Objectives:

Within three years of implementation start date, develop and implement a state wide educational and screening plan for the workforce who are interacting with at risk populations.

Within three years of implementation start date, develop specific trainings for interactions with at risk populations.

Within three years of implementation start date, provide information and awareness of Fetal Alcohol Spectrum Disorder trainings for 250 Department of Human Services, juvenile justice and community mental health staff.

- Develop a designated position at Department of Community Health under the Public Health Administration to coordinate and support local workgroup and provide consultation to assist in promotion, prevention activities and services
- 2. Determine baseline of the prevalence of conducting alcohol screening for women of child bearing age
- 3. Develop reimbursement for health care providers to screen women of child bearing age
- Develop readily available on-line training on screening, interpretation and follow up
- Provide screening tools for use by workforce and/or individuals
- 6. Provide self-screening tools for distribution
- Develop fact sheet for other agencies, organizations, and workforce on the importance of screening
- 8. Encourage workforce to promote universal screening
- Provide resources for providers to use if they have a positive screen
- Develop and distribute a packet of information to be provided to women when prenatal alcohol exposure is determined
- Offer "Train the Trainer" sessions to increase the number of touch points for screening and intervention
- 12. Develop safety and sensitivity trainings for select workforce providers
- 13. Promote the use of the "Alcohol Free Baby and Me" modules in all home visiting programs
- Provide training on encouragement and reinforcement techniques (Screening, Brief Intervention, and Referral to Treatment and Motivational Interviewing) for health care provides
- 15. Provide training on Project Choices
- 16. Collaborate with family planning providers to incorporate Centers for Disease Control and Prevention "Project Choices" into their clinic protocols in a pilot test area



### INTERVENTION

### Providing treatment and support to individuals who are identified as having a diagnosed condition.

# A. General Population

### Objectives:

Within two years of implementation start date, develop lists of evidence-based resources available to the public to learn about Fetal Alcohol Spectrum Disorder evaluation and treatment.

Within three years of implementation start date, develop a sustainable funding strategy for services; evaluation; and treatment for women, children, adults and families impacted by Fetal Alcohol Spectrum Disorder.



### Activities:

- Establish one fulltime employee (Departmental Specialist 13) under Behavioral Health and Developmental Disabilities Administration to support programs, operations, monitoring and administration of the overall FASD plan
- Assist public and private insurers in establishing reimbursement mechanism for evaluation and treatment services
- Promote September Recovery Month and request governor signed proclamation for it
- Develop documents containing current requirements for referral and diagnostic evaluation and provide diagnostic referral requirements to pediatric health care providers, human services agencies and education
- Develop and maintain list of neuro-psych health care providers that will accept referrals and third-party payment for Fetal Alcohol Spectrum Disorder evaluation in Upper Peninsula and Lower Peninsula
- Promote usage of the Substance Abuse and Mental Health Services Administration's treatment locator available 365/24/7
- 7. Develop list of MI alcohol support groups
  - State website
  - Providers
  - Human Service Agencies
- Develop public information and education using social and digital media with list of Michigan alcohol treatment centers
  - State website
  - Providers
  - Department of Human Services

# B. Women of Reproductive Age

### Objectives:

Within one year of implementation start date, develop list of evidence-based resources available to the public to learn about Fetal Alcohol Spectrum Disorder prevention, evaluation and treatment.

Within two years of implementation start date, identify the proportion of home visiting clients who have been screened and identified with risk levels of alcohol use and referred to counseling and/or treatment.

- Provide evidence-based Fetal Alcohol Spectrum Disorder factsheets developed by the Substance Abuse and Mental Health Services Administration's Fetal Alcohol Spectrum Disorder Center, the National Organization on Fetal Alcohol Syndrome and the Centers for Disease Control and Prevention Fact Sheets for use in public programs statewide and in health care provider offices and clinics
- Continue with Parent-Child Assistance Program as Enhanced Women's Services in local counties
- Explore expansion of Parent-Child Assistance Programs to additional counties to prevent generational Fetal Alcohol Spectrum Disorder
- Educate women of reproductive age regarding the Substance Abuse and Mental Health Services Administration's treatment locator available 365/24/7



### C. Children and Adolescent

### Objective:

Within two years of implementation start date, initiate the evidence-based treatment model, Parent Child Interaction Therapy for children with Fetal Alcohol Spectrum Disorder within at least two community mental health services programs.

### Activities:

- 1. Determine sites and obtain agreement to participate
- Establish relationship with Central Michigan University to implement training on the Parent Child Interaction Therapy model
- 3. Meet with community stakeholders
- Conduct training for staff on Parent Child Interaction Therapy
- 5. Initiate services
- 6. Implement a quality improvement process
- 7. Evaluate the pilots

# D. Youth Affected by FASD in Transition

### Objective:

Within five years of implementation start date, develop and conduct pilot at one site for youth with Fetal Alcohol Spectrum Disorder who are aging out of state foster care and educational systems to be linked with community support advocates.

### Activities:

- Analyze data on school drop-out rate, substance use, involvement in theft and petty crimes
- 2. Recruit community support advocates
- Develop pilot in a county to address delinquency issues for youth with Fetal Alcohol Spectrum Disorder
- 4. Provide structure and expectations for pilot
- 5. Evaluate against using baseline data
- Confirm buy-in with partners from county probate court, community mental health agencies, and potential connections with Department of Human Services, Michigan Rehabilitative Services, Department of Education/Special Education and Western Michigan University
- Design and set up parameters and measurements for the pilot with county probate court and community mental health agencies
- Involve partners at Michigan Rehabilitative Services and Western Michigan University for potential employment/postsecondary opportunities
- Establish measurements and evaluation tools for individualized successful outcomes
- 10. Obtain and analyze metrics and re-tool pilot as necessary
- 11. Confirm buy-in on pilot with Western Upper Peninsula Special Education Transition Department
- Design pilot with transition coordinator and obtain additional buy-in from Upper Peninsula-Pathways, Department of Human Services, Michigan Rehabilitative Services, and Department of Corrections
- Determine size of pilot, obtain diagnoses for potential students with FASD characteristics, and develop training for Michigan Rehabilitative Services, Department of Human Services, and Department of Corrections
- Identify individuals who may qualify for mental health services through Developmental Disabilities diagnosis
- 15. Establish parameters for pilot, measurements, and overarching goals
- Determine local pilot coordinator from either Department of Education or the Pre-paid Inpatient Health Plan or both.
- 17. Implement pilot and reassess progress at regular intervals
- 18. Retool pilot as necessary on yearly basis

# E. Adults Affected by Fetal Alcohol Spectrum Disorder

### Objective:

Within five years of implementation start date, develop for adults (age 26 years and older) diagnosed with Fetal Alcohol Spectrum Disorder, a multisystem pilot project to facilitate community linkage and support.

### Activities:

- 1. Develop pilot
- Develop Fetal Alcohol Spectrum Disorder specific training and information for criminal justice workers (police, probation, correction re-entry, lawyers and court officers)
- 3. Train work force individuals to work with pilot participants
- 4. Develop individualized supports such as:
  - Peer and family mentoring
  - Para-professional Fetal Alcohol Spectrum Disorder training
  - · Post-secondary education opportunities
- 5. Evaluate pilot
- Obtain buy-in for pilot from community mental health agencies, Arc, with possible Department of Human Services, Community Housing Network and local community college involvement
- 7. Identify adult population and pilot parameters
- 8. Locate pilot coordinator and develop plan for three year pilot
- 9. Establish numbers and measures for pilot
- 10. Evaluate pilot yearly and retool as needed

# F. Parents, Partners, Family and Caretakers

# Objectives:

Within two years of implementation start date, provide Fetal Alcohol Spectrum Disorder 101 Training to 250 parents, caretakers, partners and extended families.

Within two years of implementation start date, conduct Families Moving Forward Program with one site.

- 1. Develop Fetal Alcohol Spectrum Disorder 101 curriculum
- Develop Fetal Alcohol Spectrum Disorder 101 training site and methods
- 3. Provide Fetal Alcohol Spectrum Disorder 101 training
- 4. Evaluate by pre and post-test the change in knowledge
- 5. Determine site for Families Moving Forward Program6. Determine and recruit participants for program
- 7. Provide technical assistance to pilot site
- 8. Implement a quality improvement process
- 9. Evaluate the outcomes of the program



# G. Populations of Color

### Objective:

Within three years of implementation start date, develop a culturally relevant intervention initiative that meets the needs of populations of color.



### Activities:

- Develop a state intervention liaison position for special populations of color for education, trainings, screenings, support, access to services and interventions
- Discuss with populations of color their needs, gaps and cultural considerations
- Determine current referral and intervention patterns for populations of color
- Identify interventions currently in use and also interventions populations of color feel would be appropriate for their culture
- Identify existing recommended interventions for populations of color
- Develop information for prevention, treatment and intervention that are culturally appropriate for populations of color (beliefs, family arrangements, etc.)
- 7. Engage focus groups representing populations of color to test and review materials for culture appropriateness
- 8. Evaluate treatment and intervention sources for capacity and convenience for populations of color
- Utilize and distribute information currently available in resource kits
- Provide training, treatment, and intervention information to providers on meeting the needs of populations of color
- 11. Provide information to providers, organizations and agencies that serve populations of color
- Determine and assure treatment and intervention providers have staff that are able to communicate with populations of color

### H. Workforce

### Objective:

Within four years of implementation start date, workforce will have resources for interventions and follow up support for women, children, adolescents and adults identified as needing services.



- Identify a system of support to assist the workforce with assisting into treatment and follow-up
  - Survey insurers on treatment coverage and initiate discussions on standardization of coverage
  - Identify services provided in the state to assist women in getting treatment
  - Identify and expand existing services for treatment based on areas within state
  - Create a list of home visitation models in communities to assist with coordination of treatment and encourage active participation
  - Develop treatment resource list for workforce
  - Provide training for professionals in the latest research and treatment for women
  - Provide targeted culturally specific training, treatment and intervention information to providers of services to populations of color
  - Encourage all health care providers to include interventions and treatment options into their treatment plans
  - Michigan Department of Health and Human Services to provide trainings on characteristics of FASD, ways to obtain a diagnosis if necessary, and reach out to the Department of Human Services foster care system for co-trainings
  - Determine potential Community Mental Health involvement through Access Center under the intellectual/developmental disabilities diagnosis or serious emotional disturbance eligibility for participants in pilot
  - Work with Probate Court and Community Mental Health to develop care plan for youth involved in the juvenile justice system
- Determine and assure treatment and intervention by providers with staff who are able to communicate with special population
- Plan and establish with two communities a system of support linkages for alcohol consuming pregnant women



# APPENDIX: Michigan FASD Activities and Accomplishments

1976	• First FAS case diagnosed in Michigan.
1988	• First National Conference for Parents of Children with FAS and Fetal Alcohol Effects, St. Joseph Mercy Hospital, Ann Arbor, MI.
1992	• Michigan Department of Public Health published "The Michigan Task Force on Drug Exposed Infants: Final Report".
1997	• FAS pilot project was established for early identification and referral, Washtenaw County, MI.
1999	• Seven FASD diagnostic centers were established in Michigan's upper and lower peninsulas.
2000	•The Interagency FAS Task Force was established in Macomb County, MI.
2002	• United States Substance Abuse and Mental Health Services FASD Regional Town Hall Meeting was held in Newaygo, MI.
2006	<ul> <li>The American College of Obstetricians and Gynecologist (ACOG) published "FASD Prevention Tool Kit - Drinking and Reproductive Health" Chair, Dr. Robert Sokol, MD FACOG, Wayne State University.</li> <li>Michigan FASD Task Force Strategic Plan, 2006-2011, developed with technical assistance from FASD Center for Excellance.</li> <li>Michigan Department of Health and Human Services, Bureau of Family, Maternal and Child Health implemented ten FASD Community-Based Prevention and Intervention mini-grants in upper and lower peninsula.</li> </ul>
2008	<ul> <li>Michigan Department of Health and Human Services, Maternal Infant Health Program (MIHP) implemented statewide alcohol risk identification screening tool for use during pregnancy and post-partum.</li> <li>Centers for Disease Control and Prevention, Great Lakes FASD Regional Training Center was established in collaboration with the State of Michigan.</li> </ul>
2009	<ul> <li>Michigan Department of Health and Human Services Bureau of Substance Abuse and Addiction Services implemented a statewide policy for FASD screening and education in substance abuse treatment programs that serve women.</li> </ul>
2010	<ul> <li>FASD Early On Service Coordinator Guidelines were completed in collaboration with the Michigan Department of Education, Michigan Department of Health and Human Services and FASD Task Force.</li> <li>The FASD International Conference was co-sponsored by Great Lakes Center for Disease Control Regional FASD Training Center and Michigan Department of Health and Human Services, Sault Saint Marie, MI.</li> </ul>
2011	<ul> <li>The Center for Disease Control and Prevention Great Lakes FASD Regional Training Center, the Michigan Department of Health and Human Services and Michigan Department of Education Early On co-sponsored a five-day statewide conference, Training Other Trainers &amp; Research Update, designed for medical and allied health providers, Lansing, MI</li> <li>The State of Michigan Interagency Strategic Plan, 2012-2014, developed with technical assistance from the FASD Center for Excellence.</li> </ul>
2012	•The Public Health Code was amended to allow reports of FASD through age 12 years in the Michigan Birth Defects Registry; expanded diagnostic reporting outside of hospitals.

2013

• FASD Regional Conference featuring keynote speaker Dr. Ken Jones, MD, Ann Arbor, MI; breakout session with State FASD Coordinator featuring Innovative Community-Based Projects serving Latino, African American and Native American communities.

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