

Long term Follow-Up Study of children with FASD in Young Adulthood

Comparison of our „Berlin Study“ to the results of the Final Report of the „Secondary
Disability-Study“ (Streissguth et al, 1997)

**The 3 rd International Conference on Fetal Alcohol Spectrum Disorder
Victoria , March 11th-14th, 2009**

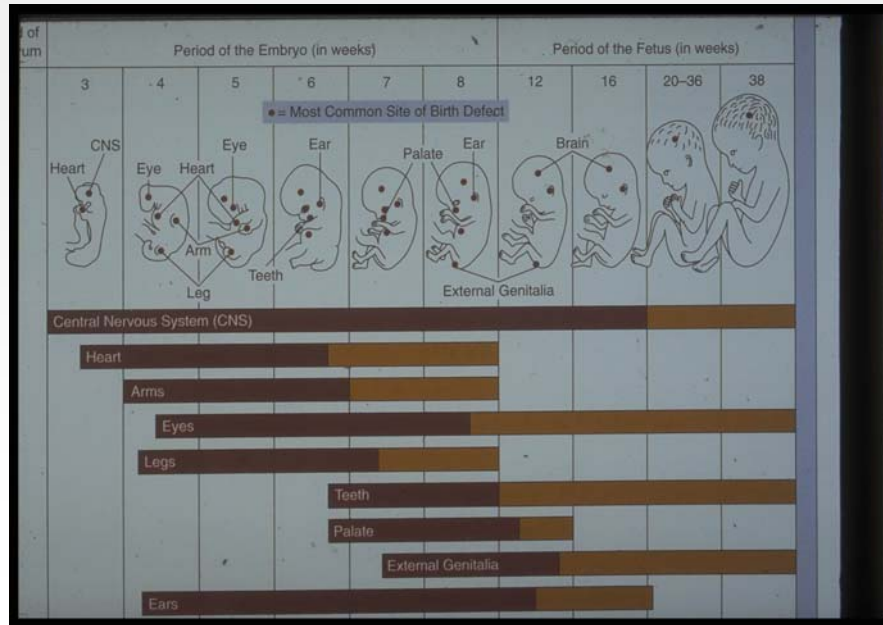
H.Spohr

Alcohol during Pregnancy

In clinical and in animal studies
ethanol is a proven teratogen agent.
In alcohol dependent women during
pregnancy this agent is definitely
capable of creating persistent develop-
mental disturbances and intellectual
disabilities in the offspring.



Critical periods for birth defects



Fetal Alcohol Syndrom (FAS)

Definition:

- Prenatal and postnatal growth deficiency
- CNS-Dysfunction (Neurology, Development, Intelligence)
- Characteristic craniofazial dysmorphic features (2 von a.-c.)
 - a. Microcephaly
 - b. Short palpebral fissures
 - c. Long philtrum / small upper lip / pattern of flattened midface



Sokol & Clarren, Alcoholism, 1989

Fetal Alcohol Effects (FAE)

Definition:

- Clear history of prenatal maternal alcohol exposure
- The child shows two of the three following FAS-criteria:

Prenatal and postnatal growth retardation

CNS-Dysfunction (Neurology, Development, Intelligence)

Craniofacial Dysmorphic Features



Sokol & Clarren, Alcoholism, 1989

Prenatal Alcohol Exposure and Persistent Developmental Consequences:

Berlin Studies

- Prospective Dystrophy-Study n = 47 / 1009 newborns *
- Euromac-Study (participation) n = 6000 newborns **
- 10-years Follow-Up Study n= 60 patients***
- FAS Follow-up Study into Adulthood n= 37 patients****

Since 1977 more than 500 children diagnosed as suffering from FAS/FAE or intrauterine alcohol exposure have been seen and partially reevaluated in our hospital

* Monatsschr Kinderhk 1992 **J Epidemiol 1994 *** Lancet 1993 **** J Pediatr 2007

FAS Follow-up Study into Adulthood

1976-2003 (n=37)

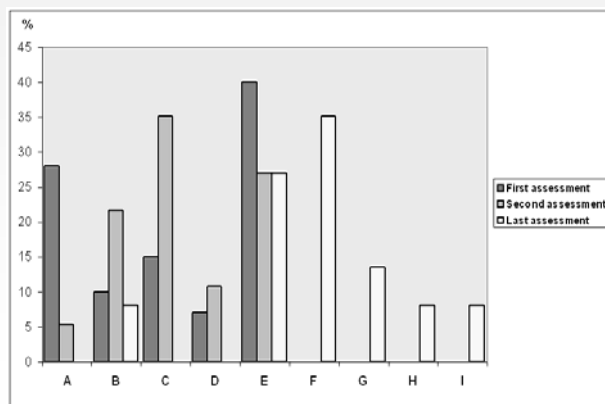
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FAS Follow-up Study into Adulthood (n=37)

Lifetime Domestic Arrangements



- A. Both biological parents
- B. Father and mother surrogate
- C. Foster family
- D. Adoptive Family
- E. Institution
- F. Dependent Living
- G. Independent living
- H. Living with partner
- I. Own family

FAS Follow-up Study into Adulthood (n=37)

Lifetime Domestic Arrangements

	First assessment	Second assessment	Last assessment
Both biological parents	10 (28%)	2 (5.4%)	-
Father plus mother surrogate	4 (10%)	8 (21.6%)	3 (8.1%)
Foster family	6 (15%)	13 (35.1%)	-
Adoptive family	2 (7%)	4 (10.8%)	-
Institution	15 (40%)	10 (27.0%)	10 (27.0%)
Dependent living	-	-	13 (35.1%)
Independent living	-	-	5 (13.5%)
Living with partner	-	-	3 (8.1%)
Own family	-	-	3 (8.1%)
Total	37 (100%)	37 (100%)	37 (100%)

Prenatal Alcohol Exposure and Persistent Developmental Consequences

Follow Up of Intelligence Quotients (n=60)

First examination	Last examination after 10 years					
	Q 115-86	85-71	70-51	50-36	35-21	<20
IQ 115-86 n=19	14	4	1	-	-	-
IQ 85-71 n=19	1	15	2	1	-	-
IQ 70-51 n=11	-	-	3	6	2	-
IQ 50-36 n=3	-	-	-	2	1	-
IQ 35-21 n=7	-	-	-	1	2	4
IQ <20 n=1						

IQ< 70 = 22 / 60

IQ< 70 = 26 /

Persistend Psychopathology

Speech disorders
Abnormal habits/ Stereotypies
Dependency problems
Hyperkinetic disorders

FAS Follow-up Study into Adulthood

Sample (n=37)

	FAS (N=22)	FAE (N=15)	Males (N=20)	Females (N=17)
Age at first assessment				
Mean (years)	3.20	2.34	2.83	2.87
SD (years)	2.76	1.44	1.67	2.98
Age at follow-up				
Mean (years)	24.71 *	21.60	24.07	22.73
SD (years)	3.48	3.30	3.10	4.29
Duration of follow-up				
Mean (years)	21.51 *	19.26	21.23	19.85
SD (years)	2.03	3.30	2.68	2.85

* p < .05

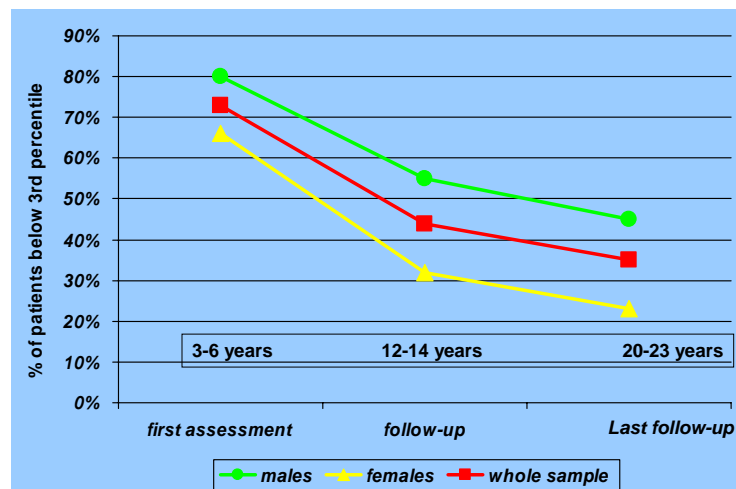
Persistent Paediatric Symptoms at last Follow-up

	% of Children with Feature:	
	Initial Examination	Follow-up
Postnatal growth deficiency	89.2	35.7
Developmental Delay	89.2	40.5*
Microcephaly	91.3	53.2
Thinned upper lip	83.8	89.9
Hyperactivity	63.0	37.8
Maxilla hypoplasia/flat midface	not done	45.9
Small palpebral fissures	not done	21.6

* i.e. mental retardation at last follow-up -

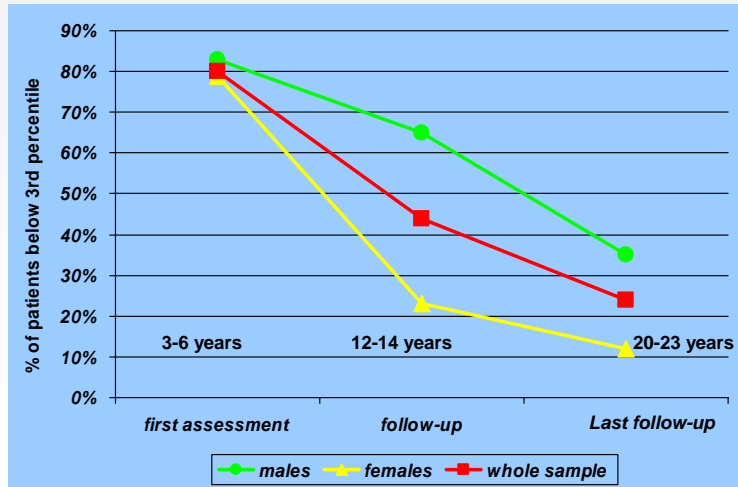
20 Years-Follow-up of Morphometric Variables (N=37)

Height



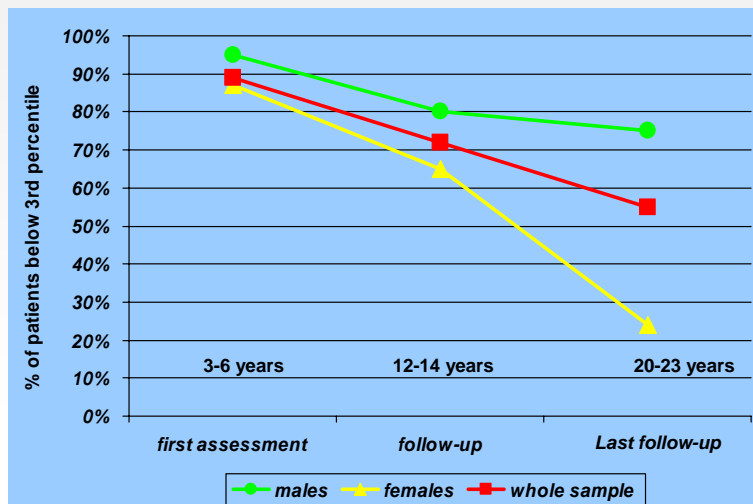
20 Years-Follow-up of Morphometric Variables (N=37)

Weight



20 Years-Follow-up of Morphometric Variables (N=37)

Head Circumference



Treatment

<u>First assessment</u>	N=37
Physiotherapy	15
Occupational therapy	5
Speech & language therapy	3
Perceptual training	3
<u>Last assessment</u>	N=37
Psychological intervention	6
Neuroleptic treatment	5
Anticonvulsive treatment	4
Stimulant treatment	2

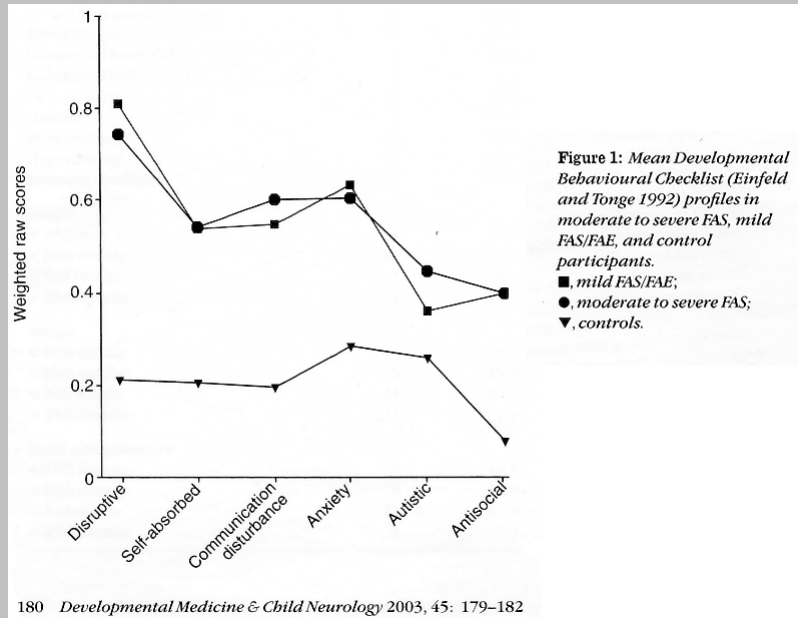
Educational Status (N=36)

	N	%
Secondary school level	5	13.9
Primary school level	13	36.1
Special education level	18	50.0

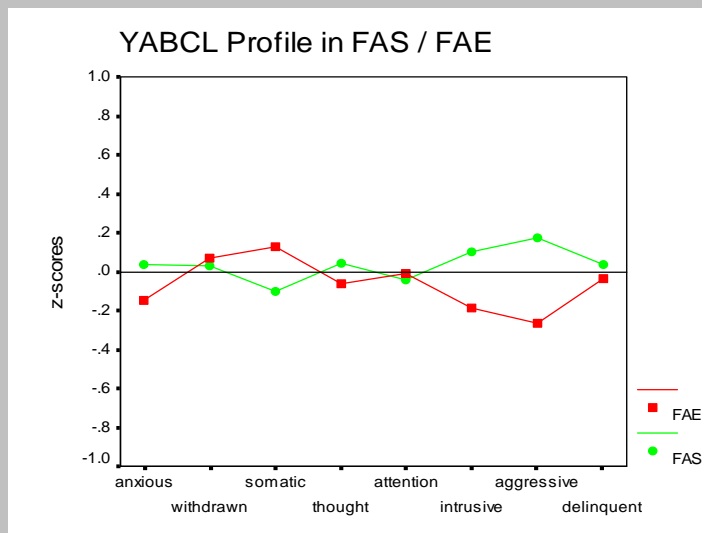
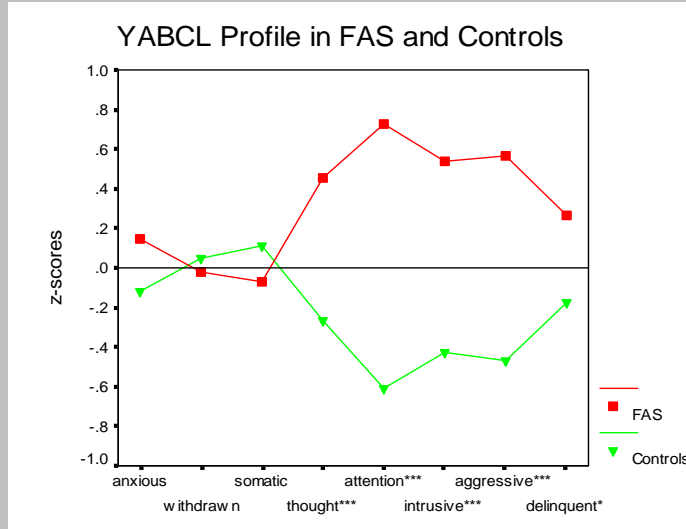
Intelligence by FAS / FAE

	All (N= 37)		FAS (N=22)		FAE (N=15)	
	N	%	N	%	N	%
Q >85	12	32.9	6	27.3	6	40
IQ 71-85	10	26.6	5	22.7	5	33.3
IQ ≤70	15	40.5	11	50.0	4	26.7

Chi²= 2.01; df=2; p=n.s.



Youth Adult Behavior Check List (YABCL)



Psychosocial Functioning

	Total (N=36)		FAS (N=21)		FAE (N=15)	
	N	%	N	%	N	%
Meeting People outside the family						
never	14	37.8	9	42.9	5	33.3
less than once a month	7	18.9	4	19.0	3	20.0
once a week to once a month	10	27.0	5	23.8	5	33.3
more than once a week	4	10.8	3	9.5	2	13.3
Independence						
buying food	11	29.7	7	31.8	4	26.7
buying cloth	13	35.1	7	31.8	6	40.0
repairing small items	10	27.0	6	27.3	4	26.7
financial budget	13	35.1	6	27.3	7	46.7

Occupational Training (N=36)

	N	%
Preparatory Training	25	69.4
school based training for a year	12	32.4
job training workshops	7	19.4
job training in sheltered workshops	9	25.0
Occupational training	21	58.3
certified apprenticeship	13	36.2
apprenticeship without certification	1	2.7
prematurely terminated	7	19.4

*multiple codings due to „Duale Occ.Train.)

Occupational Status

	Total (N=36)	
	N	%
Employed	2	5.6
Temporarily working	1	2.8
Household	2	5.6
Family business	1	2.8
Unemployed	11	29.7
Sheltered workshop	6	16.2
Does not apply (age)	9	25.2
Disabled	4	11.1

Results

School

Primary and secondary school level; (18/37)	49 %
Special education level;(19/37)	51 %

Occupational training (22/36)

Certified apprenticeship; (14/36)	38.8 %
Apprenticeship without certification; (1/36)	2.7 %
Prematurely terminated; (7/36)	19.4 %

Final report to the centers for control and prevention

Seattle 1996, University of Washington (1996)

Streissguth AP, Barr HM, Kogan J, & Bookstein FL.

“Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE)“.

Secondary Disability-Study

Streissguth et al, 1997 (Final report)

Fetal Alcohol and Drug Unit Seattle ,Washington

Age 3-51years (median 14.2 years)

90 patients older than 21 years ; (median 25,6 years)

FAS: m=26; f=27; FAE m=17; f=20;

60% white, 25% Native American, 14% black and hispanic

Secondary disabilities in clients with FAS and FAE”

Ann P. Streissguth et al. 1997

1. Mental health problems
2. Disrupted school experience
3. Trouble with the law
4. Confinement, inpatient psychiatric care
5. Inappropriate sexual behavior
6. Alcohol and drug problems
7. Dependent living
8. Problems with employment, unemployment

FAS Follow-up Study into Adulthood

(Berlin Study I)

All patients were white german kids, living in Berlin and were diagnosed in infancy as

Fetal Alcohol Syndroms (FAS) or

Fetal Alcohol Effects (FAE)

All patients in this long term follow-up study were in care of foster-parents (34) or had been adopted (3).

FAS Follow-up Study into Adulthood

(Berlin Study II)

Usually in Germany neglected children were taken out of the families of chronic alcohol abusing mothers within the first 3 or 4 years of life or postnatally.

Official caretakers are involved in the selection of the foster-parents and were watching the development of all children in their foster-homes up to the age of 18 years.

Educational help usually can be continued beyond this age into young adulthood.

Differences of the two studies

1. S: 90 patients older than 20 years (out of a total study-group of 473 patients) were investigated
B: 37 patients were followed up (1976-2003)
2. S: Cross-sectional study in adulthood (1992-1996)
B: Individual follow-up study from early infancy to adulthood
2. B: All children were living with foster-parents or were adopted
S: We have no detailed informations, but we suppose that in the Seattle-study only few patients were grown up in foster-families

S: Seattle-study

B: Berlin-study

Protective Factors

Streissguth et al, 1997

- Being diagnosed before the age of 6 years
- Living in a stable home for over 70% of life
- Never having experienced violence against oneself
- Staying in each living situation for more > 2.8 years
- Experiencing a good quality home from the age 8-12 years
- Having applied for therapeutic help and assistance
- Having diagnosis of FAS (rather than FAE)
- Having basic needs met for at least 13% of life

Results: Protective Factors

Diagnosis:	35/37 of our patients were diagnosed before the age of 6
Living place:	Stable homes for more than 3 years for all
Good quality-life:	Between 8.-12. year good quality life for all patients
Violence:	10% of our clients experienced physical violence in early childhood and an unknown number of patients suffered from sexual abuse in first years of life
Therapeutic help:	Many have applied for therapeutic help and assistance
Basic needs:	All met basic needs for at least 13% of life

“Secondary disabilities”

Streissguth et al, 1997

1. Mental health problems

90% of FAS/FAE subjects:

- a) 61% ADHD in childhood;
- b) ca.50% clinical Depression in adulthood

2. Disrupted school experience

60% FAS/FAE > 12 years:

- a) due to learning disabilities
- b) due to behavioral disturbance

“Secondary disabilities”

Streissguth et al, 1997

3. Trouble with the law

60% charged or convicted with a crime

- a) 14% in childhood (6-11 years of age)
- b) 58% of all adult clients

4. Confinement

50% of all subjects (> 12 years) experienced:

- a) 23% due to inpatient psychiatric care
- b) 15% inpatient chemical dependency care;
- c) 35% incarcerated for a crime

“Secondary disabilities”

Streissguth et al, 1997

5. Inappropriate sexual behavior

50% older than 12 years.:

- a.) sexual advances
- b.) exhibitionism, voyeurism
- c.) promiscuity

6. Alcohol and drug problems

30% of all FAS/ FAE-subjects older than 12 years,

- a.) FAE > FAS
- b.) age group 21-51 years > als 12-21 yearsJ

“Secondary disabilities”

Streissguth et al, 1997

7. Dependent living

80% needed some sort of assisted living ((group home, living with family or friends)

8. Problems with employment, unemployment

80% needed ongoing job training, could not keep a job or were unemployed

Results

(Berlin Study)

Living place

Independent living; (11/37)	29.5 %
Dependent living; (26/37)	70.5 %

Employment

Employed or earning money (6/37)	16.2 %
Unemployed (31/37)	83.8 %

Berlin Study

Dependent living

70% needed some sort of assisted living ((group home, living with family or friends)

a.) FAS=F AE, m=f (70-73%)

b.) f FAE (70%) < mFAE (100%) !

Problems with employment, unemployment

83% needed ongoing job training, could not keep a job or were unemployed

„You know Mom, we have made it together quite well over 18 years. We had problems, maybe because you thought, I was a healthy child and treated me like that. You really couldn't know that my brain doesn't work just normal.



Letter from Esther to her mother, when she learned her diagnosis of FAS in 2000

Executive Dysfunction (EDF)

- - attention and inhibition
- - task mangement
- - planning
- - monitoring
- - coding

Smith u.Jonides, (1999)

Fetal Alcohol Spectrum Disorder



Fazit

A child born with FAS will suffer from persistent physical, mental and psychiatric disabilities which will handicap this person severely in adolescence and especially in adulthood.

A child born with FAE will suffer from identical lifelong problems but this person often is handicapped by a missing diagnosis !

„Protective factors“ are very important to prevent secondary disabilities!

But they seem to be of limited value to prevent adult FASD-patients of living a dependent life with only a small chance of getting a job.