

WA State FAS Diagnostic & Prevention Network (FAS DPN)



Profiles of 1,400 Patients Evaluated for FASD at the
WA FAS DPN by Interdisciplinary Teams using the 4-Digit Code

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WA State FAS DPN Patient Profile (n = 1,400)

The Washington State FAS DPN electronic clinical / research database was utilized to construct a comprehensive profile of all 1,400 WA State residents (birth through adult) who received an interdisciplinary FASD diagnostic evaluation using the FASD 4-Digit Diagnostic Code at one of the 7 WA FAS DPN clinics in the first 13 years (1993-2005) of operation. All had prenatal alcohol exposure.

WA State FAS DPN Patient Profile (n = 1,400)

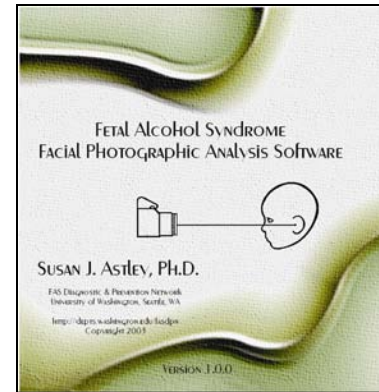
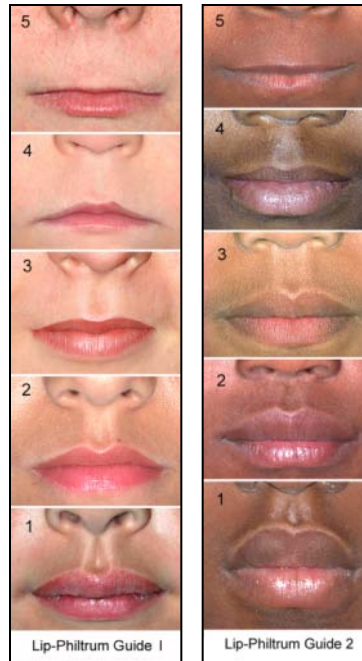
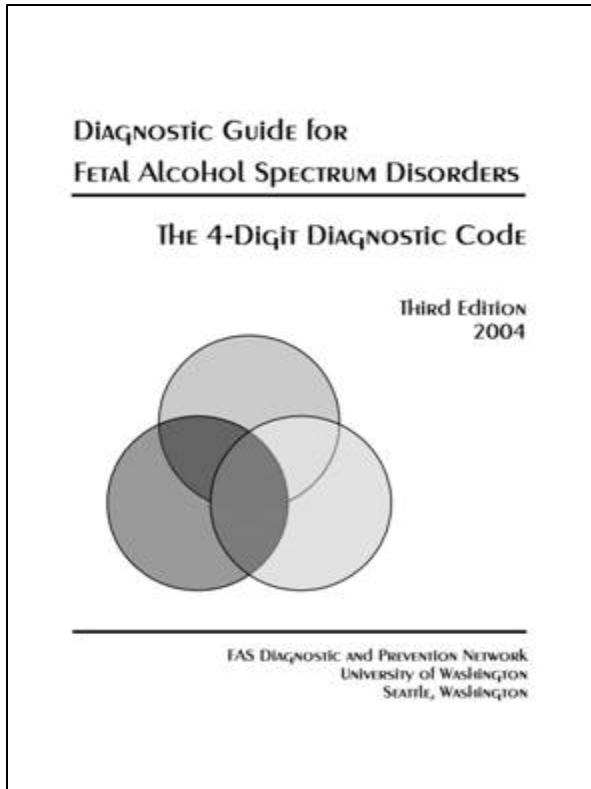
The outcomes are reported in:

Astley SJ. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network.

Can J Clin Pharmacol Vol 17(1) Winter 2010:e132-e164;
March 26, 2010.

www.fasdpn.org/pdfs/astley-profile-2010.pdf

FASD 4-Digit Diagnostic Code



4-Digit Diagnostic Code Grid									
One Example of FAS									
		3 4 4 4							
significant	significant	definite	4	X	X	X	4	high risk	
moderate	moderate	probable	3	X				3	some risk
mild	mild	possible	2					2	unknown
none	none	unlikely	1					1	no risk
Growth Deficiency	FAS Facial Features	Brain Dysfunction		Growth	Face	Brain	Alcohol		Gestational Alcohol

All Diagnostic Tools and Courses available at cost or free on the web.

www.fasdpn.org

Interdisciplinary FASD Diagnostic Team

Team includes:

- Pediatrician
- 2 psychologists
- SLP
- OT
- Social Worker
- family advocate



FASD diagnostic evaluation conducted in one 4-hour appointment.



FASDPN Clinics located statewide.

Core clinic at Center on Human Development & Disability, UW

fasdpn.org

Contact: (206) 598-7666

fasdclin@uw.edu

Abbreviated Case-Definitions of 4-Digit Code

	3	4	3	4		
R a n k	4	≤ 2 %	All 3 features	Structural / Neurological Abnormalities	Confirmed High	4
	3	3 - 5 %	2 features	Severe Dysfunction	Confirmed Moderate	3
	2	6 -10 %	1 feature	Moderate Dysfunction	Unknown	2
	1	> 10 %	No features	No Dysfunction	Confirmed Absent	1
	Growth	Face	CNS	Alcohol		

3434 is one of twelve 4-Digit Codes for FAS

Example of 4-Digit Codes for FAS and PFAS

A FAS (alcohol exposed)

2433	3433	4433
2434	3434	4434
2443	3443	4443
2444	3444	4444

B FAS (alcohol exposure unknown)

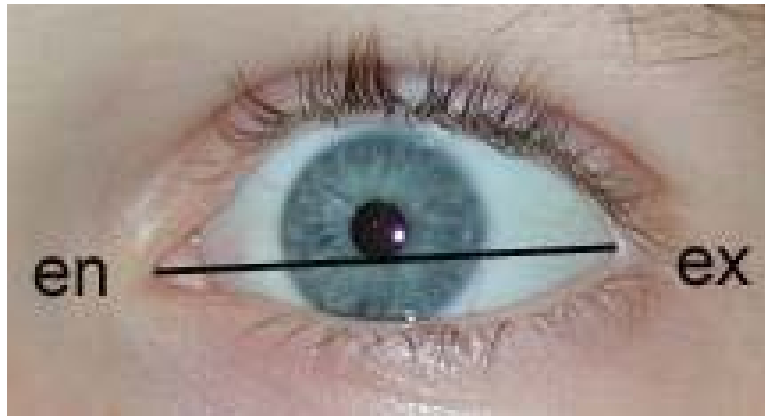
2432	3432	4432
2442	3442	4442

C Partial FAS (alcohol exposed)

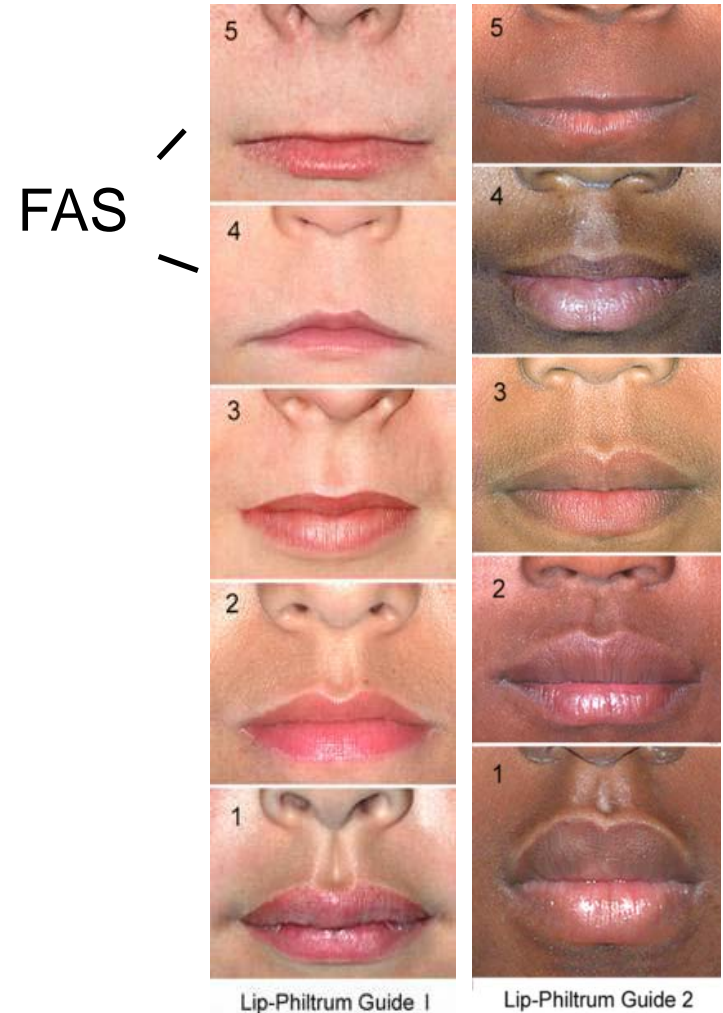
1333	1433	2333	3333	4333
1334	1434	2334	3334	4334
1343	1443	2343	3343	4343
1344	1444	2344	3344	4344

3 Diagnostic Facial Features of FAS

- | | |
|--------------------|--------------|
| 1) Short PFL | ≤ -2 SD |
| 2) Smooth Philtrum | Rank 4 or 5 |
| 3) Thin Upper Lip | Rank 4 or 5 |

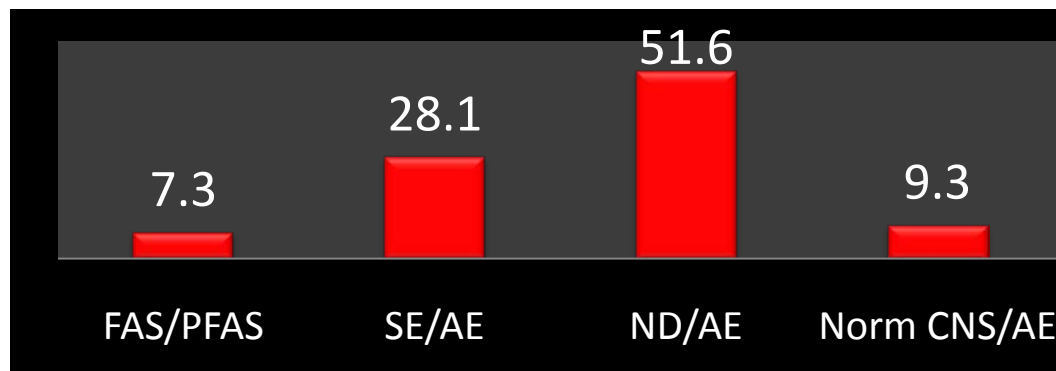


Palpebral fissure length (PFL) =
endoncanthion to exocanthion



FASD Diagnostic Outcomes for 1,400 Patients

4-Digit Code FASD Diagnostic Categories	N	%
A. FAS / Alc Exposed	52	3.7
B. FAS / Alc Unknown	7	0.5
C. PFAS / Alc Exposed	95	6.8
E. Sentinel Physical Findings / Static Encephalopathy / Alc Exposed	95	6.8
F. Static Encephalopathy / Alc Exposed	299	21.4
G. Sentinel Physical Findings / Neurobehavioral Disorder / Alc Exposed	160	11.4
H. Neurobehavioral Disorder / Alc Exposed	562	40.1
I. Sentinel Physical Findings / Alc Exposed	34	2.4
J. No Sentinel Physical Findings or CNS Abnormalities / Alc Exposed	96	6.9



Data Support 3 Distinct FASD Subclassifications based on FASD 4-Digit Code

1. **FAS / PFAS**
Diagnostic Categories A, B, C
2. **SD/AE** (Static Encephalopathy/Alcohol Exposed)
Diagnostic Categories E, F
'severe ARND'
3. **ND/AE** (Neurobehavioral Disorder/Alcohol Exposed)
Diagnostic Categories G, H
'moderate ARND'

Diagnostic Group Abbreviations/Definitions

Diagnostic Groups	FAS Face	CNS	Alcohol
FAS / PFAS	face	severe	alc
SE/AE (severe ARND) Static Encephalopathy/Alc Exposed		severe	alc
ND/AE (moderate ARND) Neurobehavioral Disorder/Alc Exposed		moderate	alc
Normal CNS/AE			alc
Control (from MRI study)			No alc

Two FASD populations are presented throughout these slides:

1. WA FASDPN Clinical population (n = 1,400)
2. MRI FASD study population drawn from the FAS DPN (n = 81)

MRI-fMRI-MRS Study

Primary Hypotheses

The following will differ between children with FAS/D and healthy/unexposed children:

- neuro-structure (size of specific brain structures)
- neuro-function (as measured by psychological, psychiatric, and fMRI assessment)
- neuro-chemistry (neurometabolites: choline and n-acetyl-aspartate)

Are the 4-Digit Code diagnostic categories (FAS, SE/AE, ND/AE) clinically distinct?

MRI-fMRI-MRS Study

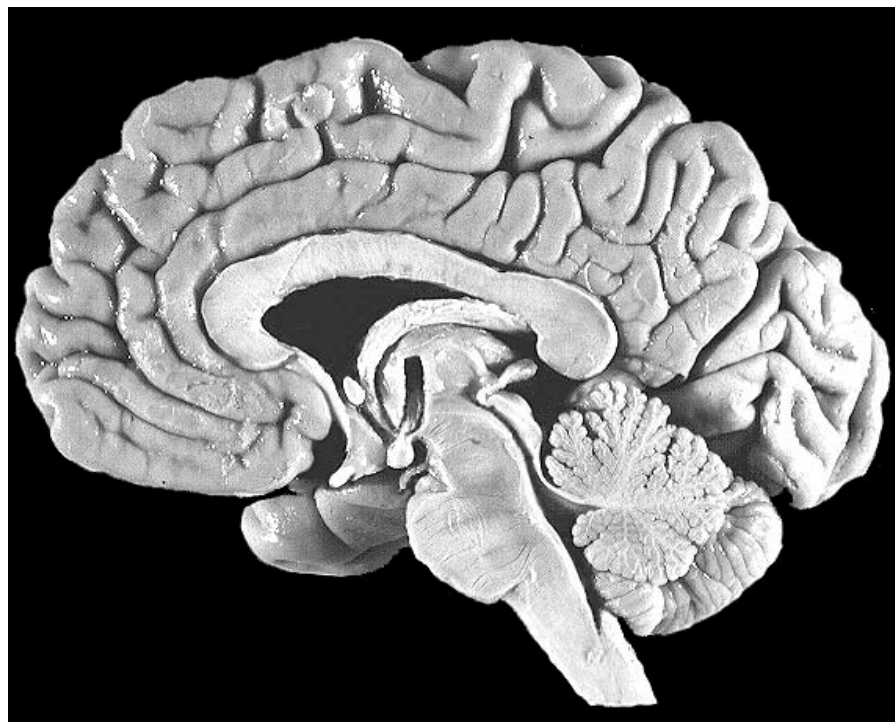
MRI: Structure

Volumes

caudate
putamen
hippocampus
frontal lobe
frontal gray matter
frontal white matter
total brain

Midsaggital Area

corpus callosum
cerebellar vermis
total brain



MRI-fMRI-MRS Study

fMRI: Functional Assessment in the Scanner

Whole brain scan for activity levels while child is participating in a N-back working memory task.

Child is presented photos of faces while in the scanner.

Child responds to task by pushing a button.

0-Back Task

Push the button when you see a man's face.

1-Back Task

Push the button when the face you are looking at matches the face you saw one slide back.

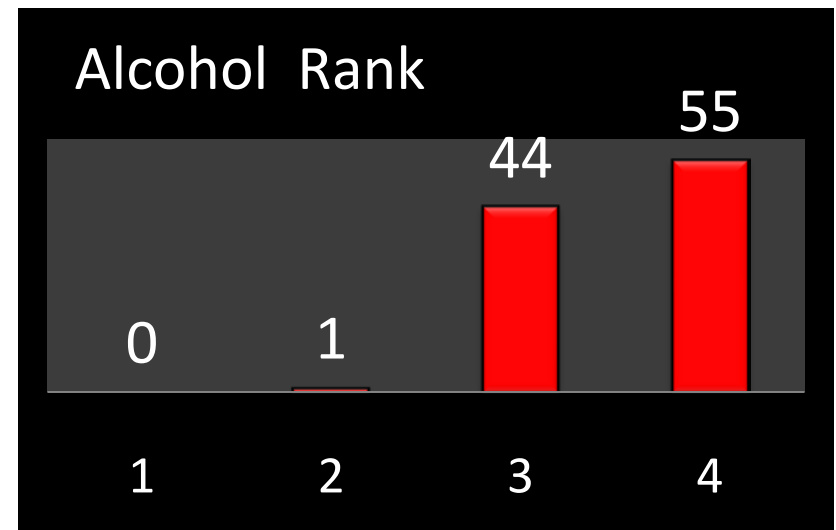
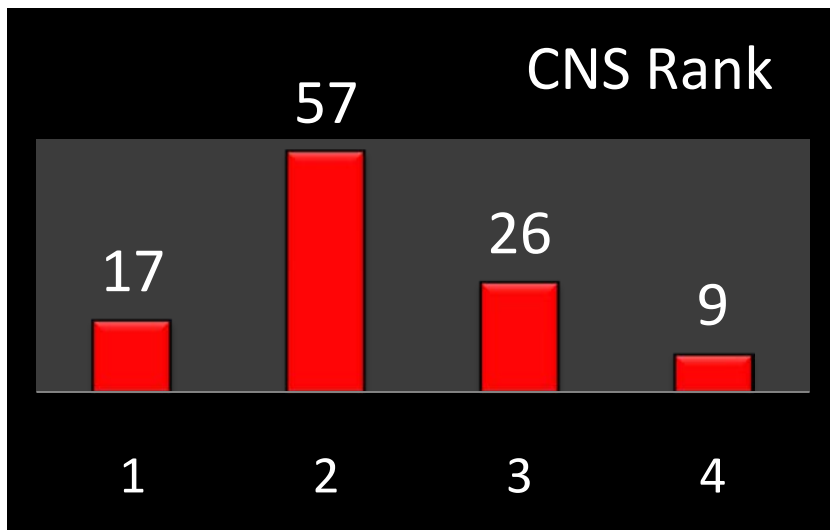
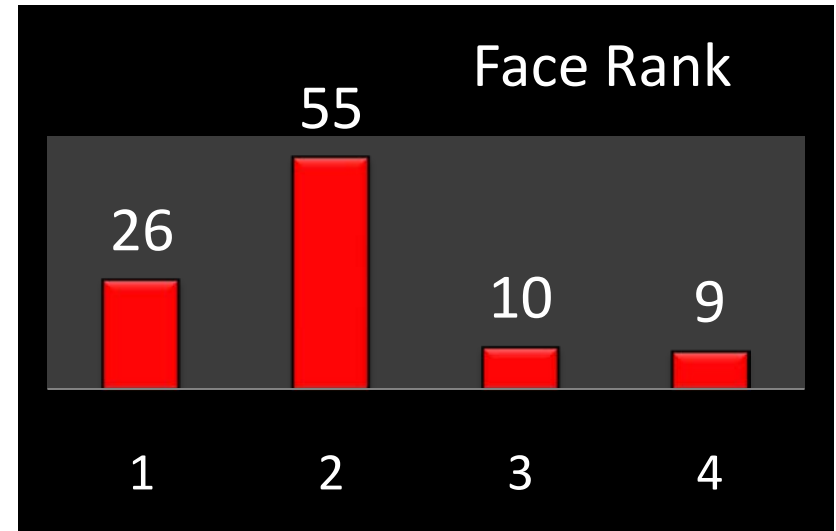
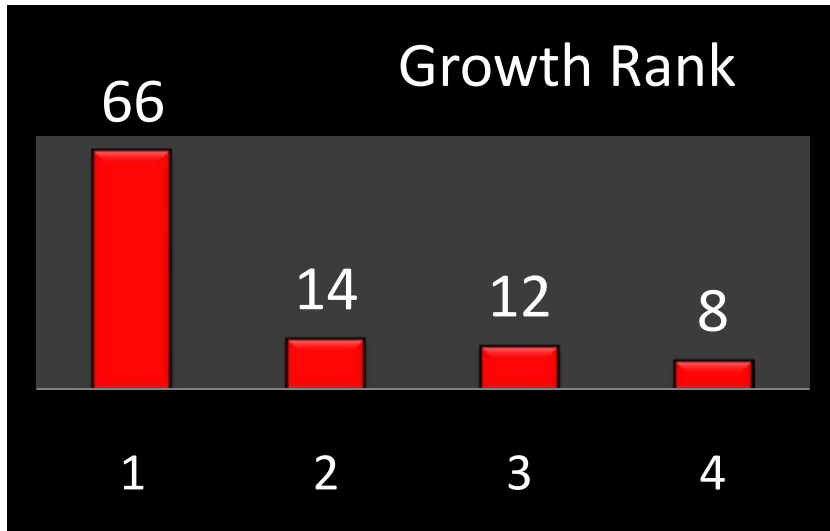
2-Back Task

Push the button when the face you are looking at matches the face you saw two slides back.

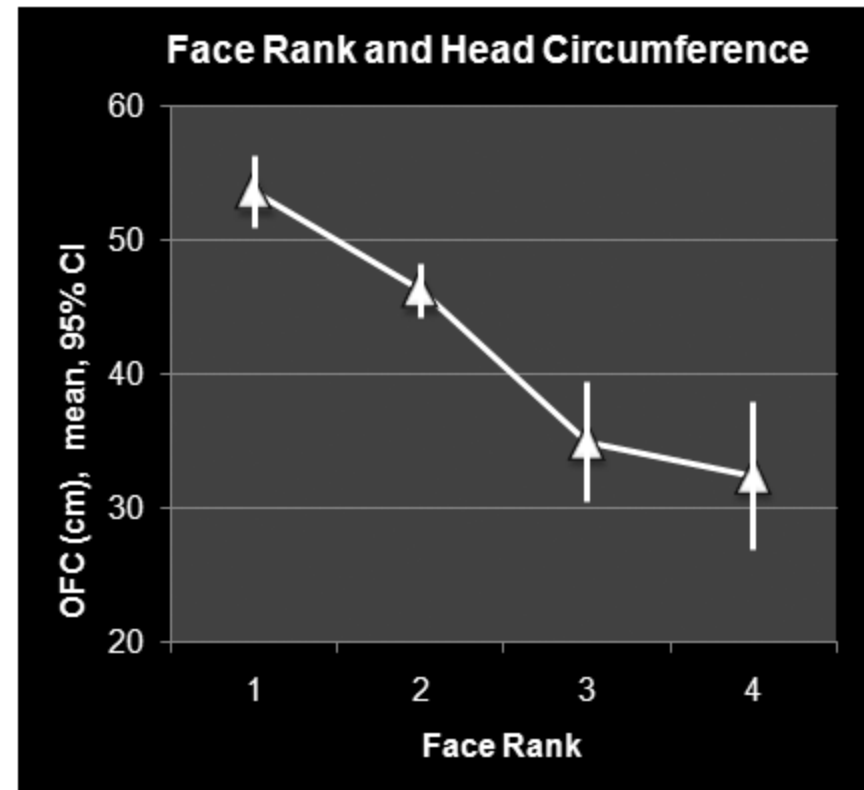
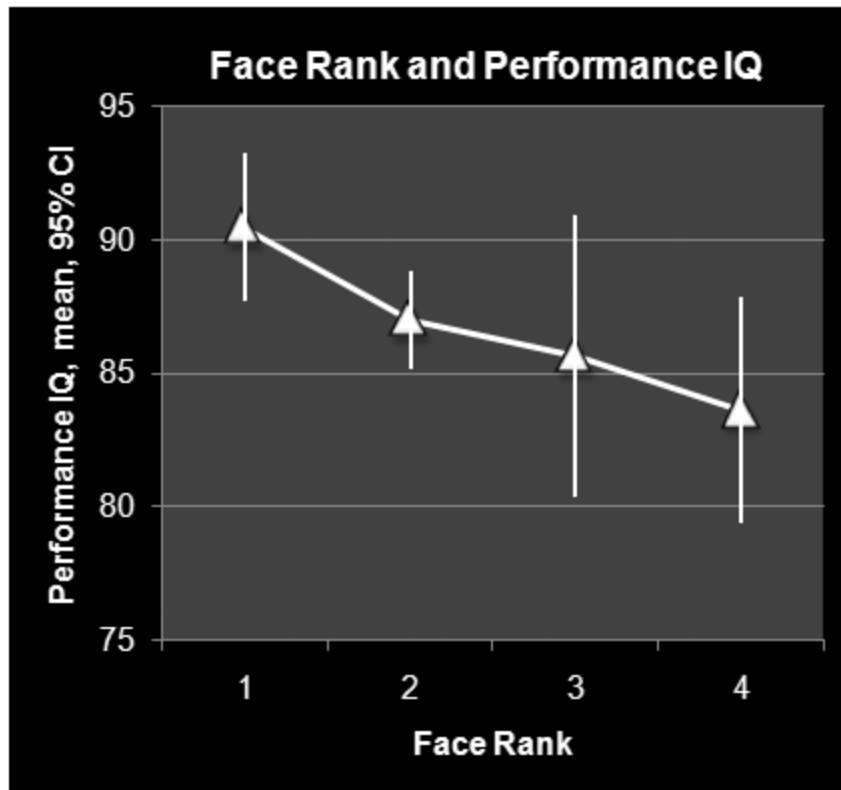
Sociodemographic Profile of 1,400

Characteristic		N	%
Gender:	male	812	58
Race:	White	684	49
	Black	92	7
	American Indian/Native Alaskan	115	8
	Other	509	36
Age at diagnosis (yrs):	0-3	258	18
	4-5	233	17
	6-10	482	34
	11-15	286	20
	16+	141	10
Annual Income	less than \$35,000	385	65

Growth, Face, CNS, and Alcohol Ranks of 1,400



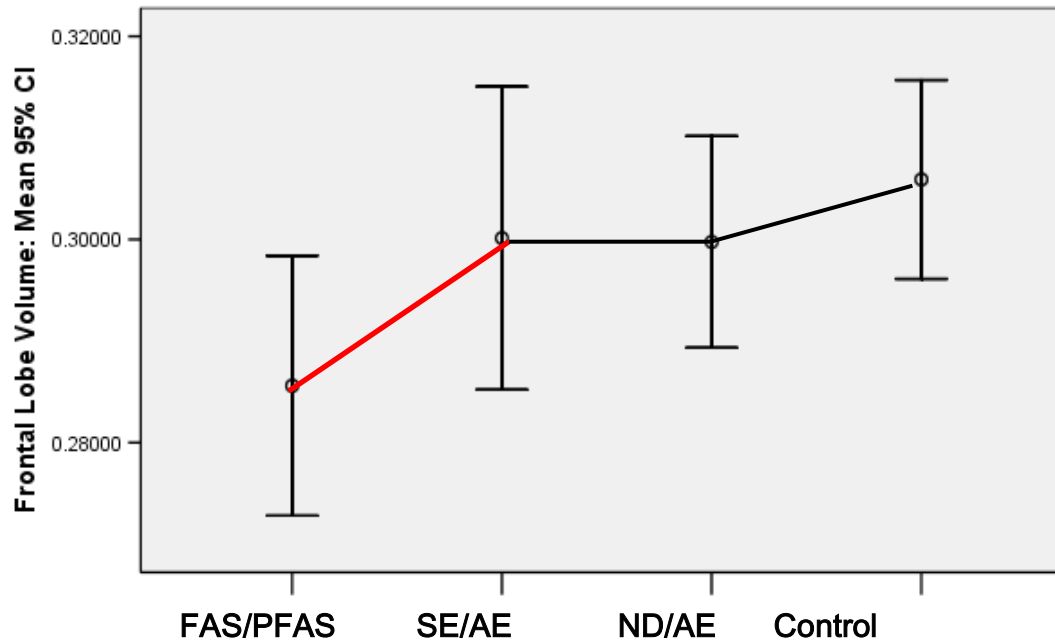
4-Digit Face Rank Predicts Brain among 1,400



- The FAS facial phenotype presents along a continuum.
- The more severe the FAS face, the more severe the CNS structural/functional abnormality.

Rank 4 FAS Face : Smaller Frontal Lobe

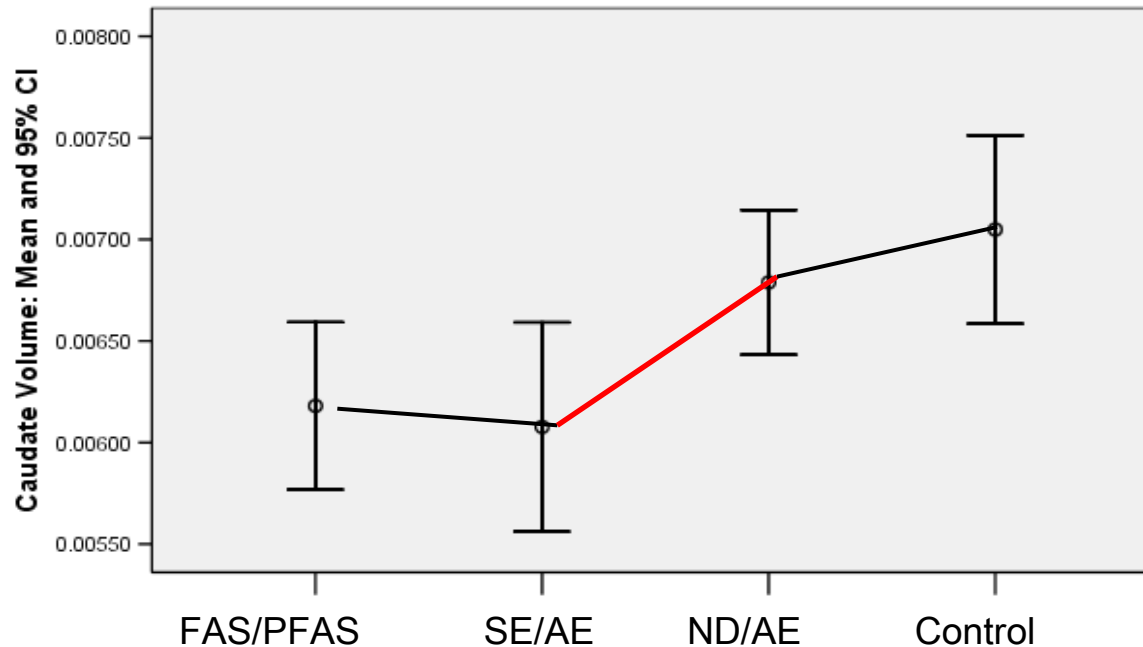
Frontal Lobe (adjusted for brain size) Across 4 Groups



MRI Study: Those with FAS/PFAS had disproportionately smaller frontal lobe volumes

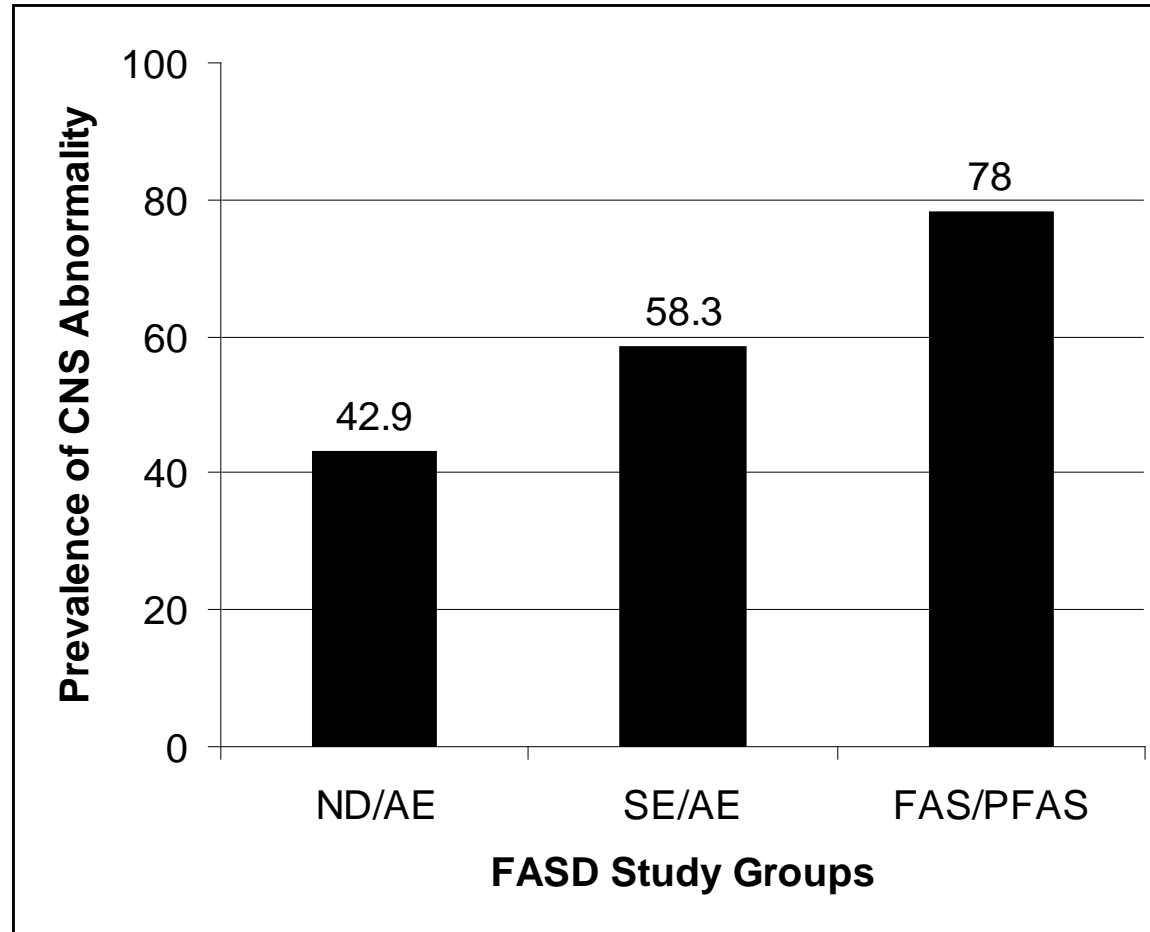
CNS Ranks 3,4 : Smaller Caudate

Caudate Size (adjusted for brain size) across the 4 Groups



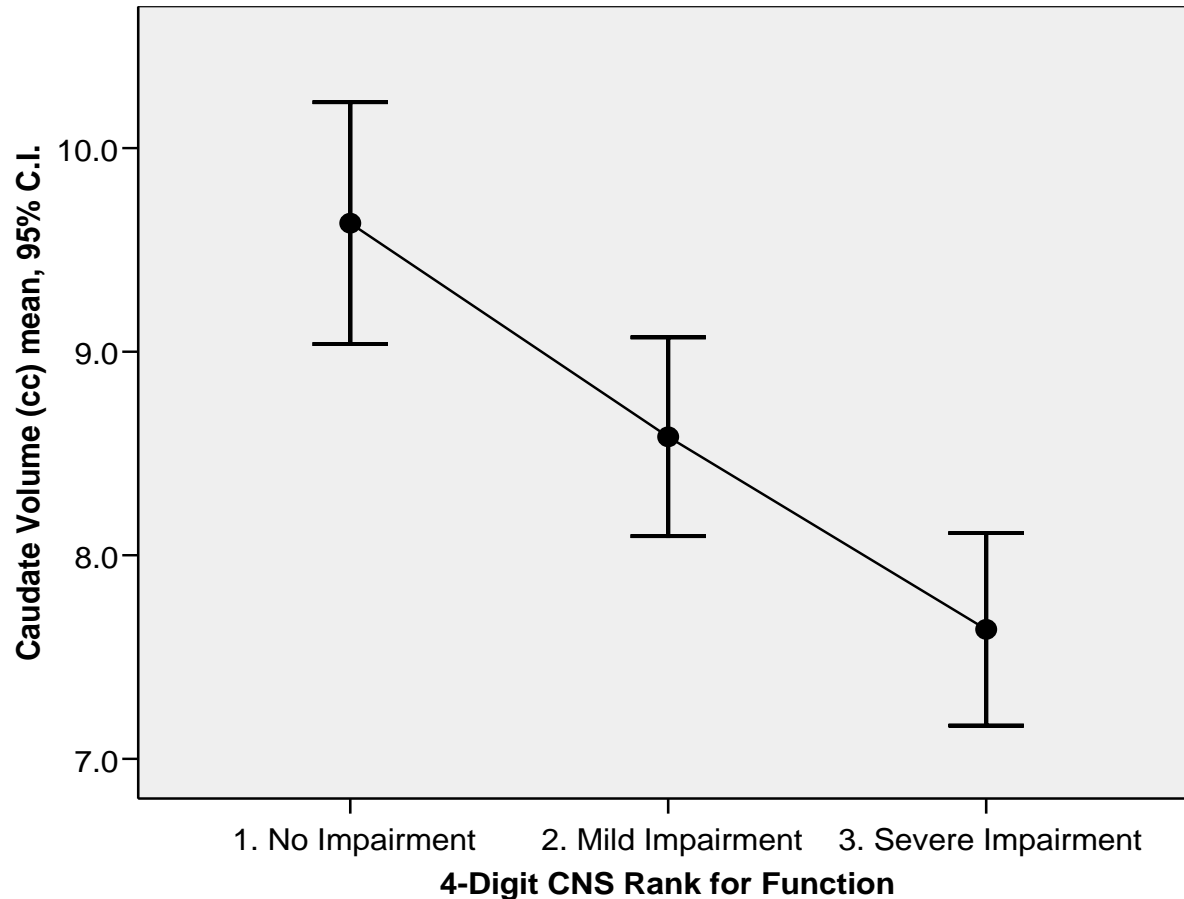
MRI Study: Those with FAS/PFAS and SE/AE had disproportionately smaller caudate volumes

Prevalence of CNS Structural Abnormalities



MRI Study: The prevalence of subjects with 1 or more brain regions that are significantly smaller than the healthy Control Group increases as severity of FASD diagnostic classification increases.

4-Digit CNS Rank Correlates with Caudate Volume



MRI Study: Caudate volume decreases significantly as CNS Functional Rank increases from 1) no impairment, to 2) mild impairment, to 3) severe impairment.

9.3% Exposed, but Unaffected

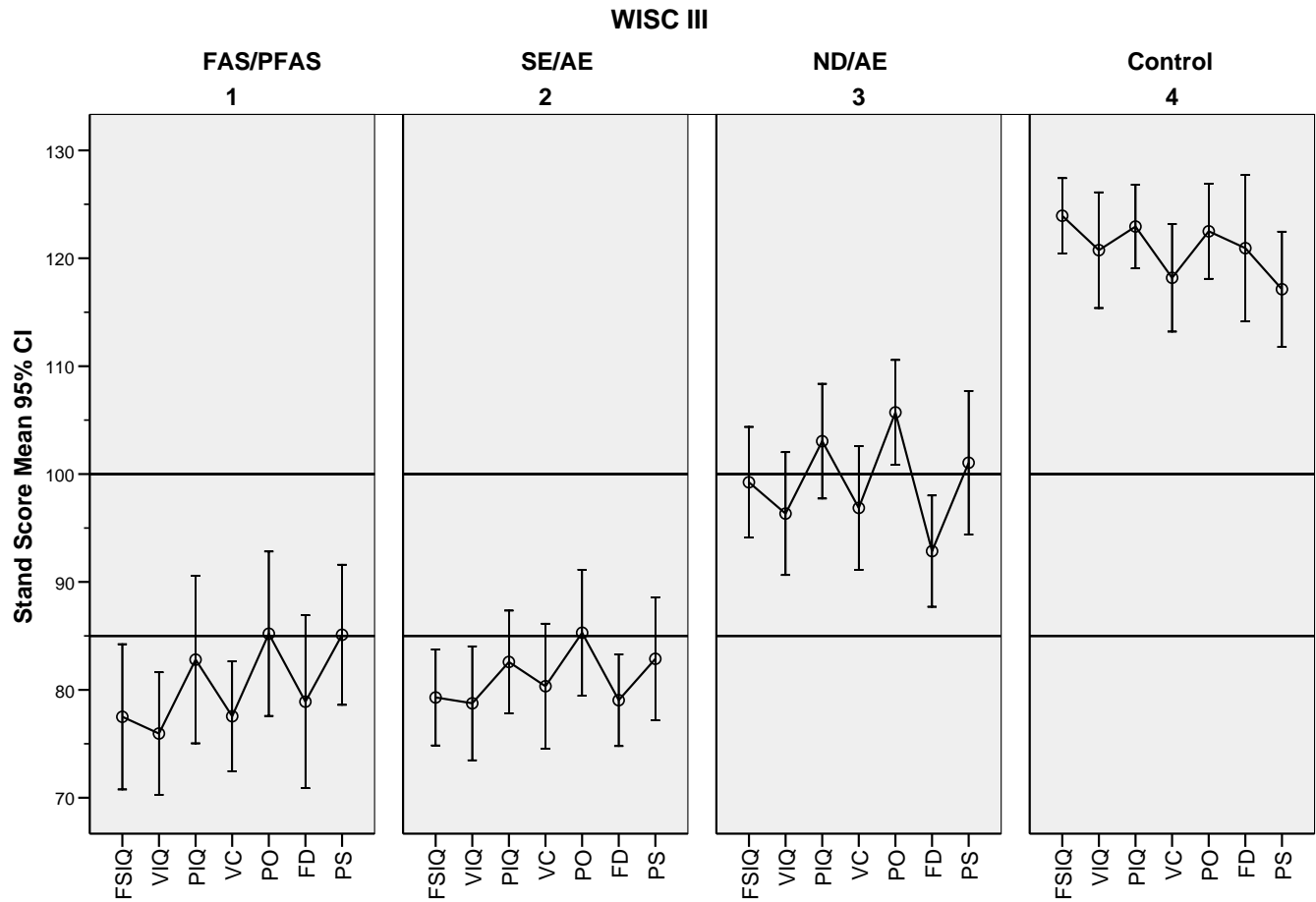
- Of the 1,400 subjects with alcohol exposure, 9.3% had no evidence of CNS abnormality.
- Their alcohol exposure levels were comparable to the SE/AE and ND/AE groups.

3 features distinguished them from the affected subjects.

1. More likely to be female
2. More likely to be younger
3. Less likely to experience adverse postnatal events

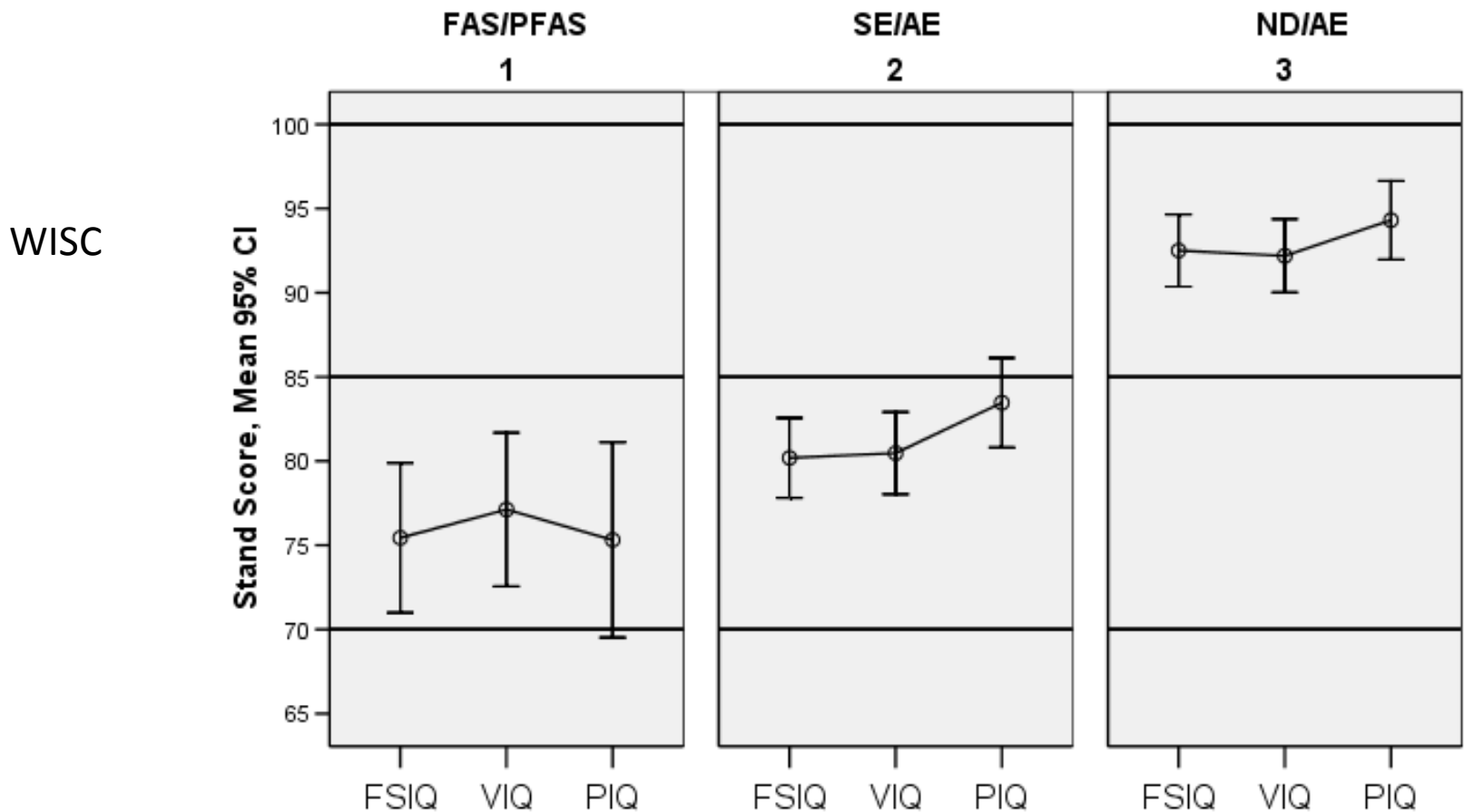
Cognitive/Behavioral Profiles of FASD: MRI Study

WISC III



Cognitive/Behavioral Profiles of FASD: Clinic Sample

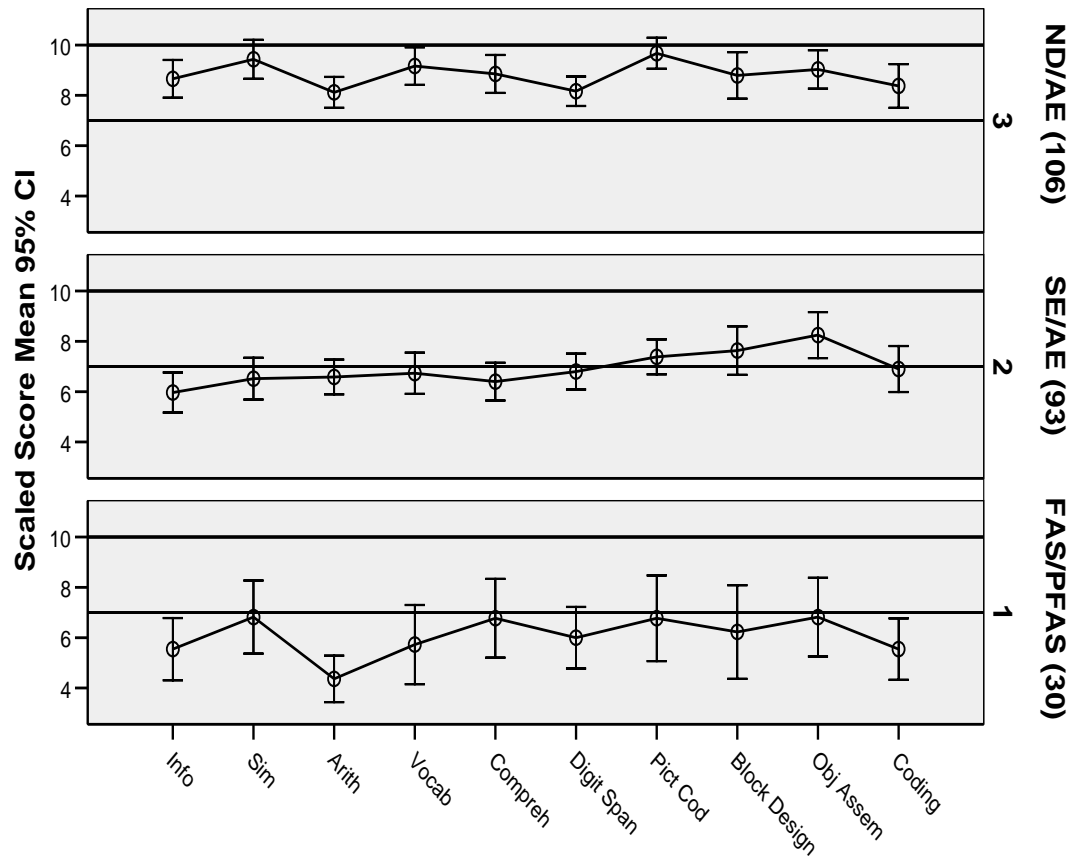
WISC Clinic Sample (8-15.9 yr)



Cognitive/Behavioral Profiles of FASD: Clinic Sample

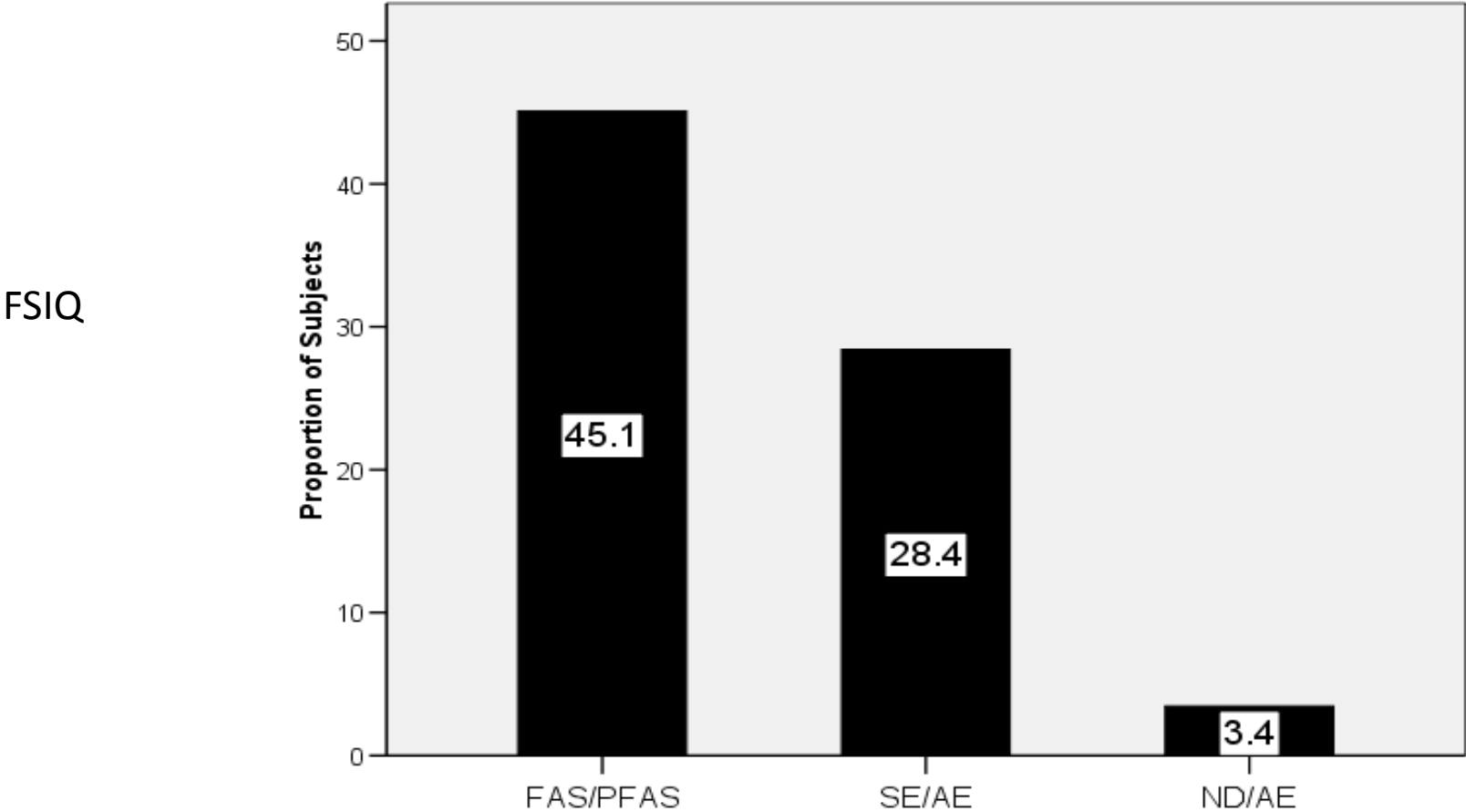
WISC: Clinic Sample (8-15.9 yrs)

WISC



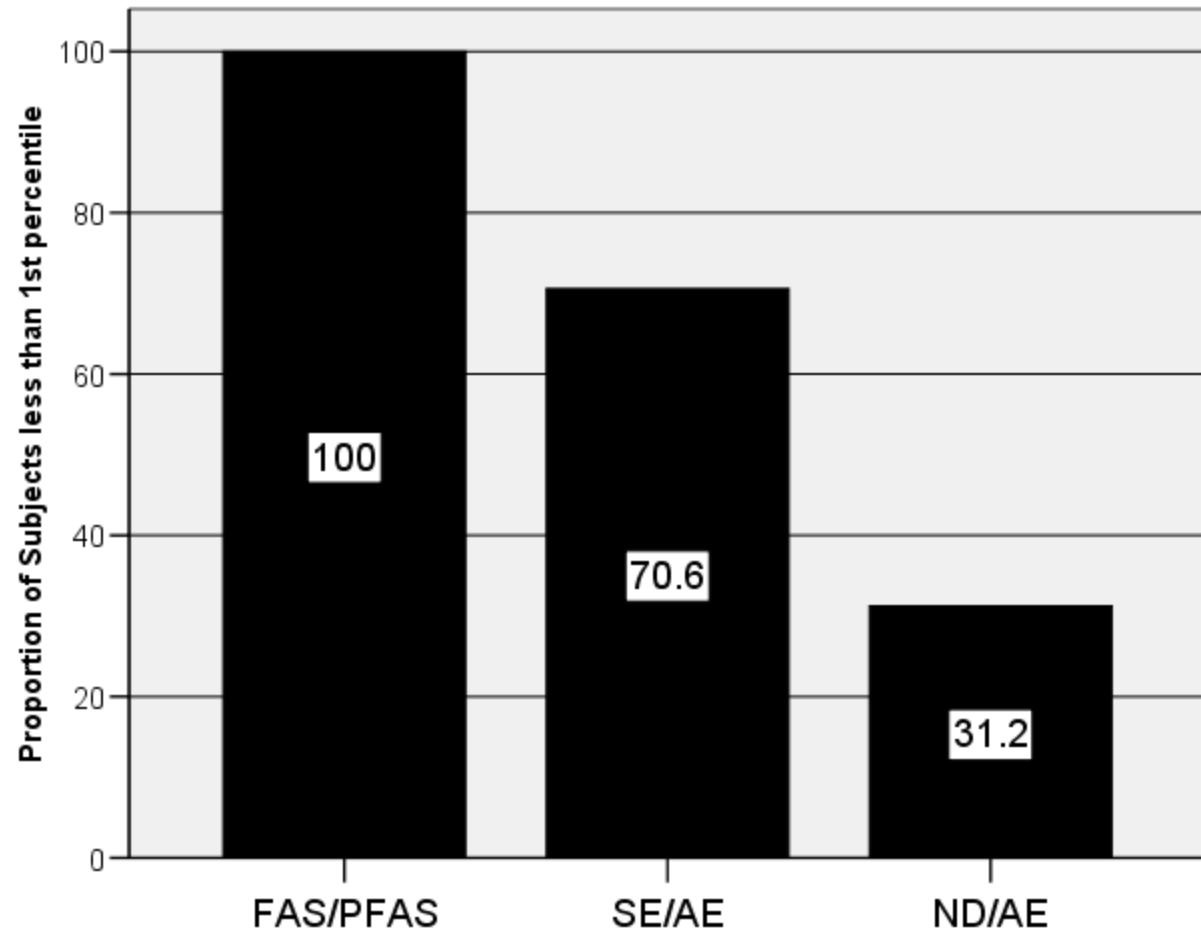
Cognitive/Behavioral Profiles of FASD: Clinic Sample

Proportion of Subjects with FSIQ < 70



Cognitive/Behavioral Profiles of FASD: Clinic Sample

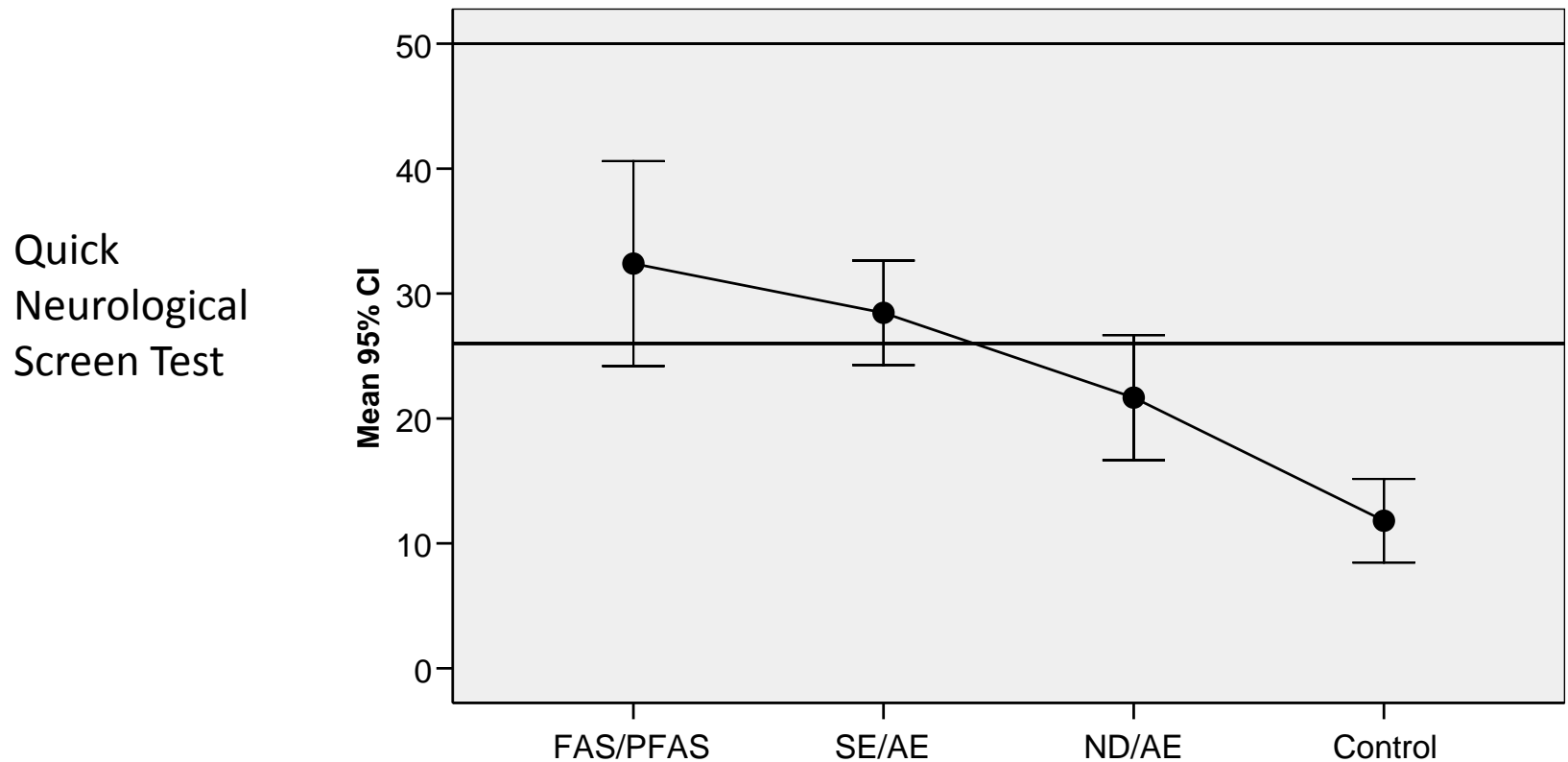
RCFT: Copy (Clinic Sample)



Rey
Complex
Figure
Test

Cognitive/Behavioral Profiles of FASD: MRI Study

QNST Total Score (26-50 borderline, >50 clinical)

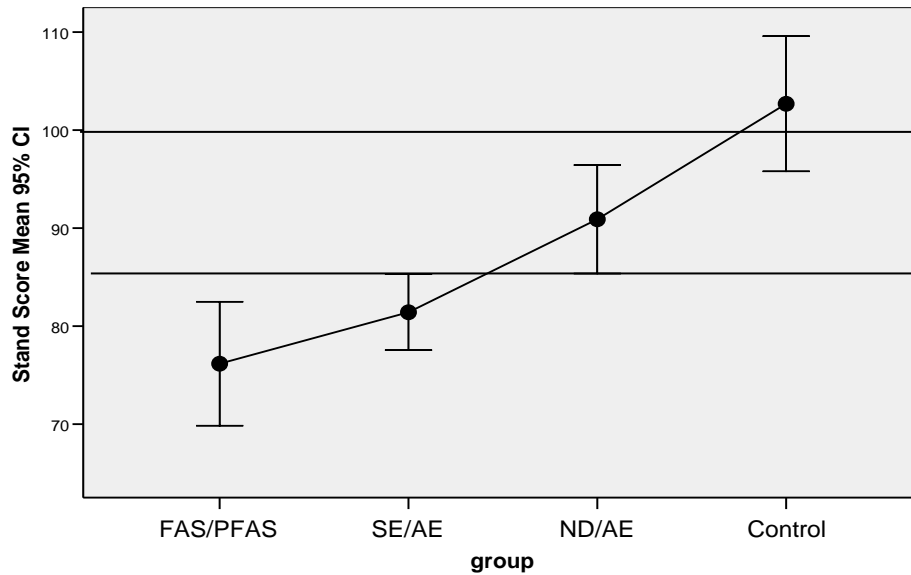


Cognitive/Behavioral Profiles of FASD

Visual Motor Integration

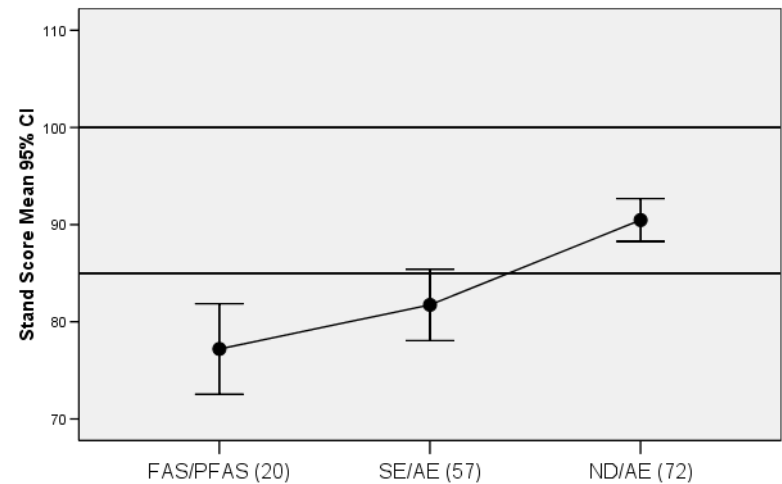
MRI Study

VMI

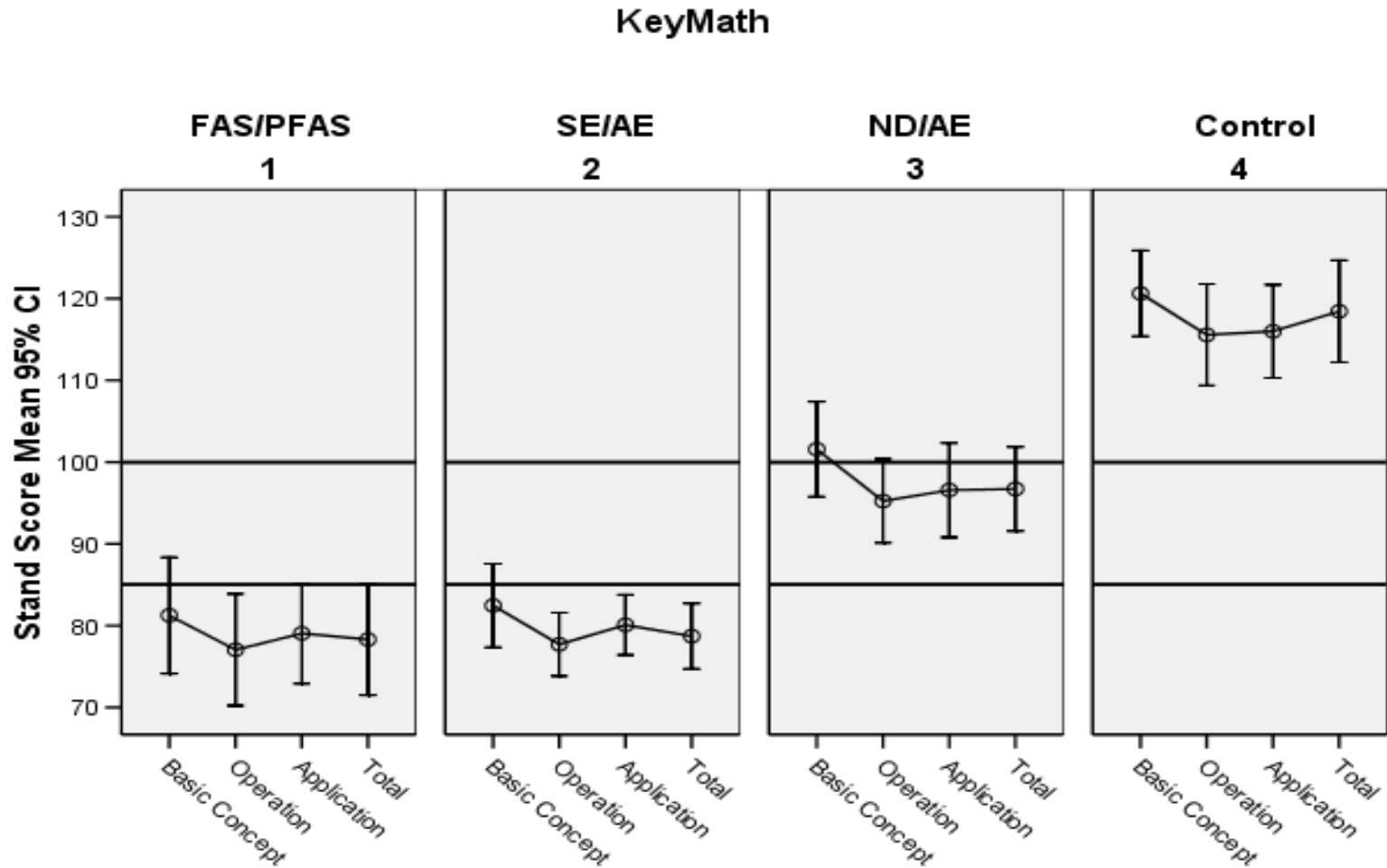


Clinic Sample

VMI: Clinic Sample

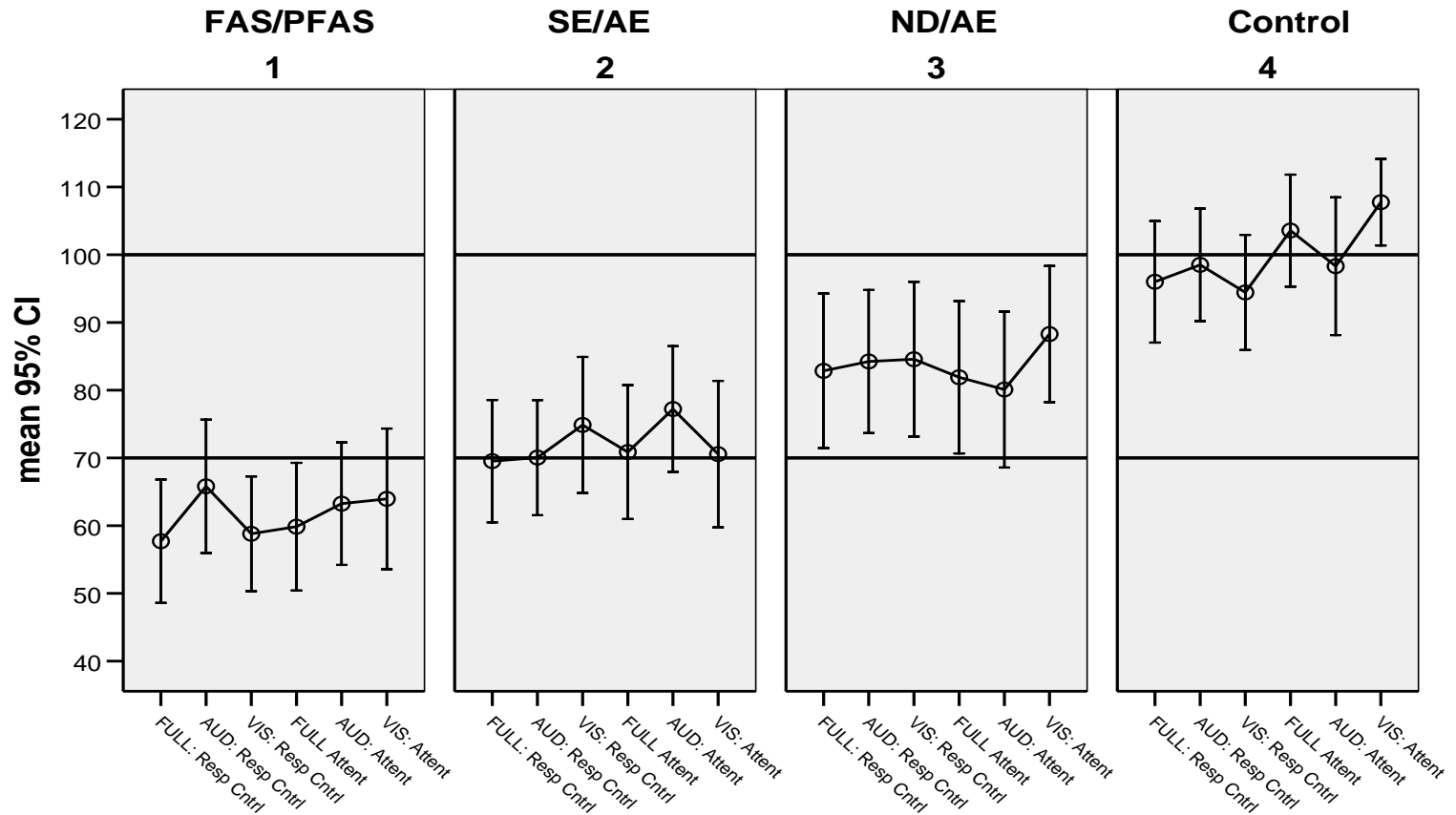


Cognitive/Behavioral Profiles of FASD: MRI Study



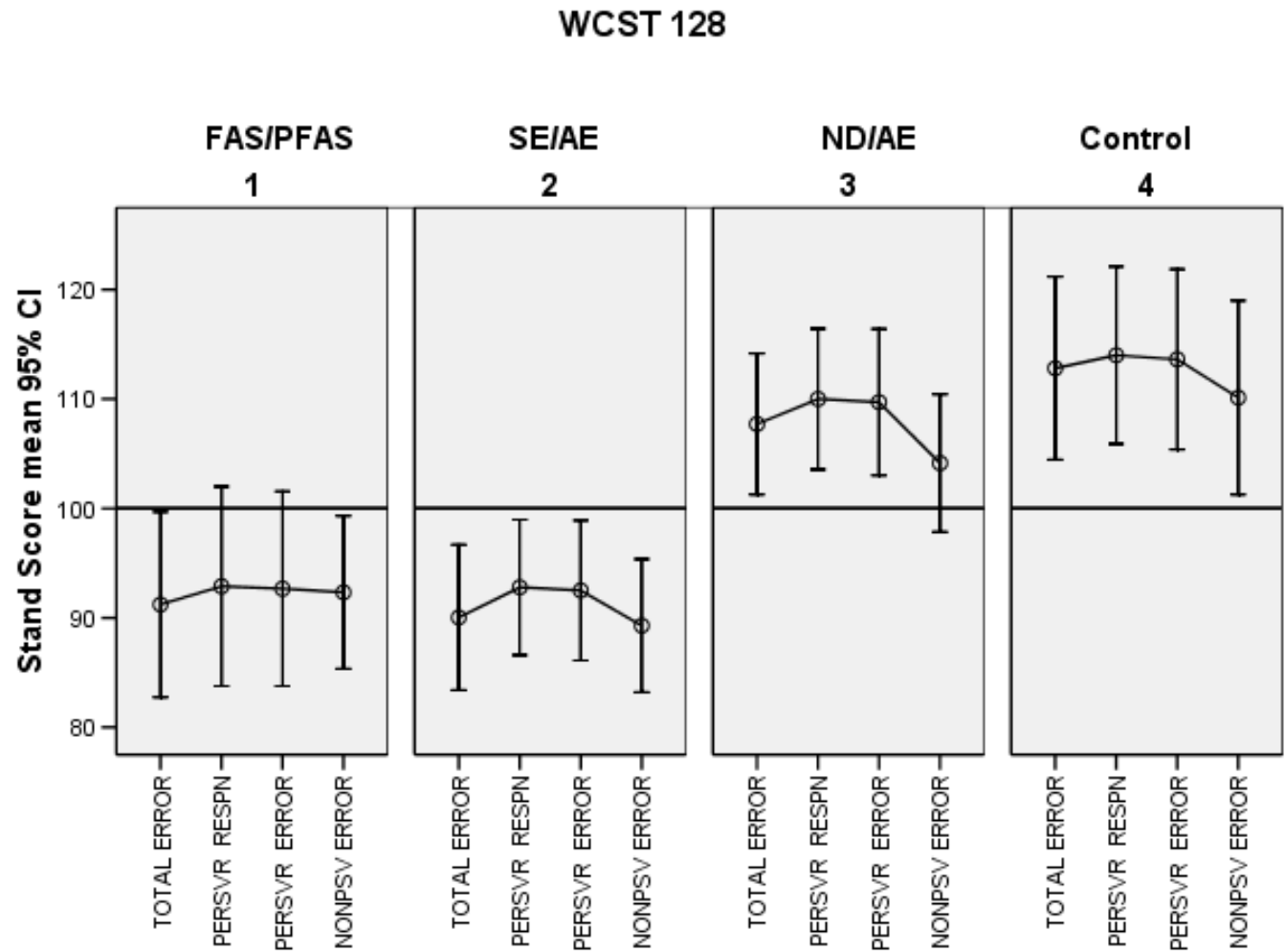
Cognitive/Behavioral Profiles of FASD: MRI Study

IVA: Auditory and Visual, Attention and Response Control Quotients



Cognitive/Behavioral Profiles of FASD: MRI Study

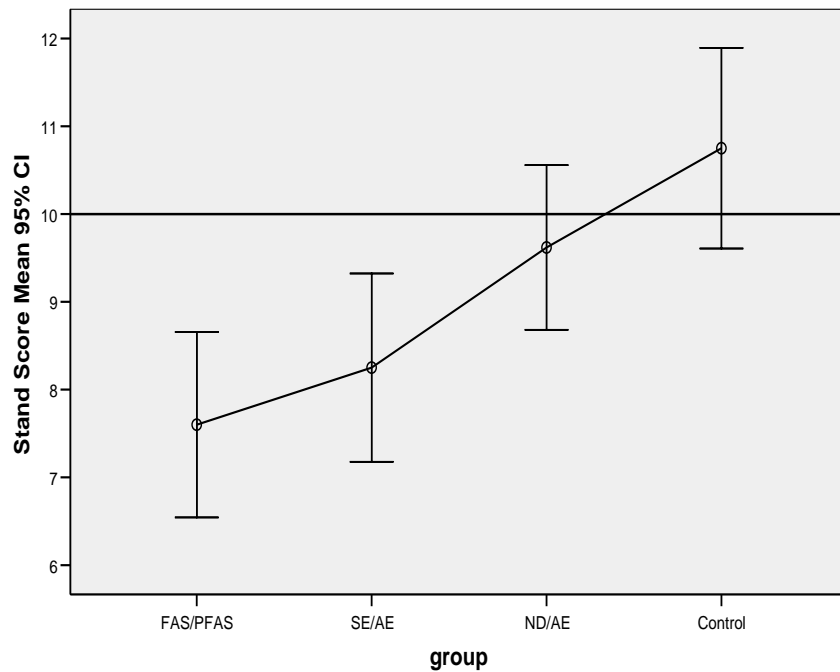
Wisconsin
Card Sort
Test



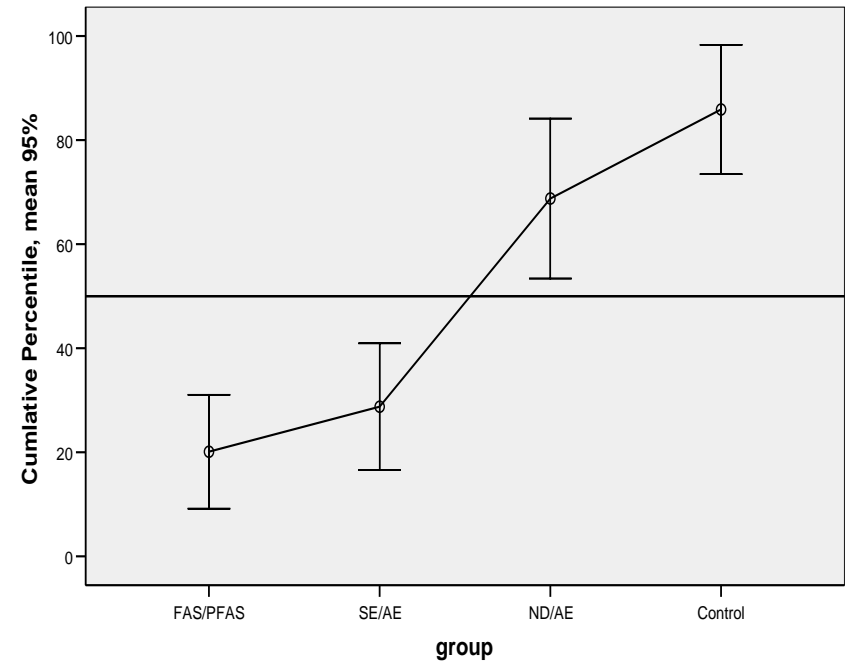
Cognitive/Behavioral Profiles of FASD: MRI Study

Delis-Kaplan Executive Function System: Tower Test

DKEF Tower: Total Achievement (dk54)



DKEF Tower: Total Rule Violations (dk55)



Significant Differences between FAS/PFAS and SE/AE

	FAS/PFAS	SE/AE
FAS Face	Yes	No
Alcohol: More days/week	6 days / week	4 days / week
Alcohol: All 3 trimesters	77%	59%
Smaller OFC	30 th percentile	43 rd percentile
Microcephalic	49% of subjects	27% of subjects
Frontal lobe	Disproportionately smaller	
Choline: Frontal/Parietal	Significantly lower	
WISC PIQ	76	82
WISC Arith	4	6
WISC mazes	2.8	6.5
Key Math estimation	5	6.4
VMI	77	89
RCFT Copy (raw)	11	18
IVA Full Response Quot.	58	70

Significant Differences between FAS/PFAS and SE/AE

Percent of Subjects with Scores below 2 SDs

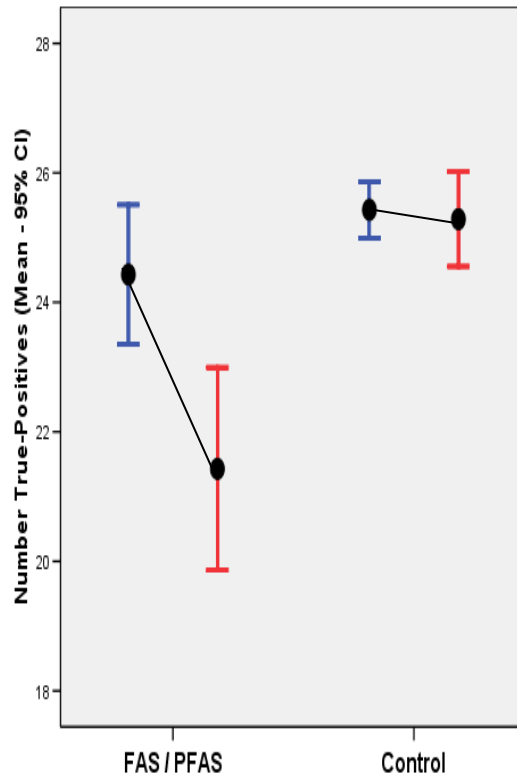
MRI Study

MRI Study: Proportion of subjects with scores 2 SDs below the mean

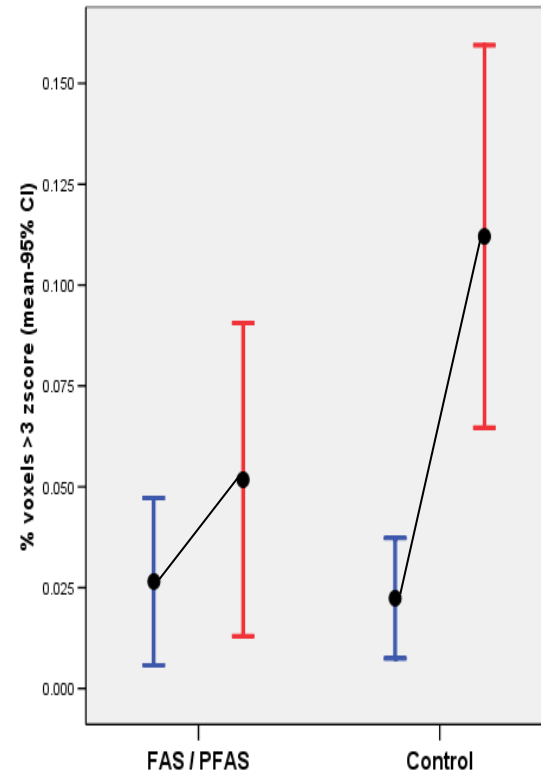
Selected Psychological Outcomes	FAS/PFAS	SE/AE	ND/AE	Control
WISC FSIQ	20	25	0	0
WIAT Basic Reading	5	21	5	0
Key Math	20	13	0	0
VMI	33	8	0	0
Rey Complex Figure Test Copy	85	88	48	0
Rey Delayed Recall	55	54	29	0
D-KEFS: Tower, Total Rule Violation	25	21	0	0
CVLT-C, Total Trials # Correct	50	63	14	0
IVA Continuous Performance Test	75	54	29	0
TOWK: Conjunctions & Transitions	43	39	7	0
Vineland Adaptive Behavior, Composite	75	83	67	6
CBCL: Internalizing Problems	60	46	38	0
BRIEF: Gen Executive Composite	85	92	76	0
ADHD	63	71	67	0

fMRI: Activation and Working Memory

Number of Correct Responses on N-Back



Level of Activation in Dorsolateral Prefrontal



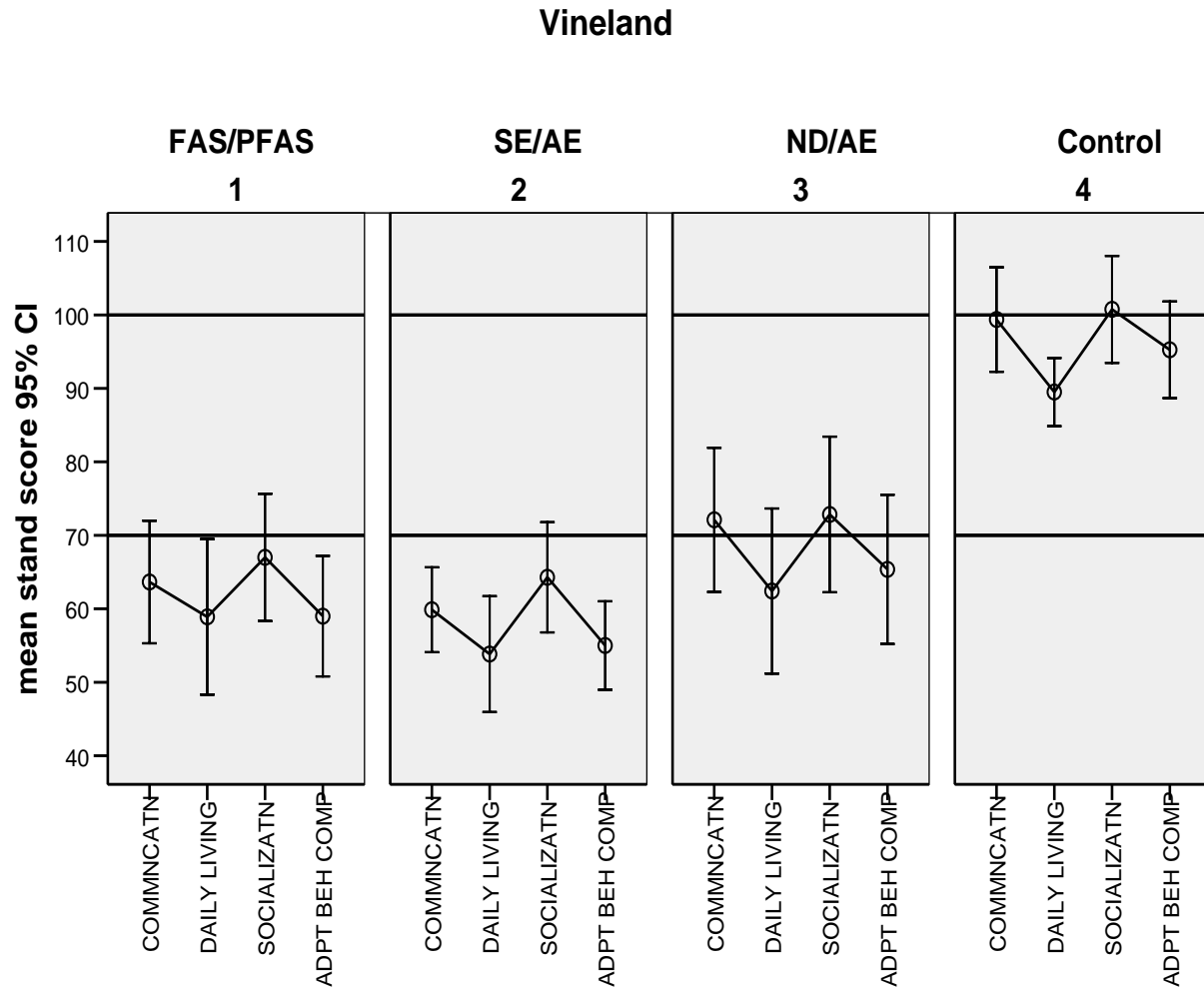
Key:

1-Back
(simple
task)

2-Back
(difficult
task)

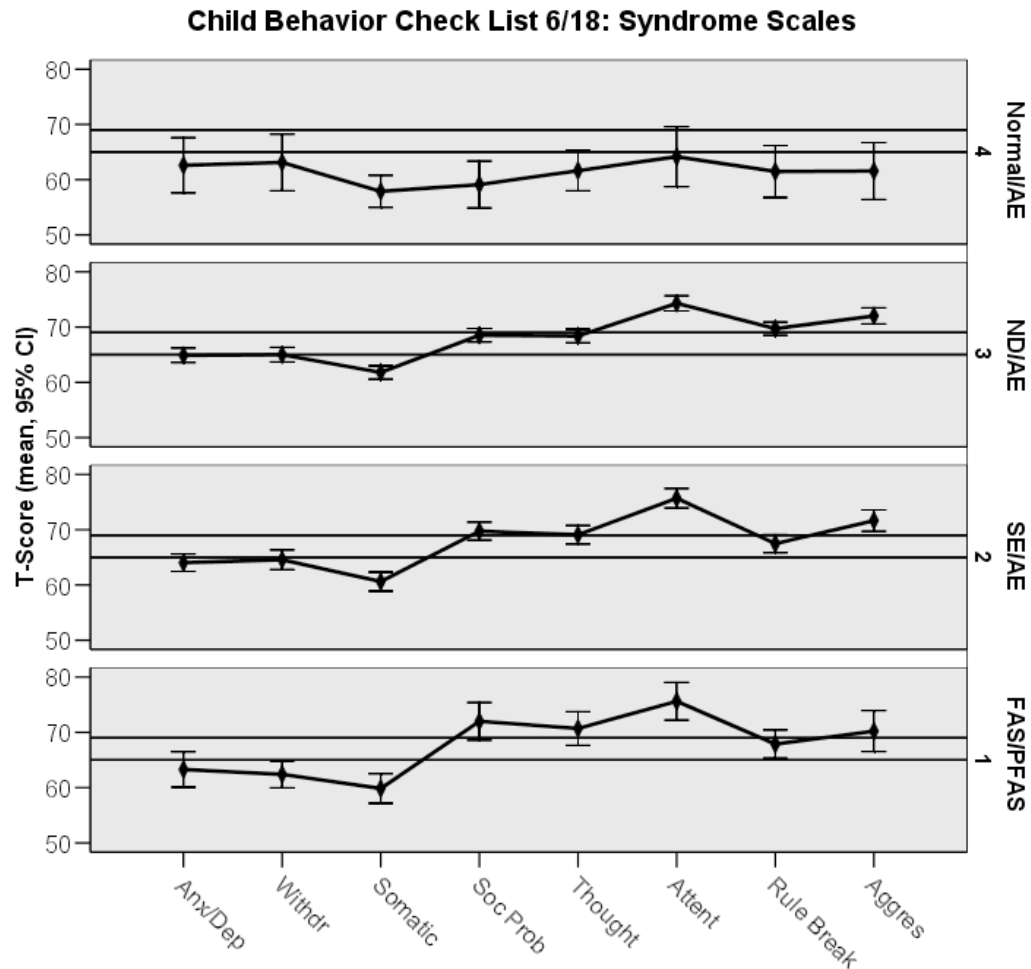
Cognitive/Behavioral Profiles of FASD: MRI Study

Vineland
Adaptive
Behavior
Scales



Parent's Report of Child's Behavior: CBCL

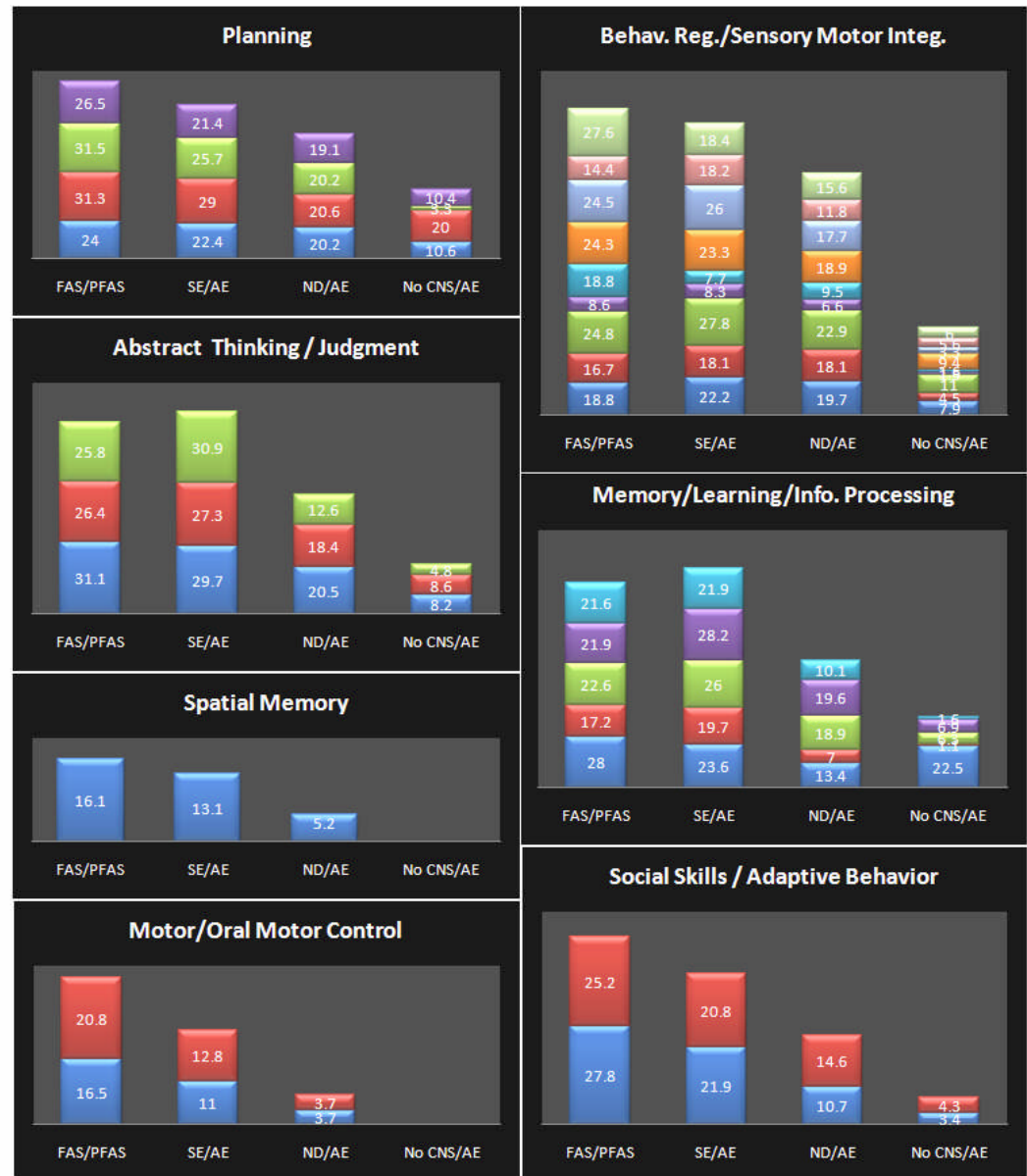
No difference between FASD groups
among FAS DPN clinical population 6-18 years of age.



Parent's Report of Child's Behavior via Parent Interview with Psychologist and MD

Note: this is before parent and clinicians know the child's FASD diagnostic outcome.

In contrast to CBCL, differences do exist between FASD groups



Prevalence of other Mental Health Disorders

Among the 1,064 FAS DPN patients 5 years of age or older:

- 82% had one or more MH disorders.
- 54% had ADD/ADHD

documented in their records.

MRIS Study				
Using Computerized-Diagnostic Interview Schedule for Children				
Proportion of Subjects with the Condition				
Condition	FAS/PFAS	SE/AE	ND/AE	Control
	N=20	N=24	N=21	N=16
AD/HD	63	71	67	0
ODD	47	58	52	13
CD	37	21	48	0
Generalized Anxiety	21	8	5	0
Separation Anxiety	16	8	14	0
OCD	11	4	14	0
PTSD	11	4	0	0
Social Phobia	11	4	10	0
Maj Depress / Dysthymic	5	8	5	0
Mania / Hypomania	5	0	0	0
Schizophrenia	5	0	0	0
Panic	0	0	5	0

Patient Satisfaction with Interdisciplinary FASD Evaluation Procedure in Seattle FAS DPN Clinic.

- 99% would recommend clinic to other families.
- 91% received information they were unable to obtain elsewhere.
- 86% found explanation of 4-Digit Code easy to understand.
- 82% were somewhat to very successful in finding recommended intervention services.
- 84% reported these services met some to all of their needs.
- Family's whose child received a diagnosis of SE/AE or ND/AE **were as likely** to report successfully accessing and benefiting from recommended intervention services as family's whose child received a diagnosis of FAS/PFAS.

WA State FAS DPN Patient Profile (n = 1,400)

- **In summary**, the existence of the WA FAS DPN diagnostic program and electronic database over the past 18 years confirms it is possible to establish and maintain a comprehensive statewide FASD diagnostic program and dataset.
- As demonstrated in this report, a broad array of clinical, research, and public health questions can be addressed with a FASD clinical dataset.

References

- Astley SJ. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol* .Vol 17(1) Winter 2010:e132-e164; March 26, 2010.
- Astley et al., Neuropsychological and behavioral outcomes from a comprehensive magnetic resonance study of children with FASD, *Canadian J Clinical Pharmacology*, 2009;16(1):e178-201.
- Astley et al., MRI outcomes from a comprehensive magnetic resonance study of children with FASD, *Alcoholism: Clinical Experimental Research* 2009;33(10).
- Astley et al., MRS outcomes from a comprehensive magnetic resonance study of children with FASD, *Magnetic Resonance Imaging Magnetic Resonance Imaging*, 2009;27:760-778.
- Astley et al., fMRI outcomes from a comprehensive magnetic resonance study of children with FASD, *J Neurodevelopmental Disorder* 2009;1:61-80.
- Astley SJ. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code*, 3rd edition, University of Washington Publication Services, Seattle WA, 2004.
- Astley SJ. Graphic cognitive/behavioral/psychiatric profiles of FASD. Slide show presented to NIAAA/CDC in 2009.

All literature referenced in this presentation can be obtained at the following weblinks:
www.fasdpn.org/htmls/literature.htm
www.fasdpn.org/pdfs/astley-graphicprofile-2009secure.pdf