




# *Improving Efficacy while Decreasing Costs of Diagnosis for Virtual FASD Teams*

International FASD Conference

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# Conflict of Interest

- None to declare



# Avoiding Bias in this Presentation

- N/A as no conflicts of interest



# Summary

- Why did we do this?
- What did we do?
- What are Brain Injury Protocols (BIP)?
- How do we use BIP?
- What does it mean?



# Objectives of this Review

- ▶ In comparing data across 3 Ontario clinics over the past 10 years it was noted that the frequency of not receiving any FASD diagnosis varied among teams from 44% to 0% while inclusion criteria were the same.
- ▶ The only variable over time were the types of tests used in assessing the various brain domains for the neurodevelopmental assessment.
- ▶ Review of the Paediatric Brain Injury (PBI) literature demonstrated that it had much to offer the FASD diagnostic process. We therefore tested the hypothesis that using Brain Injury Protocol (BIP) increased our diagnostic rate.
- ▶ An increased diagnostic rate would result in increased efficacy and decreased costs due to reduced number of reassessments.



# The Three Teams

Involved in this research



# The Diagnostic Teams

- The 2 community teams are virtual teams
- The work is supported by a variety of different agencies in each specific geographic location so all costs of the diagnostic process are covered for the family
- One team is a private team which charges a flat fee for the entire diagnostic process and includes all appointments, the Family Mtg and a School Mtg.
- Assessments are completed over a period of time and appointments are scattered
- Team meets once assessments are complete



# Members of the Team

- Social Worker
- Developmental Paediatrician
- Neuropsychologist
- Psychometrist
- Occupational Therapist
- Speech and Language Pathologist





# Intake Process for Virtual Teams

- ▶ Referral is screened by an intake specialist/Social Worker
  - ▶ Confirms eligibility status
  - ▶ Completes referral and consent forms
  - ▶ Confirmation of guardianship

Referral is sent to Diagnostic Team Co-ordinator

- ▶ Triage done according to age;
- ▶ severity of symptomatology
- ▶ reasons for referral



# Eligibility Criteria across the Teams



# Eligibility for Diagnostic Service

- ▶ The child resides in specific geographic region for the community Virtual teams and within Ontario for the private team
- ▶ The child is between birth & 6:11 years or birth and 18yr 11mth
- ▶ There is confirmed prenatal exposure to alcohol from a reliable source or presence of 3/3 facial features

# Three Teams During the Sampling Period

	W Team	P Team	R Team
Type	Virtual	Virtual	Private
Eligibility Criteria	*	*	*
Geographic Limits	Region	Region	Province
Multi-Disciplinary Team	*	*	*
Social Work	*/-	*	*
PAE Confirmation	*	*	*
Diagnoses <sup>☆</sup>	*	*	*
Share some Team Members	*	*	*
Family Centred	*	*	*
Trained in Winnipeg	*	*	*

☆ Philosophy of diagnosing whatever is relevant to data collected on child



# Definition of confirmed PAE

- Presence of 3/3 facial features as determined by MD with specialized training
- Report of observed PAE from reliable source and/or other documentation of very high risk of PAE as per the literature (e.g.:+ve blood alcohol levels; etc.)



# FASD Diagnosis consists of 2 equal parts

- Part 1: Medical Assessment
- Part 2: Delineate brain injury

# Part 1: Medical Assessment

- ▶ Birth History: Confirmation of alcohol exposure
- ▶ Facial Features are determined either manually or via computer
- ▶ Family History: Mental Health
- ▶ Social History: Attachment and PTSD

# FAS Facial Photographic Analysis Report

## IDENTIFICATION

Name John T Doe  
 First Middle Last  
 Subject I.D. None  
 Source of Photo Clinic  
 Gender Male  
 Race Caucasian/Caucasian  
 Birth Date 1/1/1990

## PHOTO ASSESSMENT

Normal PFL Chart: Scandinavian (Stromland '99) Lip-Philtrum Guide: Caucasian  
 Normal ICD Chart: Caucasian (Hall '89) Frontal 3/4 View Lateral

	Frontal	3/4 View	Lateral
File Name	Demo Frontal	Demo 3/4	Demo Lateral
Date of Photo	6/22/1998	6/22/1998	6/22/1998
Age (yrs) in photo	8.47	8.47	8.47
Date of Photo Assessment	6/22/1998	6/22/1998	6/22/1998
Photo Assessor	Astley	Astley	Astley

Length of Real Internal Measure of Scale (sticker) placed on forehead (mm) 19.05  
 Length of Internal Measure of Scale in Frontal Photo (pixels) 155.2

	In photo (pixels)	True Length (mm)	Z-score
Left Palpebral Fissure Length:	<u>208.5</u>	<u>28.2</u>	<u>1.04</u>
Right Palpebral Fissure Length:	<u>205.5</u>	<u>27.7</u>	<u>0.67</u>
Mean Palpebral Fissure Length:	<u>207.0</u>	<u>28.0</u>	<u>0.86</u>
Inner Canthal Distance (ICD):	<u>200.0</u>	<u>24.5</u>	<u>-2.24</u>

Flat Philtrum (5-point rank): In Frontal Photo 3 In 3/4 Photo 3

Thin Upper Lip: Circularity (perimeter<sup>2</sup>/area) 44.2 5-Point rank (Circ) 2 5-Point rank (Scale) 2

down eyebrows  ptosis  strabismus  epicanthal folds   
 flat midface  protruding ears  flat nasal bridge  hypertelorism

Other anomalies present: hypotelorism

Comments:

Other syndromes present: None reported

## PHOTO QUALITY

	Frontal	3/4 View	Lateral
Side showing		Right	Left
Head rotation (5-point rank/degrees) to subject's Right (+) or Left (-)	<u>0°</u>	<u>0</u>	<u>0</u>
Head tilt (5-point rank) toward subject's Right (+) or Left (-) shoulder			
Head tip (degrees) Up (+) or Down (-) from Frankfort Horizontal Plane	<u>0°</u>		
Exposure (3-point rank)	<u>1 (good)</u>	<u>1 (good)</u>	<u>1 (good)</u>
Focus (3-point rank)	<u>1 (good)</u>	<u>1 (good)</u>	<u>1 (good)</u>
Facial Expression (3-point rank)			
Reliability of ABC-Score for palpebral fissure length (5-point rank)	<u>1 (very good)</u>		
Reliability of ABC-Score for philtrum (5-point rank)	<u>1 (very good)</u>	<u>1 (very good)</u>	
Reliability of ABC-Score for upper lip (5-point rank)	<u>1 (very good)</u>		

## OUTCOME

ABC-Score A B A  
 PFL Philtrum Lip  
 Data Used mean 3/4 view circularity

4-Digit Diagnostic Code for Face 1: FAS features absent



Demo Frontal



Demo 3/4



Demo Lateral



# Part 2: Brain Injury Diagnosis

## (Neurodevelopmental Assessment)

- ▶ Collaborative Effort (importance of clinical judgement)
- ▶ Operates under Circle of Care
- ▶ Social Worker
- ▶ Speech and Language Pathologist
- ▶ Occupational Therapist
- ▶ Neuropsychologist & Psychometrist



# FASD Diagnosis

- Based on whole team meeting and their collaboration:
- Part 1 + Part 2 = FASD Diagnosis



# Importance of Clinical Judgement

- GUIDELINES are guidelines
- Complexity = Variability
- Consensus of ALL Multi-disciplinary team members
- Team Members therefore must have experience in assessment of children under the age of 6 as well as up to 18 or 21 years
- May need to have different Team or add in different Team Members as needed

# Risks/Benefits of Deferring or giving “ At Risk” Diagnosis in Children under age 6

- ▶ Deferral or At Risk may leave child as not eligible for some services
- ▶ Deferred Diagnosis or At Risk may not be recognized by community services
- ▶ Such diagnoses are often better than child receiving an incorrect diagnosis (e.g.: ASD)
- ▶ Some communities have found it better to use: Unspecified NDD Diagnosis (DSM 5: 325.9)
- ▶ Any diagnosis of a child under age 6 relies even more upon the clinical judgement and experience of the OT and SLP on the Team
- ▶ If an infant identified as having had a high risk of PAE or known PAE then should be followed by local I&CD Programme and as they ID increasing difficulties then referred to the Diagnostic Team when child and family ready



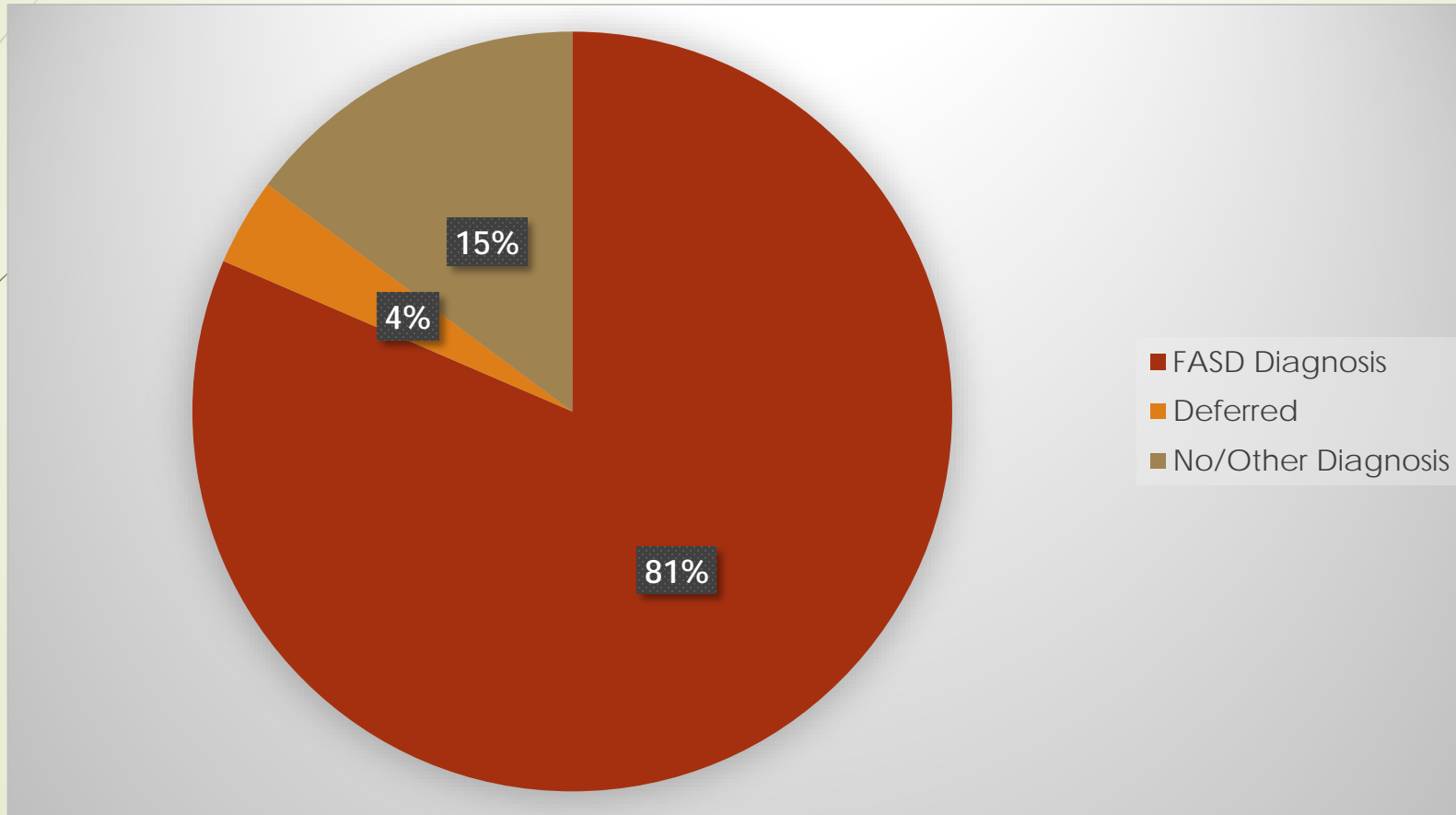
# Research Results



## 3 Ontario FASD Clinics

- 2 publicly funded clinics with virtual teams
- 1 private clinic (specializes in all forms of paediatric Brain Injury)
- All with full multi-disciplinary teams as described above
- Some staff overlap amongst clinics
- All used same confirmation of PAE at time of sampling
- When compared FASD diagnostic rates there were striking differences (i.e.: 100% to 61%)

# FASD Diagnoses (77%) across 3 clinics





# Diagnoses previously given instead of FASD

- ADHD
- GDD
- Deferred until older
- Learning Disability
- None or No diagnosis

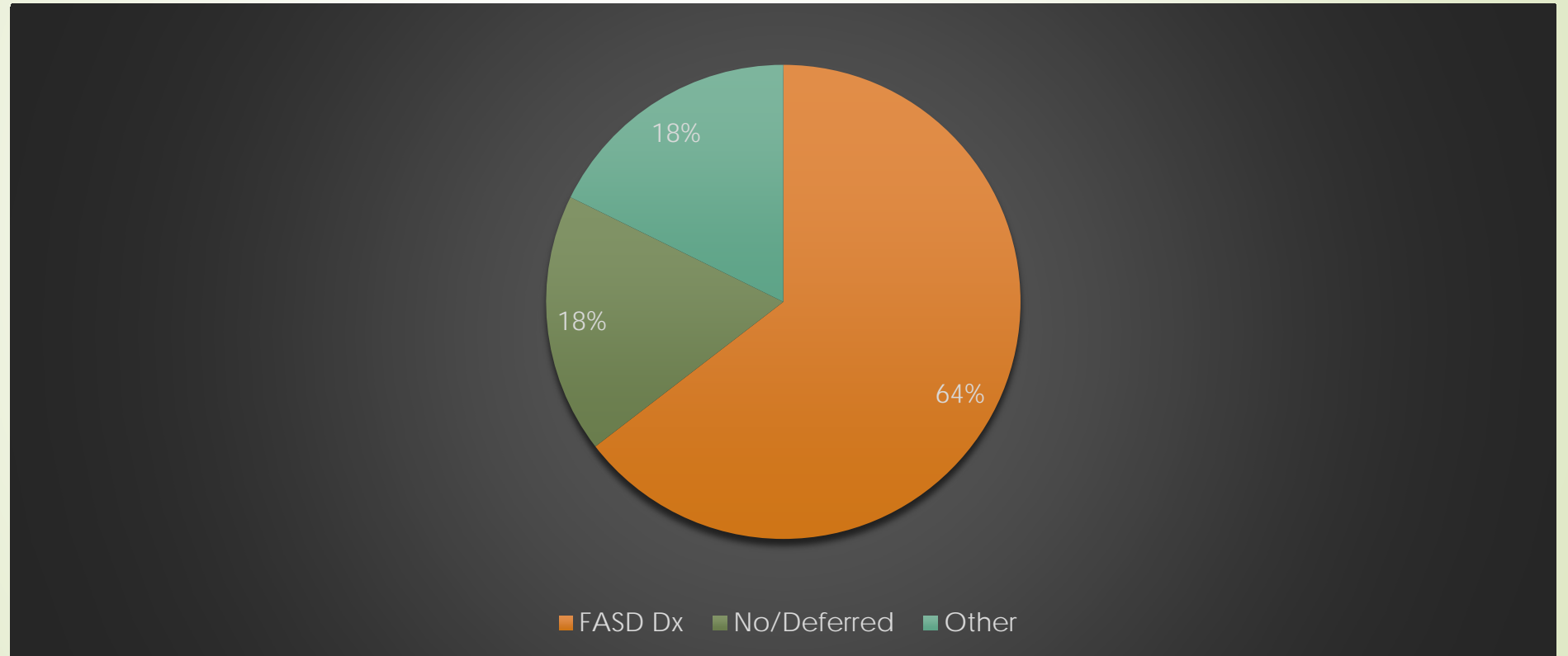




# Defining the problem

- If clinic is specifically created to diagnosed FASD and when use the current literature informed screening process before access to clinic why are so many not receiving a diagnosis?
- Clinics shared some staff members (e.g.: SLP, OT, MD) which should decrease variability in FASD Diagnosis rate
- Limits our credibility with management and ultimately with funders
- Increases possibility of agencies withdrawing their contribution as not effective use of staff time = not effective use of agency money.

# FASD Diagnosis in 2 community clinics





# Why not more FASD Diagnoses?

- ▶ Community Clinics (2):
  - ▶ Diagnostic Rates of FASD varied between 73% & 61%\*
- ▶ Private Clinic:
  - ▶ Diagnostic Rate of FASD was 100%\*
- ▶ Hypothesis: Differences were in tests used to determine extent of brain injury.

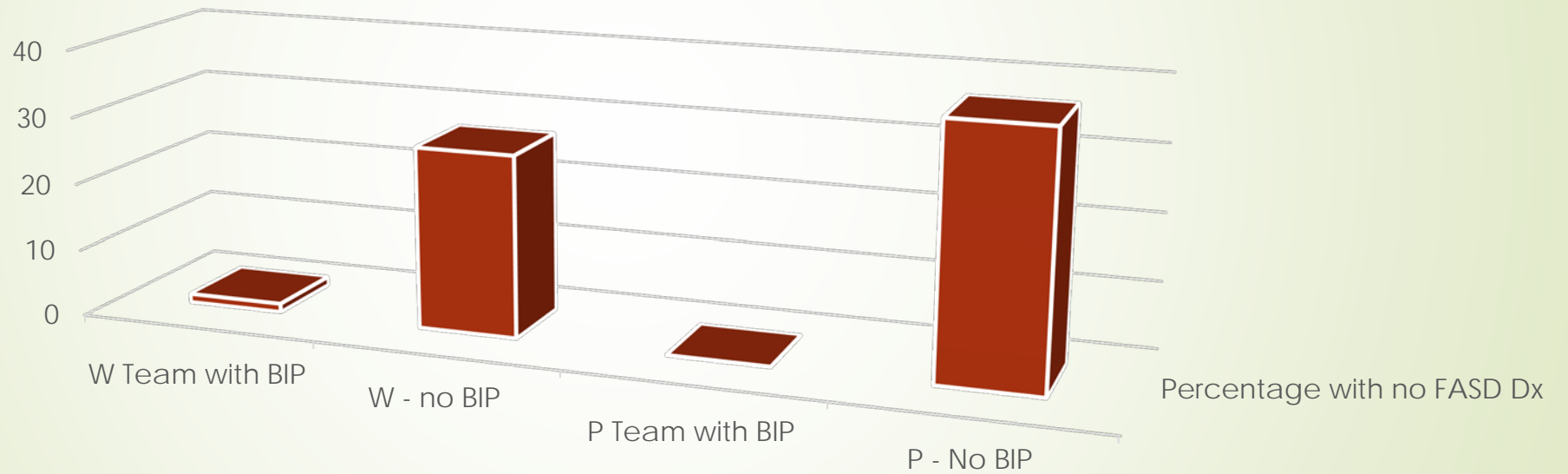
■ \*During sampling time (Caution for possible sampling error: one clinic has computerized data bank while others supplied data manually)



# Method

- All clinics employed same Brain Injury Protocols (BIP) for a period of time (at least 4 years)
- One clinic switched from using BIP (9 years) to not using them (2 years)
- One clinic switched from not using BIP (7 years) to using them (4 years)
- One clinic consistently used BIP (10 years)
- Compared diagnostic rates of FASD with and without BIP

# Results: Brain injury protocol used across 2 virtual teams



# Difference between using BI Protocols

Team	No Diagnosis: With BI Protocols	No Diagnosis: No BI Protocols
W	1.25%	27%
P	0%	37%



# Why more FASD diagnoses with BIP?



# Applying Brain injury Protocols to FASD

- ▶ Variability in population means base rates are very important
- ▶ Pattern of results on individual subtests as well as between subtests very important
- ▶ Questionnaires are not enough on their own (direct testing and/or observation, patterns of behaviour during testing and in other settings)
- ▶ Specific Test lists based on Brain Injury Protocols



# Non BIP Diagnostic Tools used

- Relied on Wechsler tests for direct assessment (e.g.: IQ\* and Academic with relevant test according to child's age)
- Questionnaires used instead of direct assessment for all forms of age appropriate EFs, processing speeds, memory, etc.
- \* IQ in TBI known to be not a good predictor or measure of outcome (Neuropsychologic assessments of memory, attention, and speed of information processing for new learning, however, are often more sensitive indicators of the effects of head injury than standard IQ tests. (Fletcher JM. Memory for verbal and nonverbal stimuli in learning disability subgroups: Analysis by selective reminding. *J Exp Child Psychol.* 1985;40:244–259 & Levin H. S. (2012). Long-term intellectual outcome of traumatic brain injury in children: limits to neuroplasticity of the young brain?. *Pediatrics*, 129(2), e494-5.)



# Brain Injury Protocols Tools & Why

- Using standardized tests known to be useful in separating mild Traumatic Brain Injury (mTBI) from other TBIs (e.g.: moderate) and from controls
- E.g.: CVLT-C and Rey Complex Figure & Recognition both reported as best predictors of outcome and identification of mTBI compared to other memory tests as both give data on active vs passive recall, short term vs long term active recall, plus types of errors (Executive Abilities data), etc. (World Congress on Brain Injury, 2012).



# Brain Injury Protocols Tools & Why

- Use of base rates:
- Base rates inform if statistical differences are important (anything under 15% worth considering)
- Need tests where there are many comparisons between subtests and where subtests are compared to mean score
- Comparisons between clusters or domains not enough
- Also need tests where language demands and memory demand for instructions are lower than typically find on Wechsler
- Therefore for over all cognitive abilities assessment use the DAS-II

# Brain Injury Protocols Tools & Why

- ▶ Use of Patterns of performance
- ▶ When base rates indicate at or over 10% of the population that may still be important in a child's life
- ▶ In order to determine look for patterns of performance
- ▶ E.g.: Processing Speed Base rate = 10% when compared to GCA\*  
but when reviewing CVLT-C noted that pattern on 5 practice trials suggests in consistent performance and that list B immediate recall is weak: evidence of processing speed deficit &/or consistently best performance on long term active recall on various memory tasks

\* GCA = General Conceptual Ability on DAS-II focusses on reasoning and conceptual abilities



# Brain Injury Protocols Tools & Why

- Use of Functional Deficits
- Evidence of functional deficits when the base rate may be at or over 10% and other wise not viewed as a deficit BUT still find evidence in pattern of performance then term it a functional deficit



# Importance of Base Rates

- ▶ Developmental variability is major factor in Brain injury assessment
- ▶ Therefore, if start to see Base rates of 10% or less then likely functional deficits (still very important)

# Examples of Base Rates

- Differences between subtest T scores within Clusters/Domains

Discrepancy Comparisons	Score 1	Score 2	Diff	Critical Value	Sig Dif	Base Rate
VCom-NVoc	53	39	14	11	Y	5-10%

- Differences between subtest T scores and Mean T Score of Core Subtests

Strength/Weakness	Subtest T-Score	Mean T-Score	Diff	Critical Value	H/L	Base Rate
Copying	37	47	-10	7	L	5-10%



# Brain Injury Tests Used by Age

Used by all 3 teams for data collection



# FASD Brain Domain Test Protocol

AGE	Brain Domain	Test	Subtests	Other (age dependent)
Birth to 2y 6m	Cognitive	Bayley III	All cognitive	Not Screener
	Motor	Bayley III	All motor	Not Screener
	Language	Bayley III	All language	Not screener
	Adaptive	Bayley III (ABAS)	Adaptive Subtest Parent/Daycare forms	Independent Observation
	Sensory	Sensory Profile 2		Clinical Judgement

# Test Protocols (Cont)

2y 6m to 4y11m	Cognitive*	DAS-II	All on Early years form	As per age at time of assessment
	Adaptive	ABAS-3	Parent and teacher forms	
	Attention/Memory*	NEPSY-II	Comp of Inst Mem for Designs Narr Mem Sent Rep	As per age at time of assessment
	Executive*	NEPSY-II	Statue Wrd Gen Sp Naming	As per age at time of assessment
	Functional Executive	BRIEF-P	Parent and Teacher Forms	
	Motor/Sensory	Sensory Processing Measure (spm) MABC 2 Beery VMI-6		Pencil Grasp (informal Observation) Clinical Judgement

# Test Protocols (Cont)

5y 0m to 7y11m	Cognitive	DAS-II	All on Early years form OR All age appropriate from Upper Years	PicCon from WISC-IV (6+) if struggle on DAS Similarities  If No SLP: add Language tests from Early Years
	Adaptive	ABAS-3	Parent and teacher forms	Interview format if possible
	Attention/Memory	NEPSY-II	Arrows Aud Att Comp of Inst Mem for Designs Mem for Names Narr Mem Sent Rep Wrd Gen List Learning	Remember to complete the delayed sections of the NEPSY tasks

# Test Protocols (cont)

5.0y to 7y, 11m	Attention/ Memory (cont)	Rey (6+y)  CVLT-C (6+y)	All Parts  All Parts	
	Executive	NEPSY-II*	Animal Sorting Design Fluency Inhibition Route Finding Wrd Generation	As appropriate to age of child at time of testing
	Motor/ Sensory			Pencil Grasp (informal Observation)

# Test Protocol (cont)

8y to 17y 11m	Cognitive*	DAS-II	All School Age + <u>all phonological subtests</u> <u>regardless of age</u>	PicCon from WISC-IV
	Memory	CVLT-C RCFT  DAS-II   NEPSY-II	All parts All parts  RecObl & Delay; DigF & B; RecPic; ReSeqOr; Qualitative Performance on PhonoPro  NarrMem, Mem for Names & SentRep	Can add more memory tests from NEPSY as needed

# Test Protocols (cont)

8y 0m, to 17y.11m	Executive	DK-EFS  BRIEF	V & D Fluency; Stroop; Sorting + Recog; Tower;  Parent & Teacher forms	20 questions (older teens) Any age: If unable to complete parts add in all EF from NEPSY: e.g.: Sort & Inhib if poor reader,
	Adaptive	ABAS-II	Parent & Teacher	
	Motor/ Sensory	DAS-II DK-EFS	Recall Designs #5 Trails (motor speed)	Pencil grasp (informal observations)
©Dr. L. A. Scott	Attention	DAS-II  CVLT-C	Digits F Recog Pic  Trial# 1 & B	



# Caveats

- Consistent capacities on memory tasks (look at raw data)
- Complete all delayed parts of all memory tasks
- NO self reports
- BRIEF does not replace direct assessment



# OUTCOMES

- Increased FASD Diagnostic rates in the community clinics
- No deferred diagnoses now so only one assessment per child (decrease burden on family as process is long and reduces costs)
- Provided evidence to management that the clinics had increased in efficiency





# Summary

- PBI literature was used to update test lists for diagnosing FASD for different age groups and used over at least 4 years to track the outcome.
- Use of BIP processes improved the diagnostic acuity and decreased assessment times.
- Increased diagnostic rates led to increased efficacy and reduced costs in these clinics.
- Schools more readily accepted and understood the results from the use of BIP therefore facilitating families' ability to advocate.




# Differences/Similarities between TBI and FASD outcomes

- Can't use strengths to augment weaknesses as custom in TBI
- Developmental Variability greater in FASD
- Usually broader spectrum of areas of deficit
- Understands less language than can use
- Deficits appear when have to integrate even 2 strengths at one time (e.g.: Processing Speed in active recall from memory)



# Changes to OT and SLP processes

- Because of increase in FASD Diagnostic rate (increased specificity) with BIP
- OT & SLP are now exploring with counterparts in Paediatric Brain Injury what tests they should be considering for FASD clinic
- Next research project!!!



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- Nicole Schween, Student
- Moira Showers, SLP
- Dr. Angelo Simone, M.D.
- Dr. Lana Weaver, M.D.



# Thanks for listening!

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