

Building a Collaborative Partnership to Address Fetal Alcohol Spectrum Disorders

“Putting the Pieces Together for Children & Families”

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Overview of today's presentation

- **Overview of FASD**
- **Background of FASD efforts in NYS**
- **PIES: the FASD Subcontract & Lessons Learned**
- **Tips for Collaboration**
- **Resources**

What is FASD?

- **An umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.**
- **These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.**
- **Not intended as a clinical diagnosis.**

What Is Fetal Alcohol Syndrome (FAS)?

- **One of the diagnoses used to describe birth defects caused by alcohol use while pregnant**
- **Characterized by certain facial features**
- **Only represents a small group of individuals**
- **FAS is not necessarily more severe than other levels of prenatal alcohol exposure**
- **Is a medical diagnosis (760.71) in the International Classification of Diseases (ICD)**

FASD and the Brain

- **Prenatal alcohol exposure causes brain damage. Affected brain structures include:**
 - **Corpus callosum**
 - **Basal ganglia**
 - **Frontal lobes**
 - **Hippocampus**
 - **Amygdala**
- **Effects of FASD last a lifetime.**
- **People with FASD can function well in life - if they have the proper supports**

What causes FASD?

- **Maternal consumption of alcohol during pregnancy**
- **Alcohol is a teratogen**
- **All alcoholic beverages are harmful**
- **Binge drinking is particularly harmful**
- **There is no proven “safe” level during pregnancy**

Number of People With an FASD?

No one knows for certain how many individuals are born each year with an FASD or how many individuals are living with an FASD

It is estimated that 1 in 100 live births are affected by prenatal alcohol exposure

Incidence rates of other disorders in the spectrum (e.g., FAE, ARND) have been estimated to be 6 to 10 times the rates of FAS

Primary Disabilities in Persons With an FASD

- **Lower IQ**
- **Impaired ability in reading, spelling, and arithmetic**
- **Lower level of adaptive functioning; more significantly impaired than IQ**

Overall Difficulties for Persons With an FASD

- **Taking in information**
- **Storing information**
- **Recalling information when necessary**
- **Using information appropriately in a specific situation**

Secondary Disabilities in Persons With an FASD

- **Mental health issues**
- **Disrupted school experience**
- **Trouble with the law**
- **Inappropriate sexual behavior**
- **Confinement in jail or treatment facilities**
- **Alcohol and drug problems**
- **Dependent living**
- **Employment problems**

Systems of Care Encountering Persons With FASD

- Education
- Child welfare
- Mental health
- Developmental disabilities
- Vocational services
- Juvenile and adult justice systems
- Substance abuse services
- Housing
- Physical health

The Economic Cost of FASD

- **FAS cost \$5.4 billion in the U.S. in 2003.**
- **Lifetime health costs for an FAS birth can range from \$860,000 to \$4.2 million.**
- **Potential savings from preventing the birth of one child with FAS is \$850,000.**
- **If a successful intervention costs less than \$850,000 per birth prevented, it is considered “cost-effective.”**

Lewin Group (2003)

FAS Annual Costs by State, 2004

Alabama	\$59.0	Kentucky	\$26.1	North Dakota	\$13.2
Alaska	\$11.3	Louisiana	\$54.3	Ohio	\$178.5
Arizona	\$98.5	Maine	\$26.5	Oklahoma	\$43.7
Arkansas	\$29.7	Maryland	\$71.5	Oregon	\$68.3
California	\$581.3	Massachusetts	\$125.3	Pennsylvania	\$207.3
Colorado	\$78.8	Michigan	\$182.9	Rhode Island	\$20.5
Connecticut	\$52.0	Minnesota	\$107.4	South Carolina	\$61.1
Delaware	\$17.6	Mississippi	\$26.0	South Dakota	\$17.9
Dist. Columbia	\$14.8	Missouri	\$95.7	Tennessee	\$43.7
Florida	\$259.4	Montana	\$17.1	Texas	\$330.3
Georgia	\$96.7	Nebraska	\$30.7	Utah	\$27.0
Hawaii	\$10.4	Nevada	\$46.0	Vermont	\$9.9
Idaho	\$18.3	New Hampshire	\$23.1	Virginia	\$118.3
Illinois	\$226.3	New Jersey	\$97.4	Washington	\$99.3
Indiana	\$102.9	New Mexico	\$22.1	West Virginia	\$15.4
Iowa	\$65.2	New York	\$361.0	Wisconsin	\$133.8
Kansas	\$40.3	North Carolina	\$81.4	Wyoming	\$9.3

Background of FASD efforts in NYS

Prior to this application, NY's efforts on FASD were viewed as uncoordinated or "one-shot" activities

1994 - NOFAS-funded public awareness campaign

1995-2000 - FASSNet Surveillance Project (DOH)

1999 - Statewide FAS conference

2003 - FASD Town Hall Meeting

2004 - Northrop Grumman Subcontract RFP

NYS OASAS application to Northrop Grumman

**Overall Project Goal: Reduce the
number of cases of FASD by
eliminating alcohol consumption
by pregnant women**

The Initiative has Two Phases:

Phase I: November 2004 -- August 2005:

- **Convene a Statewide Task Force**
- **Conduct a Needs Assessment**
- **Develop a Strategic Plan, including an Implementation & an Evaluation Plan**

Phase II: September 2005 -- August 2009**

Subcontractors will:

- **Implement plans**
- **Collect Evaluation data**
- **Document the Implementation process**

****Project is now slated to end March 31,
2007**

Required Scope of Work

Five required elements:

1. **Create state-level administrative focus**
2. **Provide for long-term or sustained funding of FASD services/activities**
3. **Develop FASD policies & procedures**
4. **Integrate FASD Services into service delivery system(s)**
5. **Organize ongoing surveillance and evaluation**

Our Identified Target Audience

- Women of childbearing years
- Pregnant Women
- Women at risk for an alcohol problem

State Rates of Female “At Risk” Drinking

Females age 18-44 years, Past Month Binge or Heavy Drinking

Alabama	12.6%	Kentucky	6.0%	North Dakota	20.7%
Alaska	16.9%	Louisiana	11.3%	Ohio	15.3%
Arizona	17.1%	Maine	20.4%	Oklahoma	12.2%
Arkansas	10.7%	Maryland	12.1%	Oregon	18.8%
California	15.3%	Massachusetts	18.2%	Pennsylvania	17.0%
Colorado	16.0%	Michigan	17.7%	Rhode Island	17.8%
Connecticut	14.8%	Minnesota	20.0%	South Carolina	14.0%
Delaware	20.0%	Mississippi	8.4%	South Dakota	23.6%
Dist. Columbia	21.1%	Missouri	16.1%	Tennessee	7.0%
Florida	15.5%	Montana	19.2%	Texas	13.7%
Georgia	9.9%	Nebraska	17.3%	Utah	10.0%
Hawaii	8.6%	Nevada	19.2%	Vermont	16.1%
Idaho	12.9%	New Hampshire	17.3%	Virginia	15.0%
Illinois	17.0%	New Jersey	11.0%	Washington	15.2%
Indiana	16.2%	New Mexico	11.5%	West Virginia	8.7%
Iowa	22.0%	New York	17.7%	Wisconsin	23.6%
Kansas	14.5%	North Carolina	9.1%	Wyoming	18.7%

PIES: New York's 4-Pronged Approach

- **Policy**
- **Intervention**
- **Education**
- **Surveillance**

Policy: Statewide FASD Prevention Task Force

Representatives from:

- **Five State agencies**
- **Statewide Addictions, Maternal Health and Prevention/Treatment Organizations**
- **Three Intervention Sites (added in Phase II)**
- **FASD “Experts”**
- **Consumers/family members**

Quarterly Meetings in Albany
Advisory role to the Subcontract
Policy & Information-sharing

Task Force Development of 15-point Program & Policy Action Plan

- **Public Awareness**
- **OASAS-Systems Collaboration**
- **Surveillance**
- **Education & Training**

Task Force Selected Three Pilot Sites for our FASD Interventions:

- **OASAS treatment system (Kingsboro Addiction Treatment Center)**
- **Family planning clinic (Planned Parenthood of South Central NY)**
- **Healthy Families NY Home Visiting Program (Buffalo Prenatal Network)**

Each site has a different target population that varies by level of risk for alcohol consumption and effective use of contraception.

Interventions to Prevent Alcohol-Exposed Pregnancies in NYS

- **Motivational Interviewing (based on “Project Choices”)**
- **Alcohol Screening & Brief Interventions (NIAAA)**
- **Referral to Family Planning for More Effective Contraceptive Methods**

Sites are providing FASD education to all clients – men and women – who access their services

Kingsboro Addiction Treatment Center (KATC) (Brooklyn)

Inpatient 28-day Chemical Dependence treatment program

Also houses a discrete 20 bed women's treatment program and a 22 bed women's residence

Funded by: NYS OASAS

Target population: Women in treatment

One of 13 state-operated Addiction Treatment Centers

Intervention strategies: Up to four MI sessions to reduce alcohol consumption and enhance the effective use of family planning (adaptation of "Project Choices")

Lessons Learned (KATC)

- **Use of Motivational Interviewing can be a challenge for traditional addiction treatment counselors**
- **Men and non-child bearing women are also interested in FASD information**
- **Need to plan for ongoing training and staff supervision, if this is a new skill**

Buffalo-Prenatal-Perinatal Network (Buffalo)

System: Healthy Families NY home visiting programs

Funded by: NYS Office of Children & Family Services

Target population: Women at risk for child abuse/neglect -- program promotes positive parenting and healthy childhood outcomes

One of 29 program sites

Intervention strategies: Family Support workers will use T-ACE screening and MI techniques to reduce alcohol consumption (for non-pregnant women) and eliminate alcohol consumption (for pregnant woman), and enhance the use of effective family planning services

Lessons Learned (BPPN)

- **Motivational Interviewing techniques fits well with a strength-based approach to working with families in many problem areas**
- **Demand for the service led to increasing the numbers of trained staff**

Planned Parenthood of South Central New York, Inc. (Binghamton)

System: Reproductive health providers

Funded by: NYS Department of Health

One of 59 family planning service sites at 110 locations

Target population: Women of Childbearing Age

Intervention strategies: Alcohol Screening and Brief intervention for all women having an initial or annual examination; referral to alcohol treatment if indicated

Lessons Learned (PPSCNY)

- **Clinicians will become more comfortable with interventions over time**
- **Women were surprised to learn of their risky drinking levels**
- **Need to plan for ongoing training – especially in light of staff turnover**

Education: Current Efforts

- **Native American**
- **WIC Providers**
- **Juvenile Justice system**

NACASA American Indian Regional FASD Trainings

- **Based on needs identified in “Listening Circles”
Needs Assessment**
- **NY has ten Tribal Nations**
- **Any prevention programming targeting Native
communities must be consistent with their
culture, beliefs and values**
- **Subcontractor: Native American Council on
Alcoholism & Substance Abuse Inc.
www.nacasa.org**

Impact of FASD on the Juvenile Justice System

- To assist juvenile justice professionals working with youth affected by FASD
- Based on “Tools for Success” curriculum developed by the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)
- Piloted in New York State in July 2006
- Shortened & Modified curriculum for use by NY professionals
- Partnership with 4 systems on Ad-Hoc Workgroup
- Pilot & roll-out trainings in 6 regions during January – February 2007

Efforts with WIC Providers

- **WIC System managed by the NYS Department of Health**
- **250 program sites serving 100,000+ women annually**
- **Mini-trainings to WIC Regional Coordinators to educate & assess need/knowledge/interest**
- **Statewide teleconference planned for April '07**
- **Distribution of FASD English & Spanish rack cards**

Surveillance

- **Subcontract Goal: Organize FASD surveillance and evaluation and make recommendations for improvement**
- **Interagency Workgroup Convened in Phase II to examine existing surveillance systems:**
 - **CMR - Birth Defects Registry**
 - **Statewide surveys to identify Alcohol Consumption among Women of Childbearing Age**
 - **Statewide surveys to identify Alcohol Consumption among Pregnant Women**

Other activities to build Infrastructure

- **Launch of OASAS FASD web pages**
- **Targeted mailings of resources during national FASD observances**
- **Survey of OASAS Providers re: FASD needs**
- **Provision of “free” trainings for system partners**
- **Designation of FASD State Coordinator**

Ten “Tips” to Create Partnerships

- Take “baby steps”
- Find a champion
- Leverage existing resources
- Collaboration is on-going
- Conduct Needs Assessment
- Involve families
- Use the media
- Maximize on existing opportunities
- Remember political considerations
- Find ways to thank-people!

Resources

- **Federal**
- **State**
- **Local community**

Internet Resources

- **NYS Office of Alcoholism & Substance Abuse Services (NYS OASAS): www.oasas.state.ny.us**
- **SAMHSA FASD Center for Excellence: www.fascenter.samhsa.gov**
- **Centers for Disease Control and Prevention (CDC): www.cdc.gov/ncbddd/fas**
- **National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov**
- **National Clearinghouse on Alcohol and Drug Information (NCADI): www.ncadi.samhsa.gov**
- **National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org**

Any questions? Contact me:

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