

Beyond Condemnation and Shame

Improving Awareness and Treatment of Children with Fetal Alcohol Spectrum Disorders and Co-Occurring Psychiatric Disorders

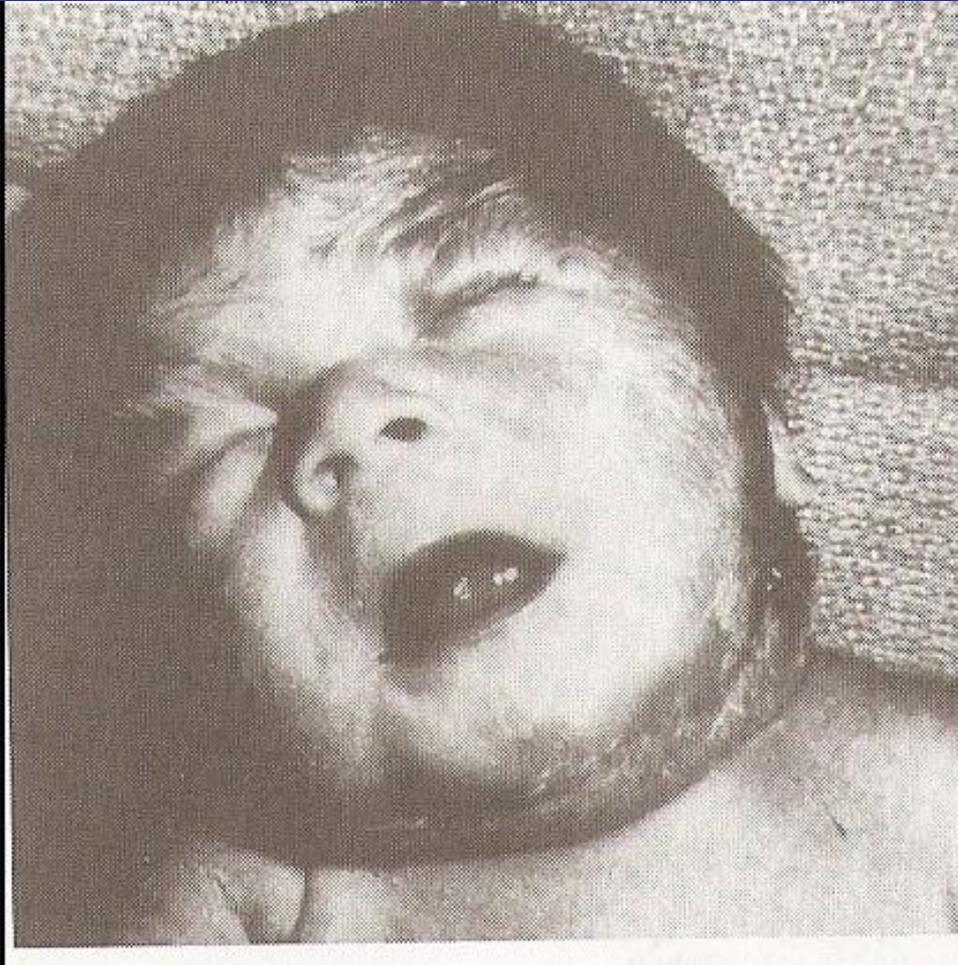
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Challenges to FASD Diagnosis and Treatment

- The Stigma of Alcoholism
- The Difficulty of Diagnosis and Lack of Professional Awareness of FASD
- Between Systems: The Absence of FASD-specific Intervention Programs
- Diverse Advocates (biological parents, foster care)
- Culturally Sanctioned Alcohol Promotion versus Public Education

“Each of their mothers was an alcoholic” 1973



Jones, Kenneth L, and David W Smith. "Recognition of the fetal alcohol syndrome in early infancy." *The Lancet* 302.7836 (1973): 999-1001.

Causes of Intellectual Disability

- Fragile X (most common inherited cause of intellectual disability) estimated to affect about 1 in 5,000 males (0.02%)
- Trisomy 21 (most common chromosomal cause of intellectual disability) has a prevalence of 0.14% (0.14/100)
- FASD (most common cause of all intellectual disabilities) estimates range from 0.5-2% of all births (1/100)

The Scope of the Problem

Between 2005 through 2010, on average 7.5 million children—about 10.5 percent of the country's under-18 population—lived with a parent abusing alcohol during any given year (Substance Abuse and Mental Health Services Administration (SAMHSA))

FASD 40 Years Later (1973-2013)

- Why does the diagnosis of FASD remain rare while social drinking during pregnancy is so common?
- Why do so few FASD-specific treatment programs exist?

Identification of
Children with
FASD



Intervention,
Treatment
and
Prevention



The Strange, Sad Tale of Phineas Gage



“The equilibrium or balance, so to speak, between his intellectual faculties and animal propensities, seems to have been destroyed. He is fitful, irreverent, indulging at times in the grossest profanity (which was not previously his custom), manifesting but little deference for his fellows, impatient of restraint or advice when it conflicts with his desires, at times pertinaciously obstinate, yet capricious and vacillating, devising many plans of future operations, which are no sooner arranged than they are abandoned in turn for others appearing more feasible. A child in his intellectual capacity and manifestations, he has the animal passions of a strong man. Previous to his injury, although untrained in the schools, he possessed a well-balanced mind, and was looked upon by those who knew him as a shrewd, smart businessman, very energetic and persistent in executing all his plans of operation. In this regard his mind was radically changed, so decidedly that his friends and acquaintances said he was "no longer Gage."

Developmental Age and FASD

Actual age = 18 years

Skill	Developmental Age Equivalent
Expressive Language=====	20yrs.
Comprehension=====	6yrs.
Money, Time Concept=====	8yrs.
Emotional Maturity=====	6yrs.
Physical Maturity=====	18yrs.
Reading Ability=====	16yrs.
Social Skills=====	7yrs.
Living Skills=====	11yrs.

Source: Adapted from: Research findings of Streissguth, Clarren et al.
Diane Malbin, 1994

Defining Neurobehavioral Characteristics of Children with FASD

- Impaired Executive function (conscious, goal-oriented behavior such as planning, execution, working memory, and inhibition of impulses in pursuit of goals)
- Behavioral dysfunction manifested by deficits in social functioning (aggressive and impulsive behavior)
- Attention and distractibility
- Language (auditory processing disorder, mixed receptive-expressive language disorder)
- Most children have borderline to low average cognitive ability

Kodituwakku , P.W. (2007). Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: a review. *Neurosci. Biobehav. Rev.* 31, 192-201.

The Difficulty of Diagnosis

- Histories of maternal alcohol consumption during pregnancy are often unknown and meconium and hair testing are expensive currently not mandated
- Criteria of fetal alcohol syndrome (facial characteristics, history of alcohol exposure) are not known by most physicians, psychologists and social workers
- Lack of biological markers (sensitive and specific physical findings, blood tests, MRI)
- Lack of sensitive and specific means of diagnosing FASD based upon neurobehavioral phenotype (*children with FASD look like the rest of the psychiatric population*)
- Clinicians and professionals have been reluctant to diagnose their children because there were no known effective treatments.

Histories suggestive of possible prenatal alcohol exposure

- Early placement in foster care (secondary to abuse or neglect, abandonment, termination of parental rights or early death of mother or father)
- Primary guardian other than the child's mother
- Early childhood behavioral and school difficulties
- Low birth weight, miscarriage, developmental delay or sibling born with positive urine toxicology (cocaine), successively poorer pregnancy outcomes
- Family history of alcoholism or substance abuse
- History of domestic violence

Almost two thirds (63%) of children with FASD suffer from at least one psychiatric syndrome that in contrast to physical features of FAS, are long-lasting, pervasive and devastating to development



Steinhausen, Hans-Christoph, and Hans-Ludwig Spohr. "Long-term outcome of children with fetal alcohol syndrome: Psychopathology, behavior, and intelligence." *Alcoholism: Clinical and Experimental Research* 22.2 (1998): 334-338.

Psychiatric Disorders and ADHD

Table 2
Prevalence Rates and Distribution of *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.)
Diagnoses or Specific Behavioral Problems by Level of Gestational Alcohol Exposure

Diagnosis or Problem ^a	Sample Prevalence Rates		Distribution by Level of Risk for Gestational Alcohol Exposure ^b									
	All Participants		No Risk: 1		Unknown: 2		Some Risk: 3		High Risk: 4		Missing Data	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Attention deficit hyperactivity disorder	919	41.2	7	0.8	137	14.9	278	30.3	454	49.4	43	4.7
Learning disorders	382	17.1	5	1.3	50	13.1	136	35.6	175	45.8	16	4.2
Oppositional-defiant/conduct disorder	354	15.9	2	0.6	64	18.1	123	34.7	147	41.5	18	5.1
Anger control problems (age > 3 years)	229	10.3	0	0	46	20.1	57	24.9	117	51.1	9	3.9
Unspecified mood disorder	224	10.0	0	0	36	16.1	79	35.3	98	43.8	11	4.9
Sleep disorder (age > 3 years)	216	9.7	1	0.5	41	19.0	55	25.5	113	52.3	6	2.8
Mental retardation	168	7.5	0	0	26	15.5	43	25.6	93	55.4	6	3.6

a. Only the diagnoses or problems with prevalence >4% are displayed; total *n* = 2,231.

b. Four-digit diagnostic code as described by Astley and Clarren (1999, 2000) was used to determine risk for gestational exposure.

Vinod Bhatara, Roland Loudenberg, and Roland Ellis Association of Attention Deficit Hyperactivity Disorder and Gestational Alcohol Exposure: An Exploratory Study *Journal of Attention Disorders* February 2006 9: 515-522.

Between Systems of Service

- While approximately 50% of children with FASD are have intellectual disability (IQ<70), many children with a diagnosis of FASD are ineligible for special services because their intellectual abilities often fall within the average range of intelligence
- While many children with FASD have co-existing psychiatric diagnoses, these diagnoses lack long-term systems of care compared to those diagnoses such as schizophrenia and bipolar disorder, where long-term models of care exist

The Trajectory of FASD



- 61% have disrupted school experiences
- 60% become involved with the criminal justice system
- 50% are incarcerated
- 49% have inappropriate sexual behaviors
- 35% have drug and alcohol problems

Fetal alcohol syndrome in the United States corrections system

- Of the 3 080 904 offenders, only one offender was reported to have a diagnosis of FAS.
- One program (1.9%) reported having a screening program for FAS in the corrections system.
- Only four programs (7.4%) reported having access to diagnostic services for FAS in the corrections facilities.
- Specialized programs for persons with mental retardation were reported for 44.4% of corrections facilities and 25.9% of community corrections facilities.

Fast, D. and Conry, J. (2004), The challenge of fetal alcohol syndrome in the criminal legal system. *Addiction Biology*, 9: 161–166. doi: 10.1080/13556210410001717042

Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects

Eighty percent of these patients were not raised by their biological mothers. For adolescents and adults, the life span prevalence was 61% for disrupted school experiences, 60% for trouble with the law, 50% for confinement (in detention, jail, prison, or a psychiatric or alcohol/drug inpatient setting), 49% for inappropriate sexual behaviors on repeated occasions, and 35% for alcohol/drug problems. The odds of escaping these adverse life outcomes are increased 2- to 4-fold by receiving the diagnosis of FAS or FAE at an earlier age and by being reared in good stable environments.

The Discovery and Evolution of Fetal Alcohol Syndrome

“The observers of FAS indeed identified an ‘evil which profoundly disturbed them,’...yet their medical expertise granted them no more power to prevent its occurrence or ameliorate its sequelae than anyone else...Yet in assuming that improved outcomes rest on individual change, rather than broader change in the social conditions that put individuals at risk, these clinicians thus made FAS merely a victim-blaming strategy...What they could not cure as physicians, they hoped to banish as moralists.”

Armstrong EM. Diagnosing Moral Disorder: The Discovery and Evolution of Fetal Alcohol Syndrome. Soc. Sci. Med. Vol. 47, No. 12, pp. 2025-2042, 1998

A Moral Disorder?

- Substance Abuse
- Child Abuse and Neglect
- Psychiatric Illness
- Poverty
- Criminal behavior
- Fetal Alcohol Spectrum Disorders (“intra-uterine child abuse”)
- “Good kids who do bad things”

Interventions for Children with FASD

- Children with cognitive and behavioral issues related to prenatal alcohol exposures most often come to the attention of the educational system because of the learning and/or behavioral issues they display, not because they have a known diagnosis of FAS.
- When this happens, schools are mandated under federal law (IDEA) to initiate an assessment of the child's individual abilities and challenges.
- The inclusion of children with special needs within regular classrooms whenever possible (educating children within the least restrictive environment)

Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Research in Developmental Disabilities* 30 (2009) 986–1006

Interventions

Structured, consistent and realistic interventions

- Realistic expectations
- Consistent routines
- Limited stimulation
- Concrete language and examples
- Multi-sensory learning (auditory, visual and tactile)
- Supportive environments
- Supervision

Because of the persistent nature of the impairments associated with prenatal alcohol exposure, there is need for interventions that address the manifestations of these impairments across the entire life-span.

Paley, Blair, and Mary J. O'Connor. "Intervention for individuals with fetal alcohol spectrum disorders: treatment approaches and case management." *Developmental disabilities research reviews* 15.3 (2009): 258-267.

“Tell the boys of New York
Juvenile Asylum that they must
follow Truth, Justice and Humanity
if they wish to become useful and
honorable men.”

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Colleen M. O’Leary, Cate Taylor, Stephen R. Zubrick, Jennifer J. Kurinczuk, and Carol Bower. *Pediatrics* 2013; 132:2 e468-e475; published ahead of print July 8, 2013, doi:10.1542/peds.2012-3002 .

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