MICHIGAN FETAL ALCOHOL SPECTRUM DISORDERS TASK FORCE STRATEGIC PLAN: OCTOBER 1, 2006-SEPTEMBER 30, 2011

Executive summary:

In July and August 2006, the Michigan Fetal Alcohol Spectrum Disorders (FASD) Task Force developed a strategic plan to provide focus and direction for its efforts. Task Force members developed a vision and mission statement and identified seven goals to address. Each goal has identified strategies and activities that will be initiated by the Task Force. The plan is designed to be comprehensive and encompassing of both prevention and treatment for FASD across the lifespan.

The vision of the Task Force is: Coming together to address Fetal Alcohol Spectrum Disorders through awareness, prevention and access to services. 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 and improving service delivery systems. Decreasing these preventable disorders and enhancing quality of life for affected individuals and their families will lessen the social and economic impact of FASD in Michigan.

The seven goals contained in the plan are: 1) Increase awareness of FASD and gain public and private support for decreasing the number of pregnant women who drink alcohol; 2) Expand and improve timely lifelong service access and delivery statewide to individuals who have FASD and their families; 3) Increase identification and diagnosis of individuals who have FASD; 4) Improve the education system's response to students who have FASD; 5) Determine and monitor the incidence and prevalence of FASD in Michigan; 6) Improve the justice system's response to individuals who have FASD; and 7) Expand, increase the diversity of and strengthen the Task Force.

Rationale:

There is a tremendous need for the State of Michigan to have a comprehensive strategic plan to address the needs and issues surrounding Fetal Alcohol Spectrum Disorders (FASD). Alcohol is the most commonly used teratogen in the western world[1] and prenatal exposure to alcohol is a leading preventable cause of birth defects and childhood disabilities in the United States.[2] It is estimated that *at least* 1,274 infants affected by prenatal exposure to alcohol were born in Michigan last year.[3,4] FASD is not a condition that is outgrown. The physical and behavioral problems that can result from prenatal exposure to alcohol last a lifetime. It is estimated that the national costs for care and treatment from individuals with Fetal Alcohol Syndrome may be up to $6 billion each year.[5] In light of these needs, the Michigan FASD Task Force has committed to taking action to facilitate the prevention of future alcohol exposed pregnancies and to guide service providers in the provision of appropriate care and treatment for those already affected.

Task force history:

The Michigan FASD Task Force first convened in January 2004. The Task Force has 32 members, representing 17 individual organizations, including representatives from various state level programs, community level FASD advocates, as well as individuals and families affected by FASD. Task Force meetings are held quarterly. Task Force members have worked to initiate several activities to improve the prevention and treatment of FASD. A pilot project was initiated by Task Force members to use photographic screening software to identify children entering foster care in Cass and St. Joseph counties for the possibility of having Fetal Alcohol Syndrome. Another Task Force member advocated within her organization to implement a

policy to direct state funded substance abuse treatment providers to provide education to clients about FASD and screening of children whose mothers were in treatment.

In the year and a half that the Task Force had met, much had been accomplished. The Task Force established a firm network of committed participants and was ready to undergo the process of developing a strategic plan to further guide and direct its activities.

Overview of the planning process and participants:
The Task Force contacted the SAMSHA FASD Center of Excellence to request technical assistance for the development of a strategic plan. Sharon Dorfman, ScM of SPECTRA was engaged to facilitate the strategic planning process. Two in person meetings and one conference call were held in July and August 2006 to develop the plan. Participants were recruited from existing Task Force members as well as additional groups not currently represented on the Task Force. Efforts were made to include representatives from public health, mental health, education, corrections, child welfare, faith communities, academia, policy makers, family groups and advocacy organizations.

Thirty-nine individuals were involved in the planning meetings. Each seven hour meeting was highly productive. The first meeting provided highlights of FASD needs and resources in Michigan, development of a SWOT (strengths, weaknesses, opportunities, threats) analysis, drafting of a vision statement, selection of key words for mission statement and identification of goals in consensus listing order. Strategic planning participants and all members of the Task Force were emailed copies of draft documents so they would have an opportunity to review them and provide feedback on the plan. Prior to the second meeting, a small group from the Task Force participated in a conference call to make revisions to the vision, mission statement and goals based upon feedback submitted by Task Force members. The second meeting focused on work in small goal-specific groups to propose champions, five-year strategies, first-year activities, and activity leads and partners. The next step for the Task Force will be to transition to implementation of the plan. The Task Force will need to design a group infra-structure, as well as develop dissemination and evaluation plans for the strategic plan.

Participants
Susan Ball, Michigan Protection and Advocacy Service (MPAS)
Shelly Bania, Community Assessment Referral & Education (CARE)
Connie Black-Pond, Southwest Michigan Children's Trauma Assessment Center (CTAC)
Michael Bray, Wayne State University/Developmental Disabilities Institute
Mary Browning, Parent Support Parents
Ann Carrellas, Association for Community Advocacy (ACA)
Mary Chaliman, Dept of Human Services (DHS)
Sara Chase, Children's Hospital of Michigan
Charisse Cossu-Kowalski, Macomb County Fetal Alcohol Resource Education and Support (MCFARES)
Audrey Craft, Michigan Department of Community Health (MDCH)
Charles & Nicola Crumb, Task Force Members
Joan Ehrhardt, Michigan Department of Community Health (MDCH)
Sherry Fernandez, Association for Community Advocacy (ACA)
Carole Flevaris, Michigan Department of Community Health (MDCH)/WIC
Heidi Gibbons, LMAS District Health Department
Maurice Hills, Michigan Department of Corrections (MDOC)

Cindy Horenstein, Salvation Army Harbor Light System
Sarah Horton Bobo, Michigan Department of Community Health (MDCH)/SEMHA
John Jokisch, Michigan Department of Community Health (MDCH)/CMH Services
Sandra L. King, Detroit Dept of Health and Wellness Promotion (DDHWP)
Cheryl Lauber, Michigan Department of Community Health (MDCH)
Marvin McKinney, WK Kellogg
Peggy McNeilly-Martin, Mecosta-Osceola Intermediate School District (MOISD)
Carolyn Morado, University of Michigan FAS Diagnostic and Intervention Clinic
Beth Morgan, Wayne State University (WSU)/Mott Center
Marybeth Novak, Catholic Human Services
Mary O'Connor, Northwest FAS Task Force
Audrey Roozeboom, Michigan Rehabilitation Services (MRS)
Amelia Siders, Ph.D., Northern Michigan Fetal Alcohol and Trauma Assessment Center
Melissa Sienkiewicz, Community Assessment Referral & Education (CARE)
Betsy Soden, Parents Supporting Parents
Vern Soden, Parents Supporting Parents
Karen Twa, Marquette General Hospital (MGH)
Joyce Washburn, Michigan Department of Community Health (MDCH)/ODCP
Jackie Wood, Michigan Department of Education (MDE)
Barbara Wybrecht, Spectrum Health
Rob Wybrecht, Task Force Member
Joan Zech, Macomb County Health Department

VISION:
Coming together to address Fetal Alcohol Spectrum Disorders through awareness, prevention and access to services

MISSION:
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 and improving service delivery systems. Decreasing these preventable disorders and enhancing quality of life for affected individuals and their families will lessen the social and economic impact of FASD in Michigan.

FIVE-YEAR GOALS:
I. Increase awareness of FASD and gain public and private support for decreasing the number of pregnant women who drink alcohol

II. Expand and improve timely lifelong service access and delivery statewide to individuals who have FASD and their families

III. Increase identification and diagnosis of individuals who have FASD

IV. Improve the education system's response to students who have FASD

V. Determine and monitor the incidence and prevalence of FASD in Michigan

VI. Improve the justice system's response to individuals who have FASD

VII. Expand, increase the diversity of and strengthen the Task Force

FIVE-YEAR STRATEGIES AND ACTIVITIES:

I. **Increase awareness of FASD and gain public and private support for decreasing the number of pregnant women who drink alcohol**

A. **Strategies to be initiated in Fiscal Year 2007**

1. Advocate for the inclusion of FASD in substance abuse treatment programs

   a. **Fiscal Year 2007 activity:** Finalize the state policy/advisory that will require inclusion of FASD information in substance abuse treatment programs
   b. *Future activity: Include the finalized policy in 2008 contracts*
   c. *Future activity: Share the finalized policy with private sector providers*

2. Advocate with medical professionals to include FASD presentations in their delivery of health care to women of childbearing age

   a. **Fiscal Year 2007 activity:** Conduct a pilot project in Detroit to identify and screen women at risk of an alcohol-exposed pregnancy)
   b. **Fiscal Year 2007 activity:** Approach medical and nursing associations to explore ways to includes FASD education in medical graduate training and professional development programs

3. Advocate with the Michigan Department of Education (MDE) to identify how and where to place prevention information in grades 3 through 12 and parent education curricula

   a. **Fiscal Year 2007 activity:** Meet with assistant superintendents to explore opportunities for inclusion of FASD awareness and prevention in curricula and professional development for teachers
   b. **Fiscal Year 2007 activity:** Advocate for expansion of legislation language in parent education programs to include "prenatal" and "birth"

B. **Strategies to be initiated in Fiscal Year 2008**

1. Advocate for FASD prevention resources to be made available through colleges and universities (e.g., in health clinics, dormitories, fraternity and sorority houses)

2. Place information about FASD into media and technology streams

C. **Strategies to be initiated in Fiscal Year 2009**

1. Advocate with decision-makers in public health programs (e.g., WIC, HIV) to more effectively educate their clients about FASD

2. Gain the support of key private sector groups to facilitate changes related to FASD prevention and services (e.g., employment, warning labels, new product development)

    a. *Future activity: Develop a partnership to work with Michigan Rehabilitation Services to approach private sector groups*
    b. *Future activity: Identify individuals in the private sector whose lives have been touched by FASD to help champion change*

D. **Strategy to be initiated in Fiscal Year 2010:** Educate legislators about FASD and their impact on business, crime and education

    1. *Future activity: Develop educational packets*

    2. *Future activity: Develop a network of individuals to meet with legislative staff about the materials*

II. Expand and improve timely lifelong service access and delivery statewide to individuals who have FASD and their families

A. **Strategies to be initiated in Fiscal Year 2007**

1. Increase training of wrap-around service providers

    a. **Fiscal Year 2007 activity:** Offer training at annual conferences
    b. **Fiscal Year 2007 activity:** Explore eligibility for wrap-around services available to individuals with FASD
    c. **Fiscal Year 2007 activity:** Develop a standard of care for FASD based on the wrap-around model

2. Conduct an environmental scan of services provided

    a. **Fiscal Year 2007 activity:** Survey task force members
    b. **Fiscal Year 2007 activity:** Identify barriers

3. Identify and publicize parent support groups

    a. **Fiscal Year 2007 activity:** Contact identified groups
    b. **Fiscal Year 2007 activity:** Survey the Yahoo group
    c. **Fiscal Year 2007 activity:** Contact PACs, ARCs, United Way, MP&A, Bridges 4 Kids and Project Perform to include and post information on websites)

B. **Strategy to be initiated in Fiscal Year 2008:** Identify ways to build FASD specialists in agencies

C. **Strategy to be initiated in Fiscal Year 2009:** Identify ways to increase parent mentors and parent partnerships

III. Increase identification and diagnosis of individuals who have FASD

A. **Strategies to be initiated in Fiscal Year 2007**

1. Implement standardized screening in women and children's substance abuse specialty program

    a. **Fiscal Year 2007 activity:** Develop policies and procedures required to use prescreen
    b. **Fiscal Year 2007 activity:** Communicate requirement of prescreen to service providers
    c. **Fiscal Year 2007 activity:** Identify trainers to educate service providers

2. Develop educational materials for post-screening (e.g., pamphlet, resource book)

    a. **Fiscal Year 2007 activity:** Identify existing materials
    b. **Fiscal Year 2007 activity:** Revise and modify existing materials
    c. **Fiscal Year 2007 activity:** Determine cost and distribution

3. Expand capacity of existing diagnostic services

    a. **Fiscal Year 2007 activity:** Identify unknown providers
    b. **Fiscal Year 2007 activity:** Assess current clinic capacity and resource needs to expand

C. **Strategies to be initiated in Fiscal Year 2008**

1. Advocate for standardized screening in foster care

2. Advocate for standardized screening in WIC

IV. Improve the education system's response to students who have FASD

A. **Strategies to be initiated in Fiscal Year 2007**

1. Advocate for mandated yearly FASD trainings for Intermediate School Districts and local SEAs

    a. **Fiscal Year 2007 activity:** Invite more representatives from the Michigan Department of Education to join the Task Force
    b. **Fiscal Year 2007 activity:** Offer continuing education credits to professionals who attend the trainings

2. Advocate for FASD to have their own educational label

a. **Fiscal Year 2007 activity:** Engage parents of children who have FASD as advocates for label change with local PAC

3. Find ways to qualify children now for special education services

4. Continue advocacy within the educational system to assure that children who have FASD receive appropriate support and services

B. **Strategies to be initiated in Fiscal Year 2008**

1. Advocate for changes in teachers' and others' certifications and in college/university curricula to include training on FASD

   a. *Future activity: Search for people in the Michigan Department of Education and explore connections to impact certification and curriculum changes*
   b. *Future activity: Pilot test the Western Michigan University's introductory curriculum that includes FASD education.*

2. Provide strategies to schools for appropriately responding to behavioral and instructional challenges of children who have FASD

V. Determine and monitor the incidence and prevalence of FASD in Michigan

A. **Strategies to be initiated in Fiscal Year 2007**

1. Identify systems that are involved with and sources of data

   a. **Fiscal Year 2007 activity:** Explore the WIC database as a source of diagnostic information
   b. **Fiscal Year 2007 activity:** Identify Department of Human Services foster care data sources and any means to link them with other data
   c. **Fiscal Year 2007 activity:** Develop a workgroup of data managers to determine parameters to study
   d. **Fiscal Year 2007 activity:** Draft a data design for the full range of sources: e.g., Meconium study, PRAMS, FIMR, BRFSS
   e. **Fiscal Year 2007 activity:** Engage devoted epidemiologist time

2. Increase the age of reportability of FASD to 8-10 years

   a. **Fiscal Year 2007 activity:** Review goal and process
   b. **Fiscal Year 2007 activity:** Set agenda with accountable people

B. **Strategy to be implemented in Fiscal Year 2008:** Improve reliability of birth certificate data on alcohol use during pregnancy

C. **Strategy to be implemented in Fiscal Year 2009:** Develop a surveillance program for FASD in Michigan

VI. Improve the justice system's response to individuals who have FASD

A. Strategies to be initiated in Fiscal Year 2007

1. Implement screening tool in Department of Corrections residential settings

   a. **Fiscal Year 2007 activity:** Use prescreen at Great Lakes Recovery Center on a pilot basis
   b. **Fiscal Year 2007 activity:** Train staff at Great Lakes
   c. *Future activity: Incorporate FASD screen into Department of Corrections provider contracts*

2. Identify interested justice system professionals

   a. **Fiscal Year 2007 activity:** Identify and contact people sympathetic to knowing more
   b. **Fiscal Year 2007 activity:** Identify interested peoples' preference for disseminating information
   c. *Future activity: Contact Disability Law Clinic*

VII. Expand, increase the diversity of and strengthen the Task Force

A. Strategies to be initiated in Fiscal Year 2007

1. Identify resources to get more people to attend Task Force meetings

   a. **Fiscal Year 2007 activity:** Publicize through one or more websites
   b. **Fiscal Year 2007 activity:** Create an awareness and education display for conferences
   c. **Fiscal Year 2007 activity:** Establish a Task Force listserv
   d. **Fiscal Year 2007 activity:** Arrange continuing education credits for Task Force meetings

2. Develop an organizational structure for accomplishing Task Force goals

   a. **Fiscal Year 2007 activity:** Develop a workgroup to determine appropriate subgroup structure
   b. **Fiscal Year 2007 activity:** Identify funding and other needed resources, e.g., grant from MDO, Substance Abuse and Mental Health Administration (SAMHSA)

B. **Strategy to be initiated in 2007:** Foster partnership relationships with broad representation

C. **Strategy to be initiated in 2008:** Assure education of all Task Force members in current FASD information

E. **Strategy to be initiated in 2010:** Create a statewide FASD organization

Appendix A
MICHIGAN FASD RESOURCES

STATE FASD COORDINATOR:

Michigan Department of Community Health
109 E. Michigan Ave, PO Box 30195
Lansing, MI 48912
Contact: Cheryl Lauber, D.P.A., M.S.N.
lauberc@michigan.gov
(517) 335-8884

DIAGNOSTIC CLINICS:

Children's Hospital of Michigan, Department of Genetics
3901 Beaubien
Detroit, MI 48201
Phone: 313-993-3891
Contact: Ellen Podeszwa, Coordinator
epodeszwa@dmc.org

Department of Psychiatry and Behavioral Neurosciences Wayne State University
71 West Warren
Detroit, MI 48207
Phone: 313-875-8550
Contact: Sandra Jacobson, Ph.D.
sjacobs@med.wayne.edu

Marquette General Hospital: Women and Children's Specialty Clinic
580 West College Avenue
Marquette, MI 49855
Phone: 906-225-4777
Contact: Sue Britton, Coordinator
sbritton@mgh.org

Northern Michigan Children's Assessment Center
1000 Hastings
Traverse City, MI 49686
Phone: 231-947-8110
Contact: Marybeth Novak, Coordinator
marybeth_novak@yahoo.com

Seminole Medical Center Department of Pediatrics
461 W. Huron Street

Pontiac, MI 48341
Phone: 248-857-7245
Contact: Colleen Noble, MD

Southwest Michigan Children's Trauma Assessment Center - WMU
1000 Oakland Drive
Kalamazoo, MI 49008
Phone: 269-387-7073
Contact: Connie Black-Pond, Coordinator
ctac@wmich.edu

Spectrum Health Genetics Services
21 Michigan Street
Suite 465
Grand Rapids, MI 49503
Phone: 616-391-2319
Contact: Barbara Wybrecht, Coordinator
Barbara.Wybrecht@spectrum-health.org

University of Michigan Medical Center - Developmental and Behavioral Pediatrician
1924 Taubmann Center
1500 East Medical Center Dr.
Ann Arbor, MI 48109-0318
Phone: 734-936-9777
Contact: Marie Heys, Coordinator
mlheys@umich.edu

ON-LINE FASD SUPPORT GROUPS:

Families and Supports Affected by FASD (for MI) http://groups.yahoo.com/group/FaSAFASD/

Adopt FAS (for families who have adopted) http://groups.yahoo.com/group/AdoptFASD2/

FAS Forum http://health.groups.yahoo.com/group/FASForum/

Fetal Alcohol Syndrome Resources http://health.groups.yahoo.com/group/FASResource/

RAD/FASD Kids http://groups.yahoo.com/group/RAD_FASDkids/

LENDING SERVICES (books, videos):

Michigan Resource Center, Phone: 517-882-9955 Toll Free: 1-800-626-4636
info@michiganresourcecenter.org
Services include distribution of printed materials, a free loan video library, a free loan resource library including research journals for professionals, electronic information searches, and

technical assistance to community groups and coalitions.

Spaulding for Children, 16250 Northland Drive, Suite 120, Southfield, MI 48075; 248-443-0300; Janice King oversees FAS resources

Guidance Center Family Resource Center, 15601 Northline Road, Southgate, MI 48195; 734-785-7705 x7725;

WEBSITES:

FAS Community Resource Center http://come-over.to/FASCRC/

National Organization on Fetal Alcohol Syndrome http://www.nofas.org/

Iceberg Newsletter http://www.fasiceberg.org/

FAS Family Resource Institute http://www.fetalalcoholsyndrome.org/index.html
Teaching Students with Fetal Alcohol Syndrome/Effects
http://www.bced.gov.bc.ca/specialed/fas/

Living with Childhood Illness and Disability (great site to help organize information)
http://www.cshcn.org/resources/living.cfm#firesafety

Foetal Alcohol Syndrome Aware UK http://www.fasaware.co.uk/

Fetal Anomalies – Demos http://www.fhs.mcmaster.ca/pblonline/fas.htm

FASD Support Network of Saskatchewan, Inc.
http://www.skfasnetwork.ca/Network%20Resources%20&%20Materials.html

Appendix B
References

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Date: August 2006