

A CALL TO ACTION:

FETAL ALCOHOL SPECTRUM DISORDERS: Awareness, Identification and Intervention for Children in Pennsylvania 2011

**OMHSAS Children's Advisory
November 3, 2011**



Reflects the research, discussion and deliberations of local, national and international researchers and clinicians, and the input of families.

The document provides recommendations to improve FASD awareness, identification, and intervention in Pennsylvania, with the goal of promoting systems of care to address this challenging problem.



Promotes early intervention to increase the possibility of positive outcomes

Encourages all involved stakeholders to implement appropriate strategies for intervening effectively with children with an FASD and their families.

FASD Workgroup

2009: FASD workgroup established by PA Office of Mental Health and Substance Abuse Services, Bureau of Children's Behavioral Health Services

- *Consulting psychologist, Cynthia Christenson, PhD*
- *Two consulting psychiatrists, Gordon Hodas, MD and John Biever, MD*
- *ECMH representative/consultant, Harriet Bicksler*
- *Children's bureau representative, Deborah Hardy, BS*
- *Family representative, Dianna Brocious*

What is FASD?

Fetal Alcohol Spectrum Disorders (FASD), as identified by SAMHSA's FASD Center for Excellence:

...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, behavioral, mental, and/or learning disabilities with possible lifelong implications.

The diagnoses:

- Fetal Alcohol Syndrome (FAS)*
- Partial Fetal Alcohol Syndrome (pFAS)*
- Alcohol Related Neurodevelopmental Disorder (ARND)*
- Alcohol Related Birth Defects (ARBD)*

Fetal Alcohol Syndrome (FAS)

- *Includes all of the following:*
 - *Three facial abnormalities:*
 - *Smooth philtrum*
 - *Thin vermilion*
 - *Small cerebral palpebral fissures*
 - *Growth retardation: height, weight, head circumference*
 - *Central nervous system involvement: cognition, intelligence, attention, behavior, memory, processing, mood, attachment, motor skills, eye-hand coordination, other*

Partial FAS (pFAS)

*Some but not all the features of FAS are present:
facial features, physical birth defects, growth
retardation and central nervous system deficits*

Alcohol-Related Neurodevelopmental Disorder


- *ARND refers to various neurological abnormalities such as functional or cognitive impairments linked to prenatal alcohol exposure, including decreased head size at birth, structural brain abnormalities, and a pattern of behavioral and mental abnormalities.*
- *Children with ARND have central nervous system deficits but not all the facial features of FAS. Their problems may include sleep disturbances, attention deficits, poor visual focus, increased activity, delayed speech, and learning disabilities.*

NOFAS: <http://www.nofas.org/resource/CAP.aspx>

Alcohol-Related Birth Defects

ARBD describes defects in the skeletal and major organ systems. Virtually every defect has been described in some patient with FAS. They may include abnormalities of the heart, eyes, ears, kidneys, and skeleton, such as holes in the heart, underdeveloped kidneys, and fused bones.

NOFAS: <http://www.nofas.org/resource/CAP.aspx>



This is not only a “women’s issue.” It is one for which all of us, women and men, mothers and fathers, families and communities need to take responsibility.

(Institute of Health Economics Consensus Statements, Government of Alberta, Vol. 4, Oct. 7-9, 2009)

Pennsylvania

FASD Executive Task Force

2006: Department of Health, Bureau of Drug and Alcohol Programs, created a stakeholder FASD workgroup of parents, advocates, physicians, researchers, service providers, nurses, and government policy makers

Vision statement:

To prevent new occurrences of FASD in Pennsylvania and provide access to support and services to affected individuals and their families

Mission statement:

To educate the citizens of the Commonwealth of Pennsylvania on the dangers of drinking during pregnancy and to enhance a system of care for individuals and their families

Pennsylvania FASD Action Plan

- *Completed in 2007, the plan defines steps that need to be taken to improve identification, diagnosis, treatment and prevention of FASD in a measurable and meaningful way*
- *Areas of focus for action steps include:*
 - *Awareness*
 - *Education*
 - *Systems*
 - *Data*
 - *Funding*

Primary Focus of FASD Workgroup

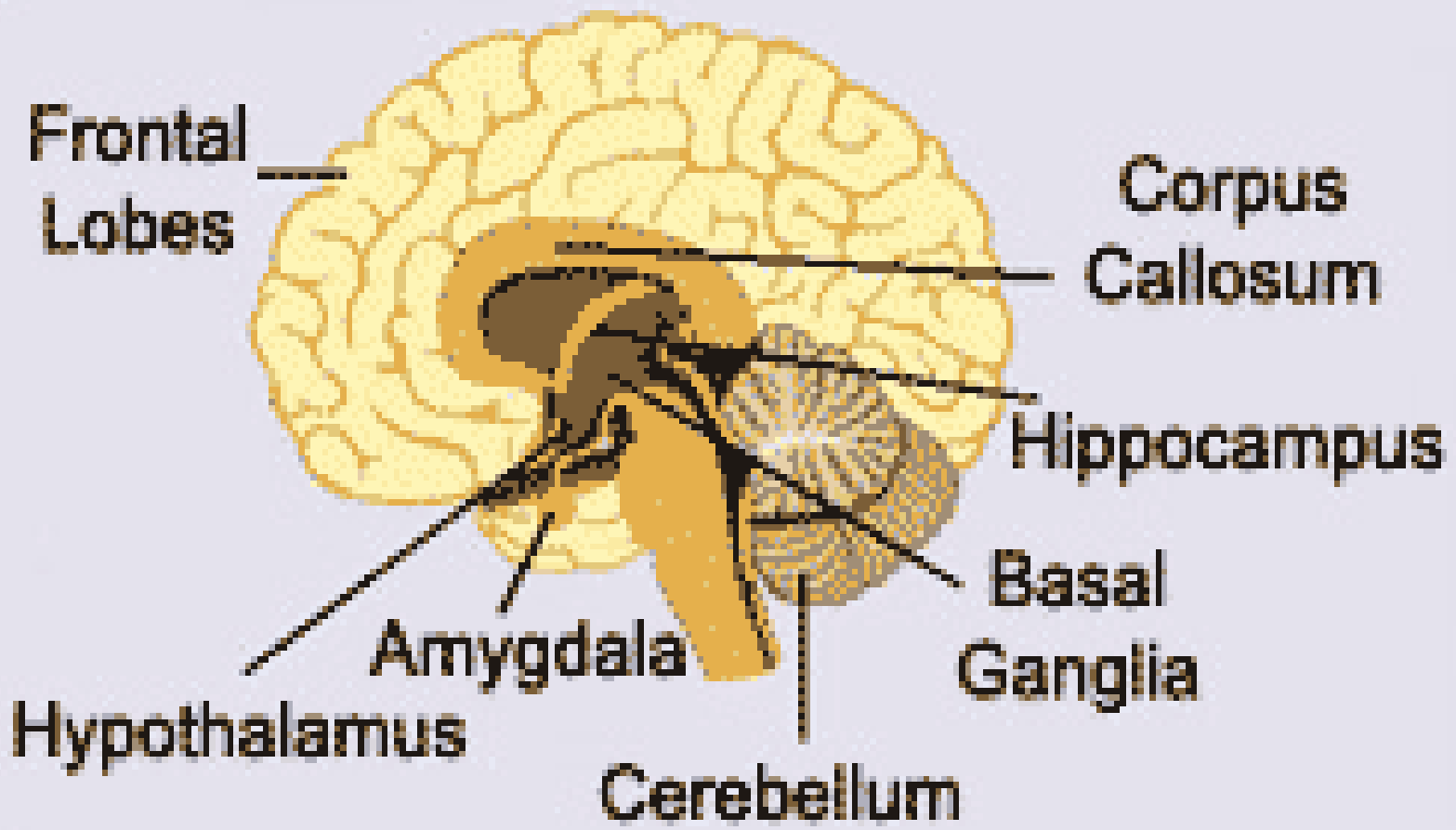
- **Awareness**
 - *Guide policy through development of an FASD Impact Paper*
 - *Utilize multi-media resources to inform all stakeholders*
- **Prevention of secondary disabilities**
 - *Provide youth and families in behavioral health services with education, supports and resources to reduce risk of secondary affects to individuals with an FASD and reduce risk of new occurrences of alcohol-exposed pregnancies*
- **Treatment/intervention**
 - *Guide practice through providing resources, training, and education to all stakeholders*

Relevant Facts and Statistics

- *FASD - “the leading known preventable cause of mental retardation and birth defects” (National Organization on Fetal Alcohol Syndrome, NOFAS)*
- *FAS prevalence: between 0.5 - 2 per 1,000 births, US*
- *FASD, much more prevalent, estimated to affect at least 40,000 newborns each year – 1 in 100 births, US*
- *PA yearly estimates: 291 FAS births, and 1,165 FASD births, for combined total of 1,456 births per year*

From a study of 80 birth mothers of children with FAS:

- *23.8% had foster parents*
- *17.5% lived in group home*
- *35 had been in a juvenile detention center*
- *22.5% were involved with Child Protective Services as a child*
- *80% had birth children who had been in foster care or Child Protective Services*
- *57.5% were sexually abused as a child*
- *46.2% were physically abused as a child*
- *51.3% were sexually abused as an adult*
- *85% were physically abused as an adult*
- *86.3% were emotionally abused as an adult*
- *95% were sexually and/or physically abused at some time*



Regarding Amount of Alcohol...

There's no safe amount, however...

Binge drinking is especially hazardous because:

- *Women who binge prior to pregnancy are more likely to have unwanted pregnancies*
- *Exposure to high levels of blood alcohol is especially likely to cause teratogenicity in the first trimester*

Primary Effects of FASD

- *Learning impairments, especially mathematics and reading comprehension*
- *Communication difficulties, including the lack of the ability to comprehend verbal and written concepts*
- *Memory problems*
- *Problems with decision-making*
- *Impulsivity*
- *Difficulty with cause-and-effect reasoning, which may contribute to difficulty in learning from experience, resulting in poor judgment and repetition of the same mistakes over and over*

Strengths of Children with an FASD

- *Friendly and outgoing*
- *Verbal*
- *Helpful*
- *Affectionate and lovable*
- *Well-intentioned*
- *Generous*
- *Determined*
- *Artistic*
- *May be intelligent, mechanical, and athletic*

Secondary Effects of FASD: Causes

- *Adverse experiences of children*
 - *In substitute care – poor fit in foster home, superimposed on prior neglect or abuse, impaired attachment, multiple placements*
 - *Lack of family and community stability*
 - *Parental substance abuse or mental illness*
 - *Abuse, neglect, domestic violence*
 - *Poverty, unstable housing, lack of opportunity*
 - *Lack of community safety and safety net*
 - *Bullying, community violence*
- *Cumulative frustration of parents, child, others*

FASD Over Lifespan: Specific Secondary Effects

- *Disrupted attachment with primary caregivers*
- *At risk of physical abuse and traumatic brain injury*
- *Possible development of reactive attachment disorder*
- *Mental health problems*
- *Substance use or abuse*
- *Incarceration or mental health hospitalization*

More Secondary Effects of FASD

- *Disrupted school experience*
- *Legal problems, including incarceration*
- *Sexual victimization, or sexually inappropriate behavior*
- *Victimization due to suggestibility or gullibility*
- *Difficulty maintaining employment and unemployment*
- *Inability to live independently*

Protective Factors

- *Early diagnosis and effective interventions*
- *The most protective environmental factors against secondary disabilities are:*
 - *Living in a stable and nurturing home of good quality*
 - *Not having frequent changes of household*
 - *Not being a victim of violence*
- *Two intrinsic characteristics are associated with a higher level of secondary disabilities:*
 - *Having FASD rather than FAS*
 - *Having an IQ above 70, rather than below*

“Red Flags”

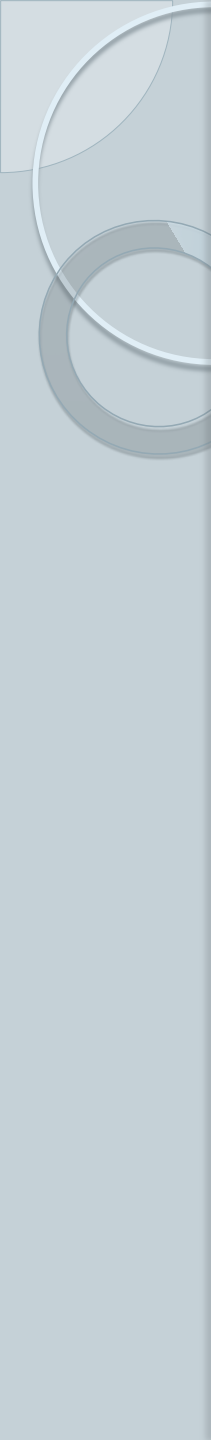
- ❖ *The child has been excluded from another preschool program for behavioral issues*
- ❖ *The child requires “hands on” or visual learning, rather than auditory*
- ❖ *The child is easily fatigued and overwhelmed by external stimulation*
- ❖ *The child has problems applying what has been learned*
- ❖ *The child is a concrete thinker and does not understand metaphors or jokes, etc.*
- ❖ *The child has been diagnosed with a mental health disorder as a preschooler, such as ADHD, oppositional defiance, or bipolar disorder*
- ❖ *The child responds to immediate feedback rather than distant consequences such as point or reward systems*
- ❖ *The child has received multiple diagnoses and has a history of failed interventions, which may include medication and treatment*

Possible Co-occurring DSM disorders for Individuals with an FASD across all ages.

- *Attention Deficit/ Hyperactivity Disorder*
- *Depression*
- *Bipolar Disorder*
- *Schizophrenia*
- *Substance use disorders*
- *Medical disorders (i.e. seizure disorder, heart abnormalities)*
- *Sensory integration disorder*
- *Reactive Attachment Disorder*
- *Posttraumatic Stress Disorder*
- *Traumatic Brain Injury*
- *Borderline Personality Disorder*

Principles for Intervention:

- *Support the family*
- *Collaborate and partner with the family*
- *Provide Information about FASD*
- *Help the child function more effectively*



Recognize that the person will function within systems differently:

“We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed.”

Dubovsky, 2000

Basic Strategies for Individualized Treatment

- *Consistent routines*
- *Limited stimulation*
- *Concrete language and examples – one direction at a time*
- *Multi-sensory learning (visual, auditory and tactile)*
- *Realistic expectations- acknowledge developmental deficits or cognitive impairments*
- *Supportive environments – build upon strengths*
- *Supervision – one to one*

Source: NOFAS FASD Interventions

Dubovsky

Recommendations

- *Distribute Call to Action and develop a public awareness campaign highlighting the needs of children and adolescents with an FASD*
- *Increase awareness and knowledge of Pennsylvania program offices, counties, managed care companies, providers, and families*
- *All child serving systems should develop a coordinated FASD awareness and training plan*

Recommendations

- *Screen and assess for FASD including learning impairments, cognitive impairments, differential functioning skill levels, and all mental health needs*
- *Support the use of specialized assessment processes including neuropsychological testing when indicated*
- *Behavioral Health providers should ensure that medical and developmental histories of the family are obtained and documented*

Recommendations

- *Utilize a multidisciplinary approach to identification and intervention of an FASD*
- *Develop an array of effective intervention and treatment approaches for children and their families*
- *Develop a life long service model – modeling, mentoring and monitoring*

Recommendations

- *Current Behavioral Health providers should develop specialized services to support and treat children with an FASD*
- *Adolescents and their families should receive developmentally appropriate supports and services for transition to adulthood*
- *Information about FASD should be included in curriculums of higher education*

Recommendations

- *Support families affected by FASD by:*

Develop a Pennsylvania National Organization of Fetal Alcohol Syndrome website (NOFAS)

Family network and peer support

Respite and alternative family support models to prevent out of home placements

Resources

- **BEAMS:** The Fasstar Trek Method:
<http://www.comeover.to/FAS/BEAM.htm>
- **The Eight Magic Keys for Teachers:**
<http://www.fasdcenter.samhsa.gov/documents/eightmagickeys.pdf>
- **SCREAMS:** <http://www.come-over.to/FAS/ScreamsArticle.htm>
- **SAMHSA:**
http://www.fasdcenter.samhsa.gov/documents/FASDGuideI2_01
- **4 Digit Code** – Washington State University:
<http://depts.washington.edu/fasdpn/index.htm>

Resources

- **NOFAS:** <http://Nofascolorado.org/fasfaq.htm>
- **Colorado Screening tool for Pregnant Women:**
http://www.coloradoguidelines.org/pdf/guidelines/sbirt/fasd_supplement_8-26-10.pdf
- **Canada – Diagnostic Guidelines:**
<http://www.phacaspc.gc.ca/fasdetaf/cdnguidelines-eng.php>
- **Canada –Calgary Ministries:** <http://www.fasdlane.com/>
- **Florida:**
<http://www.doh.state.fl.us/family/socialwork/pdf/fasd.pdf>
- **Alaska:** www.hss.state.ak.us/fas/

Assessments for Infants and Children

- Recommended Evaluation Tools:
(Please read the articles on [Early Intervention for Infants with FAS](#) first)
- [Bayley Scales of Infant Development](#) for cognitive and motor evaluations from ages 0-2.
- [K-ABC is useful for cognitive evaluations](#) for children ages 3-5.
- [Peabody Individual Achievement Test-Revised \(PIAT-R\)](#) measures scholastic achievement in children, grades K-12.
- [Vineland Adaptive Behavior Scales](#) for children of all ages is essential to measure functional abilities and life skills.

Source: FAS Community Resource Center, FAStar

<http://come-over.to/FASCRC/>