The National Academies of Science, Engineering and Medicine Presentation

Ira L. Cohen, Ph.D.

January 12, 2024

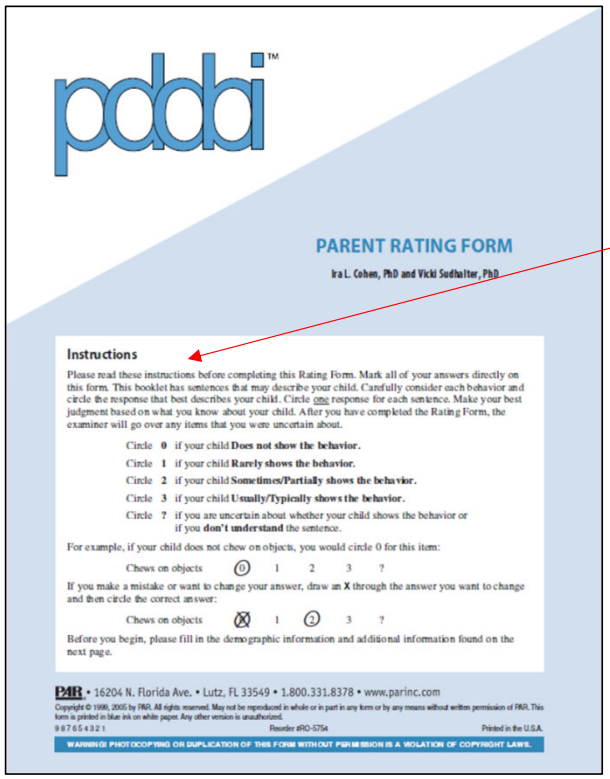
Key Points from the

"Technical Report to the National Coalition for Access to Autism Services (NCAAS):

Department of Defense Reports to the Congress Regarding the Autism Care Demonstration (ACD) projects' Use and Analyses of the PDD Behavior Inventory (PDDBI)" and

How the PDD Behavior Inventory (PDDBI) is Scored and Interpreted

PDDBI Rating Forms (Cohen and Sudhalter, 2005)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PARENT RATING FORM

Ira L. Cohen, PhD and Vicki Sudhalter, PhD

Instructions

Please read these instructions before completing this Rating Form. Mark all of your answers directly on this form. This booklet has sentences that may describe your child. Carefully consider each behavior and circle the response that best describes your child. Circle one response for each sentence. Make your best judgment based on what you know about your child. After you have completed the Rating Form, the examiner will go over any items that you were uncertain about.

Circle **0** if your child **Does not show the behavior.**
Circle **1** if your child **Rarely shows the behavior.**
Circle **2** if your child **Sometimes/Partially shows the behavior.**
Circle **3** if your child **Usually/Typically shows the behavior.**
Circle **?** if you are uncertain about whether your child shows the behavior or if you **don't understand** the sentence.

For example, if your child does not chew on objects, you would circle 0 for this item:

Chews on objects (0) 1 2 3 ?

If you make a mistake or want to change your answer, draw an **X** through the answer you want to change and then circle the correct answer:

Chews on objects (X) 1 (2) 3 ?

Before you begin, please fill in the demographic information and additional information found on the next page.

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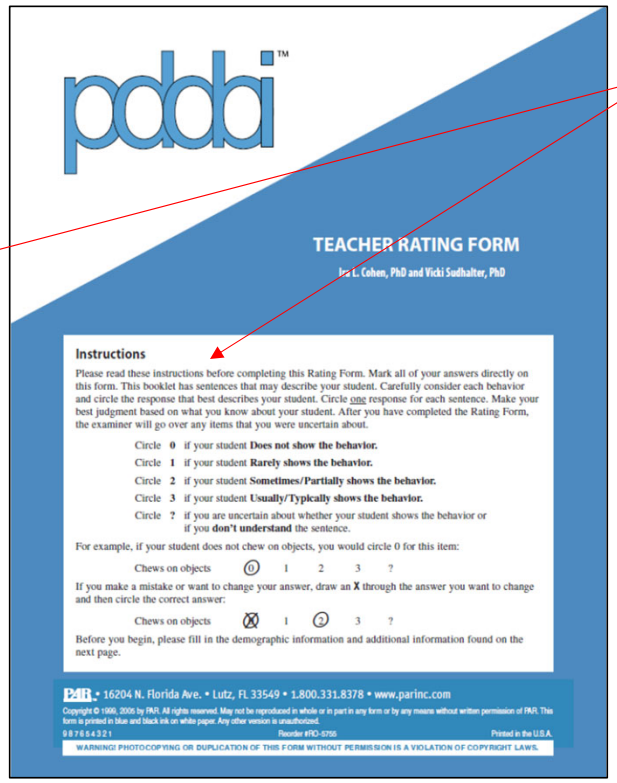
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TEACHER RATING FORM

Ira L. Cohen, PhD and Vicki Sudhalter, PhD

Instructions

Please read these instructions before completing this Rating Form. Mark all of your answers directly on this form. This booklet has sentences that may describe your student. Carefully consider each behavior and circle the response that best describes your student. Circle one response for each sentence. Make your best judgment based on what you know about your student. After you have completed the Rating Form, the examiner will go over any items that you were uncertain about.

Circle **0** if your student **Does not show the behavior.**
Circle **1** if your student **Rarely shows the behavior.**
Circle **2** if your student **Sometimes/Partially shows the behavior.**
Circle **3** if your student **Usually/Typically shows the behavior.**
Circle **?** if you are uncertain about whether your student shows the behavior or if you **don't understand** the sentence.

For example, if your student does not chew on objects, you would circle 0 for this item:

Chews on objects (0) 1 2 3 ?

If you make a mistake or want to change your answer, draw an **X** through the answer you want to change and then circle the correct answer:

Chews on objects (X) 1 (2) 3 ?

Before you begin, please fill in the demographic information and additional information found on the next page.

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Instructions

Please read these instructions before completing this Rating Form. Mark all of your answers directly on this form. This booklet has sentences that may describe your child. Carefully consider each behavior and circle the response that best describes your child. Circle one response for each sentence. Make your best judgment based on what you know about your child. After you have completed the Rating Form, the examiner will go over any items that you were uncertain about.

Circle **0** if your child **Does not show the behavior.**
Circle **1** if your child **Rarely shows the behavior.**
Circle **2** if your child **Sometimes/Partially shows the behavior.**
Circle **3** if your child **Usually/Typically shows the behavior.**
Circle **?** if you are uncertain about whether your child shows the behavior or if you **don't understand** the sentence.

For example, if your child does not chew on objects, you would circle 0 for this item:

Chews on objects (0) 1 2 3 ?

If you make a mistake or want to change your answer, draw an **X** through the answer you want to change and then circle the correct answer:

Chews on objects (X) 1 (2) 3 ?

Before you begin, please fill in the demographic information and additional information found on the next page.

Critique of ACD Reports

I was asked by NCAAS to review **six** reports, all of which used the PDDBI to determine if the children receiving services improved over time. **Here I will focus on just the FY 2018 fourth quarter and 2020 annual reports**:

- **Report to Congress: The Department of Defense Comprehensive Autism Care Demonstration Quarterly Report to Congress Fourth Quarter, Fiscal Year 2018; and**
- **Report to the Committees on Armed Services of the Senate and House of Representatives: The Department of Defense Comprehensive Autism Care Demonstration Annual Report 2020**

In these reports, multiple problems were evident with how the PDDBI was scored and interpreted, which is especially problematic given that their findings have implications for military families needing help for their ASD children

I will cover how the PDDBI is scored and interpreted but first…

I will focus on four issues

Four Issues With ACD's Use of the PDDBI

All Leading to Unsupportable Conclusions

1. Failure to read the manual and understand how the PDDBI is scored leading to:
   a) the discarding of 89% of their original sample secondary to false statements about the PDDBI and its scoring system;
   b) eliminating non-verbal children from the analyses; and
   c) likely eliminating responders
2. Confounding of informants across time points
3. Failure to take the goals of intervention into account leading to examination of only one measure, the Autism Composite, along with lack of consideration of possible mitigating factors (e.g., SIB)
4. Failure to read the manual and understand the clinical significance of change in PDDBI scores along with the lack of matched comparison samples leading to false conclusions about the efficacy of ABA intervention

The DoD Discarded 89% of its original Sample Size

DoD ACD Rept to Congress 4th Quarter, Fiscal Year 2018, p.9:

"Of the 16,044 beneficiaries currently enrolled in the ACD, approximately 14,000 beneficiaries had at least one completed and submitted outcome measure. Of those 14,000 beneficiary files, this report reviews and analyzes 651 beneficiaries with usable scores for comparison of the PDDBI only. Many beneficiary scores noted "0," indicating an incomplete or an unable to answer sections of the PDDBI based on a variety of factors (i.e., direction to not complete a section if the child is non-verbal)."

My response on p.10 of the "Technical Report":
The reason for the elimination of most of the data, i.e., scores of "0" is factually incorrect...
A score of "0" means that the behavior being rated is not present.

It does not mean that the item is missing.

I can only conclude that the persons responsible for scoring the PDDBI had not bothered to read the manual.

If we take this description to its logical conclusion, it would imply that forms for which the child was reported to not show a behavior were not included in the analysis thereby invalidating the interpretation of the results ***since it is possible that cases who had improved (e.g., no longer showing repetitive language or hand flapping) would not be included in the follow-up results, likely biasing the data toward cases that did not change because of the significant number of discarded forms. Until these "missing" data are rescored and included, all of the analyses are suspect.*** *[Emphasis in the original.]*

Assumption: "0" Indicates Incomplete if Child is Non-Verbal

- ***Instructions to not complete a section if the child is non-verbal does not mean that section is incomplete***
  - **PDDBI Manual:** ***"If a respondent has left items in the Semantic/Pragmatic Problems or Expressive Language sections blank because the child cannot say words, the examiner should give a score of "0" for each of the items."*** Immediately after this, **a prorating system for scoring other missing items is described.** (pg. 7)
  - **Possible Consequence** - Children who did not show language on “baseline” and who subsequently improved, i.e., "responders" would not be [and likely were not] counted (because they were dropped from the analysis)
- **Therefore, none of these or subsequent scores *in any of the other reports* can be trusted**
- **A "Garbage In/Garbage Out" problem using a computer science analogy**
- **This issue was never addressed in later reports even though DoD officials, including Dr. Bienia who presented at your last meeting, were informed of the problem, personally, by me at the Pentagon (2/6/20)**
- **Additional help to the DoD was offered at this meeting and was not taken**

Confounding of Parent and Teacher Reports Over Time

"... **the current contract requirements did not specify reporting scores by outcome measure form type (parents vs(.) teacher form)**." **(page 9, 2018 report)**

That is, initial and final reports may have been between parent (first) and teacher (last) or vice-versa

This failure is justified by stating (page 11) that **interrater reliability between parents and teachers for the AUTISM composite score is very high**

- **This is false**
- **In the PDDBI Manual, the correlation is 0.32, largely due to differences in the severity of challenging behaviors as perceived by parents compared with teachers**
    - This issue was also discussed at my meeting at the Pentagon and on a later remote meeting
    - **This confounding was deemed by the agency to be due to a failure to note, in the PDDBI manual, that raters should be the same on follow-up, i.e., inconsistency in informants is ok**

Rater Consistency Is Important

- The PDDBI is a parent/teacher rating instrument
- Like other rating scales, the PDDBI does not use research assistants trained to a high inter-rater reliability criterion (like the ADOS), nor is it required
- The Manual does not say that parent and teacher forms are interchangeable
- In fact, there exist tables (E5-E7) to evaluate the magnitude of parent-teacher discrepancies (can be of clinical importance)
- Parents and teachers see the child in different situations and children do behave differently in different environments and with different people, especially with "challenging" behaviors
  - **This is a common observation by researchers in many studies** (e.g., Lane et al., (2013) Research in Autism Spectrum Disorders, 7, 1196-1203)
  - **The same can be said for parents, one of whom may have been deployed for a while and not had an opportunity to see their child's progress**
- **In interpreting change over time where that judgment has implications for funding intervention, consistency, *including informants*, is critical**
- **Despite being informed of this critical element *three years ago*, I was recently informed that the DoD just changed its TRICARE manual last month to acknowledge the importance of this factor**

Failure to Take the Goals of Intervention Into Account When Interpreting the Autism Composite and Failure to Consider Mitigating Factors

- The ACD reportedly provides funding only for interventions that tackle core deficits in ASD
- **In all these reports, there is no indication as to what the goals of intervention were for a given child**
- As I will describe to you, the AUTISM composite assesses core domains but there are six different domains in this measure and progress in each of these will take time
- **For the AUTISM composite score to change by a very large effect size (one standard deviation in a year; their requirement), changes would have to take place in many or most of these component domains for each child**
  - None of the reports provided information on change in these component domain scores
  - None tied change in scores to the goals of intervention
- In some cases, severe problems with **"non-core" hyperarousal, intense anxiety, self-injury and aggression problems might take priority over change in core deficits** as they would impact the ability of the child to participate in therapy aimed at mitigating core deficits. *Yet, ACD presumably would not provide funding for this*, **and the Autism composite score does not measure this**
  - It is unknown what percentage of cases had such problems that were of such high priority. None of the reports provided information on these other domains

The 2020 report to Congress

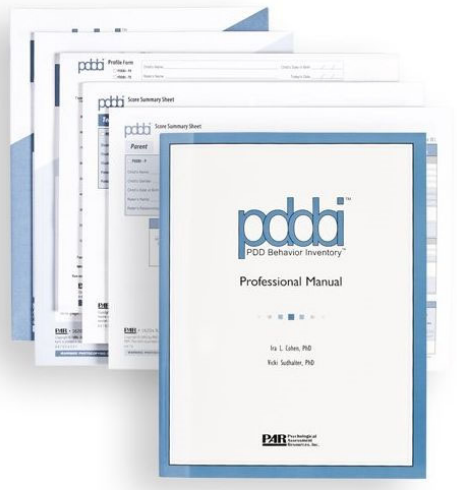
This report provided more detailed analyses of their data (*still failing to take scoring issues into account*) on 3794 children

- Improvements were seen in the AUTISM Composite scores, but the changes seen were minimized by the ACD indicating (pg. 17) that they "**did not know whether these were related to ABA services, maturation, other services received, etc.**"
- They also state (pg. 18): **"Although there was a statistical difference in scores at 12 and 18 month(s), the presented changes do not necessarily indicate clinical improvement especially since the gains are extremely small.** ***To our knowledge, there is no available literature defining how much change would be considered clinically significant..." [italics mine]***
- And (page 24), "… **the findings are clear that ... the small changes noted are not related to ABA services.**"

Clinical Validity and Causal ABA Comments

- The maturation effect seems unlikely since PDDBI scores are **age-normed**
- The data were still compromised and there were no matched comparison samples (goals, methods, IQs, fidelity, etc.) so they couldn't conclude anything about cause
- **The PDDBI Manual has a section on Clinical Validity (pg. 73) and there are multiple published papers on its clinical validity**
- While the mean changes in scores were about 2 to 3 points, the PDDBI Manual indicates that Autism Composite Means for children with ADOS-G Autism (more severe) vs ADOS-G Spectrum (less severe) differ by 5 points
- Therefore, their group was becoming less severe over time
- Grouping all cases without knowing which of the Domains that comprise the AUTISM Composite are being addressed by the therapists means watering down the actual effect as **it assumes all children had the same goals (see appendix)**
- The only thing that can be concluded is that **even with the data quality problems**, many cases in this report improved over time, especially in those cases where such improvement is particularly important (young children and very severely affected children)

How the PDDBI is Structured, Scored, and interpreted



PDDBI DIMENSIONS, DOMAINS and AUTISM COMPOSITE

Two Independent Dimensions Contain The Domains

APPROACH-WITHDRAWAL PROBLEMS (AWP; Higher Scores are More Severe) and

RECEPTIVE/EXPRESSIVE SOCIAL COMMUNICATION ABILITIES (REXSCA; Higher Scores Indicate Better Abilities)

Each Domain in a Dimension Contains Clusters of Items

Bracketed Domains Make Up AUTISM/C

Table 1 PDDBI domain and autism composite descriptions

Abbreviation	Description and characteristics
AWP	Approach-withdrawal problems dimension. Higher domain T-scores indicate greater severity
SENSORY	Sensory/perceptual approach behaviors—staring at objects, pica, repetitive toy play, hand flapping, etc.
RITUAL	Ritualisms/resistance to change—carrying out rituals or indicating dissatisfaction with a change in the environment or routine
SOCPP	Social pragmatic problems—problems reacting to the approaches of others, understanding social conventions, or initiating social interactions
SEMPP	Semantic/pragmatic problems—echolalia, perseverative language, unusual voice quality, etc.
AROUSE	Arousal regulation problems—emotional constriction, hyperactivity, sleeping problems, etc.
FEARS	Specific fears—fears and anxieties associated with withdrawal from social or asocial stimuli
AGG	Aggressiveness—Aggressiveness toward self or others and associated negative mood states
REXSCA[a]	Receptive/expressive social communication abilities dimension. Higher domain scores indicate increasing levels of competence
SOCAPP	Social approach behaviors—non-vocal social communication skills such as paying attention, joint attention, effective use of gesture, imaginative skills, social play skills, imitation skills, etc.
EXPRESS	Expressive language—ability to speak sounds associated with the English language as well as competence with grammar, tone of voice, and conversational pragmatics
LMRL	Learning, memory, and receptive language—memory for locations and movement sequences, understanding possessives, prepositions, adverbs, etc.
AUTISM/C	Autism composite—a measure of lack of appropriate social communication skills along with repetitive/ritualistic behaviors

[a] Each of these domains in the REXSCA dimension is highly correlated with tested IQ [Pearson r (n = 76) ranging from 0.63 to 0.77] and with the Vineland Communication Domain score [Pearson r (n = 238) ranging from 0.52 to 0.69] (Cohen and Sudhalter 2005)]

Example of a Domain and its Clusters – Parent Form

In the SENSORY Domain there are 5 clusters with 4 items per cluster

Cluster raw scores are computed by summing the item scores

The domain raw score is computed by summing the cluster scores

This same procedure is applied to all other domains

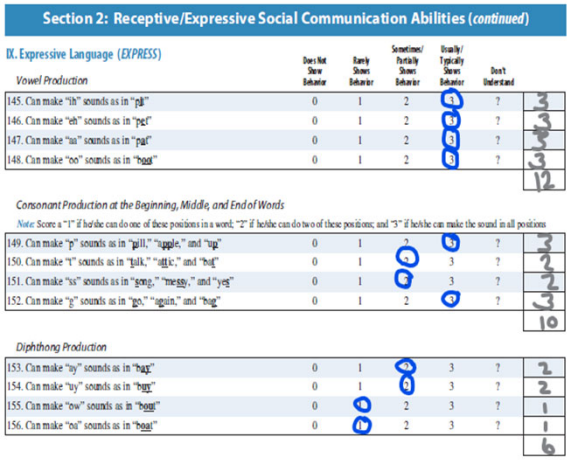
While domains have the same names across Parent and Teacher forms, clusters can differ (e.g., the "sleep regulation problems" cluster is not assessed in the Teacher form)

Section 1: Approach/Withdrawal Problems

I. Sensory/Perceptual Approach Behaviors (*SENSORY*)	Does Not Show Behavior	Rarely Shows Behavior	Sometimes/ Partially Shows Behavior	Usually/ Typically Shows Behavior	Don't Understand	
Visual Behaviors						
1. Stares at or looks out of sides of eyes at his/her own image in mirror	0	1	(2)	3	?	2
2. Stares at or looks out of sides of eyes at objects (e.g., toys, strings)	0	1	2	(3)	?	3
3. Stares at or looks out of sides of eyes at his/her fingers or hands	0	(1)	2	3	?	1
4. Stares at or looks out of sides of eyes at lights or shiny objects	(0)	1	2	3	?	0
						6
Non-Food Taste Behaviors						
5. Licks or mouths objects	0	(1)	2	3	?	1
6. Licks or mouths hands	0	(1)	2	3	?	1
7. Chews on objects	0	1	2	(3)	?	3
8. Eats (swallows) inedible (non-food) objects (e.g., dirt, paper, plastic)	0	1	(2)	3	?	2
						7
Touch Behaviors						
9. Rubs or taps own face or arms repetitively	0	(1)	2	3	?	1
10. Rubs or taps own torso (i.e., stomach, chest) or legs repetitively	0	1	2	(3)	?	3
11. Rubs or taps rough objects (e.g., sandpaper, unshaved faces) repetitively	0	1	2	(3)	?	3
12. Rubs liquid-like substances (e.g., water, saliva) repetitively	0	1	2	(3)	?	3
						10
Proprioceptive/Kinesthetic Behaviors						
13. Flaps hands up and down	(0)	1	2	3	?	0
14. Makes odd or unusual finger movements (e.g., flicks fingers)	0	(1)	2	3	?	1
15. Holds fingers, hands, or arms in odd or unusual postures (e.g., spreads fingers apart, holds hand bent at the wrist, holds arms out to the side)	(0)	1	2	3	?	0
16. Jumps repetitively	(0)	1	2	3	?	0
						1
Repetitive Manipulative Behaviors						
17. Repetitively twiddles or bangs objects or flaps objects back and forth	0	1	2	(3)	?	3
18. Spins objects (e.g., wheels of toy cars, strings) in a repetitive manner	0	(1)	2	3	?	1
19. Throws objects around, rips or tears paper or other material	0	1	(2)	3	?	2
20. Repetitively moves objects back and forth (e.g., turns pages back and forth, opens and closes doors, turns lights on and off)	0	1	(2)	3	?	2
						8
					Sum of Items 1-20 →	*SENSORY* 32

Figure 2.2. Example of calculating PDDBI raw domain score.

Correct Scoring for "Non-Verbal" Case Who Can Make Word Sounds But Who Has No Syntactic, Semantic or Pragmatic Language Skills



Section 2: Receptive/Expressive Social Communication Abilities (*continued*)

IX. Expressive Language (*EXPRESS*)

Vowel Production

	Does Not Show Behavior	Rarely Shows Behavior	Sometimes/ Partially Shows Behavior	Usually/ Typically Shows Behavior	Don't Understand	
145. Can make "ih" sounds as in "pit"	0	1	2	3	?	3
146. Can make "eh" sounds as in "pet"	0	1	2	3	?	3
147. Can make "ai" sounds as in "pat"	0	1	2	3	?	3
148. Can make "oo" sounds as in "boot"	0	1	2	3	?	3
						12

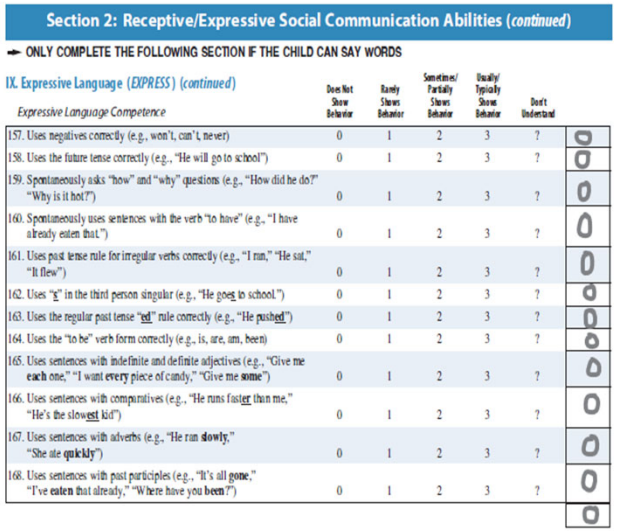
Consonant Production at the Beginning, Middle, and End of Words

Note: Score a "1" if he/she can do one of these positions in a word; "2" if he/she can do two of these positions; and "3" if he/she can make the sound in all positions

149. Can make "p" sounds as in "pill," "apple," and "up"	0	1	2	3	?	3
150. Can make "t" sounds as in "tilk," "attic," and "bat"	0	1	2	3	?	2
151. Can make "ss" sounds as in "song," "messy," and "yes"	0	1	2	3	?	2
152. Can make "g" sounds as in "go," "again," and "bag"	0	1	2	3	?	3
						10

Diphthong Production

153. Can make "ay" sounds as in "bay"	0	1	2	3	?	2
154. Can make "uy" sounds as in "buy"	0	1	2	3	?	2
155. Can make "ow" sounds as in "boat"	0	1	2	3	?	1
156. Can make "oa" sounds as in "boat"	0	1	2	3	?	1
						6



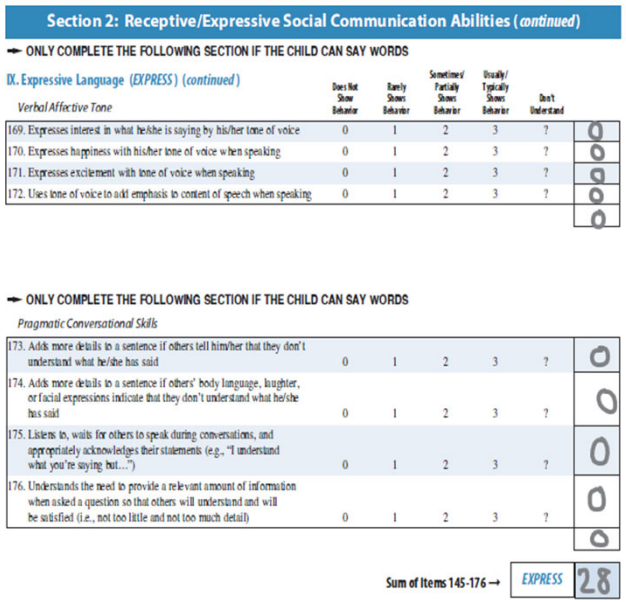
Section 2: Receptive/Expressive Social Communication Abilities (*continued*)

➡ **ONLY COMPLETE THE FOLLOWING SECTION IF THE CHILD CAN SAY WORDS**

IX. Expressive Language (*EXPRESS*) (*continued*)

Expressive Language Competence

	Does Not Show Behavior	Rarely Shows Behavior	Sometimes/ Partially Shows Behavior	Usually/ Typically Shows Behavior	Don't Understand	
157. Uses negatives correctly (e.g., won't, can't, never)	0	1	2	3	?	0
158. Uses the future tense correctly (e.g., "He will go to school")	0	1	2	3	?	0
159. Spontaneously asks "how" and "why" questions (e.g., "How did he do?" "Why is it hot?")	0	1	2	3	?	0
160. Spontaneously uses sentences with the verb "to have" (e.g., "I have already eaten that.")	0	1	2	3	?	0
161. Uses past tense rule for irregular verbs correctly (e.g., "I ran," "He sat," "It flew")	0	1	2	3	?	0
162. Uses "s" in the third person singular (e.g., "He goes to school.")	0	1	2	3	?	0
163. Uses the regular past tense "ed" rule correctly (e.g., "He pushed")	0	1	2	3	?	0
164. Uses the "to be" verb form correctly (e.g., is, are, am, been)	0	1	2	3	?	0
165. Uses sentences with indefinite and definite adjectives (e.g., "Give me **each** one," "I want **every** piece of candy," "Give me **some**")	0	1	2	3	?	0
166. Uses sentences with comparatives (e.g., "He runs faster than me," "He's the slowest kid")	0	1	2	3	?	0
167. Uses sentences with adverbs (e.g., "He ran **slowly**," "She ate **quickly**")	0	1	2	3	?	0
168. Uses sentences with past participles (e.g., "It's all **gone**," "I've **eaten** that already," "Where have you **been**?")	0	1	2	3	?	0
						0



Section 2: Receptive/Expressive Social Communication Abilities (*continued*)

➡ **ONLY COMPLETE THE FOLLOWING SECTION IF THE CHILD CAN SAY WORDS**

IX. Expressive Language (*EXPRESS*) (*continued*)

Verbal Affective Tone

	Does Not Show Behavior	Rarely Shows Behavior	Sometimes/ Partially Shows Behavior	Usually/ Typically Shows Behavior	Don't Understand	
169. Expresses interest in what he/she is saying by his/her tone of voice	0	1	2	3	?	0
170. Expresses happiness with his/her tone of voice when speaking	0	1	2	3	?	0
171. Expresses excitement with tone of voice when speaking	0	1	2	3	?	0
172. Uses tone of voice to add emphasis to content of speech when speaking	0	1	2	3	?	0
						0

➡ **ONLY COMPLETE THE FOLLOWING SECTION IF THE CHILD CAN SAY WORDS**

Pragmatic Conversational Skills

173. Adds more details to a sentence if others tell him/her that they don't understand what he/she has said	0	1	2	3	?	0
174. Adds more details to a sentence if others' body language, laughter, or facial expressions indicate that they don't understand what he/she has said	0	1	2	3	?	0
175. Listens to, waits for others to speak during conversations, and appropriately acknowledges their statements (e.g., "I understand what you're saying but...")	0	1	2	3	?	0
176. Understands the need to provide a relevant amount of information when asked a question so that others will understand and will be satisfied (i.e., not too little and not too much detail)	0	1	2	3	?	0
						0

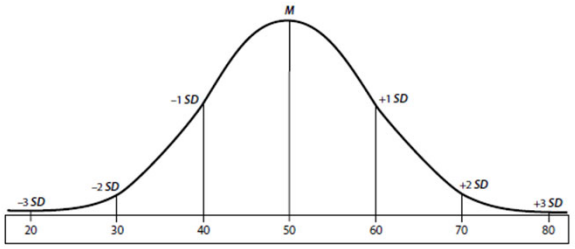
Sum of Items 145-176 → *EXPRESS* 28

15

Scoring and Interpretation

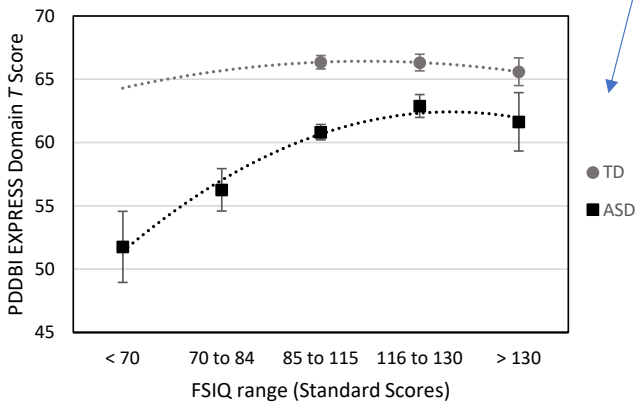
Raw Scores are Transformed (on-line or by consulting tables) into Age-Standardized T-Scores (50 +/- 10 points)

The T-Scores Are Normally Distributed Based on a Well-Diagnosed ASD Sample (ADI-R, ADOS-G, DSM IV, Clinician)



Dimension/Domain/**Composite**	*T* score		
Approach-Withdrawal Problems Dimension SENSORY, RITUAL, SOCPP, SEMPP, AROUSE, FEARS, AGG **REPRIT/C, AWP/C**	Mild problems/ Atypically low for ASD	Average for ASD	Severe problems/ Atypically high for ASD
Receptive-Expressive Social Communication Abilities Dimension SOCAPP, EXPRESS, LMRL **EXSCA/C, REXSCA/C**	Low abilities/ Atypical for ASD	Average for ASD	High abilities/ Atypical for ASD
AUTISM	Mild/ Atypically low for ASD	Average for ASD	Severe/ Atypically high for ASD

Figure 3.1. Distribution and interpretation of PDDBI *T* scores.



On-Line PDDBI T-Score Profile Output for a Two-Year-Old With ASD

Domain/Composite Score Summary

Domain/*composite*	Raw score	*T* score	90% CI
Approach/Withdrawal Problems			
Sensory/Perceptual Approach Behaviors (SENSORY)	24*	52	46–58
Ritualisms/Resistance to Change (RITUAL)	0	40	33–47
Social Pragmatic Problems (SOCPP)	6	56	46–66
Semantic/Pragmatic Problems (SEMPP)	0	42	33–51
Arousal Regulation Problems (AROUSE)	21	59	52–66
Specific Fears (FEARS)	10	49	43–55
Aggressiveness (AGG)	1	41	36–46
Repetitive, Ritualistic, and Pragmatic Problems Composite (REPRIT/C)	30*	53	47–59
Approach/Withdrawal Problems Composite (AWP/C)	62*	52	48–56
Receptive/Expressive Social Communication Abilities			
Social Approach Behaviors (SOCAPP)	37	48	43–53
Expressive Language (EXPRESS)	8	40	34–46
Learning, Memory, and Receptive Language (LMRL)	3	42	35–49
Expressive Social Communication Abilities Composite (EXSCA/C)	45	44	39–49
Receptive/Expressive Social Communication Abilities Composite (REXSCA/C)	48	43	39–47
Autism Composite (AUTISM)	102*	51	45–57

Note. "---" = missing data. | *Scale was calculated using prorated score(s).

○ Average for ASD ● Severe problems/low abilities

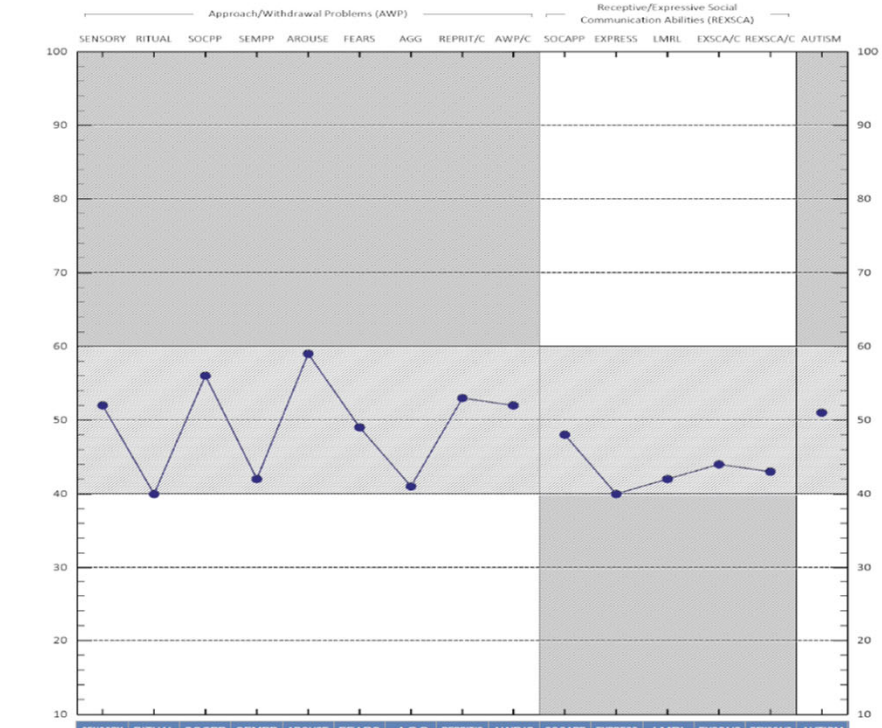
Discrepancy Score Summary

Discrepancy score	Absolute difference	Cumulative percentage
SOCPP-SOCAPP	8	62.7
SEMPP-EXPRESS	2	91.3

Autism Spectrum Disorder Decision Tree

ASD CLASSIFICATION

Minimally Verbal ASD
(ASD-DT classification node 1.2)



	SENSORY	RITUAL	SOCPP	SEMPP	AROUSE	FEARS	AGG	REPRIT/C	AWP/C	SOCAPP	EXPRESS	LMRL	EXSCA/C	REXSCA/C	AUTISM
T-score	52	40	56	42	59	49	41	53	52	48	40	42	44	43	51
90% CI	46–58	33–47	46–66	33–51	52–66	43–55	36–46	47–59	48–56	43–53	34–46	35–49	39–49	39–47	45–57
Raw score	24*	0	6	0	21	10	1	30*	62*	37	8	3	45	48	102*

AWP & AUTISM Few to no problems | Average for ASD | Severe problems

REXSCA High abilities | Average for ASD | Low abilities

Note. "---" = missing data. | *Scale was calculated using prorated score(s).

Cluster Score Summary Tables Are Also Computed

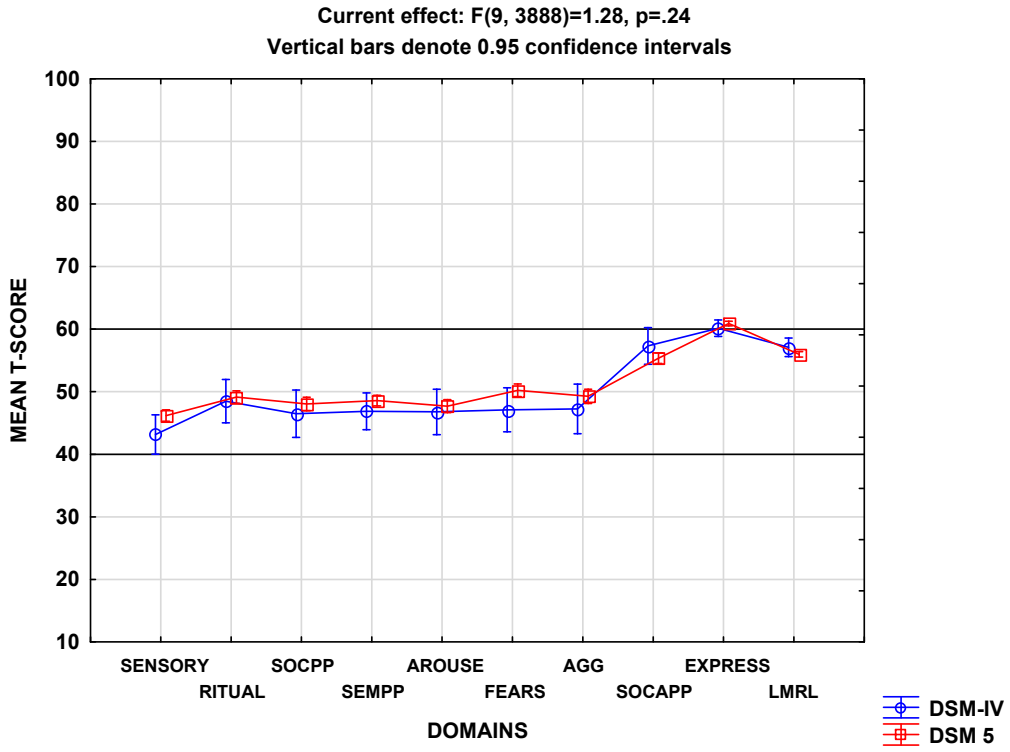
(See Appendix)

- Cluster scores enable one to "drill down" to see which clusters contribute most to the overall domain T-score and can be helpful in making clinical decisions and in treatment planning
- Cluster scores within domains can be qualitatively examined along an ordinal dimension for their clinical importance and can be qualitatively monitored for change over time
- Percentile ranges are at 4 ordinal levels:
  - < = 33rd %ile Low for ASD
  - 34th-74th %ile Moderate for ASD
  - 75th-94th %ile High for ASD
  - > = 95th %ile Very High for ASD

DOMAIN PROFILES FOR ASD CASES ARE CONSISTENT ACROSS DSM-IV (IBR/DD) AND DSM V (YALE) CRITERIA*

*(CONTROLLING FOR AGE AND IQ LEVEL)

MEANS +/- 95% CIs ARE WITHIN THE EXPECTED RANGE FOR ASD



*Thanks to James McPartland, Ph.D., Director, Yale Developmental Disabilities Clinic, for some of this data

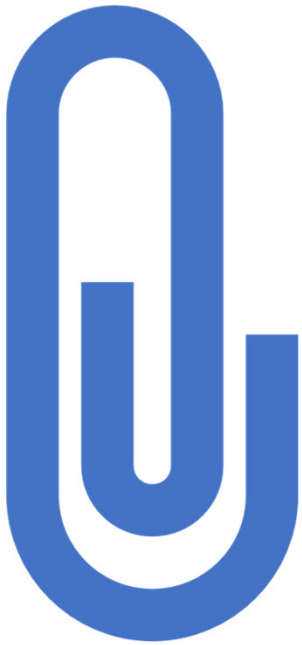
PDDBI Summary

- Reliability established (Internal Consistency of items in domains; Interrater; Test-Retest)
- Validity established (Correlation Matrices across domains and composites; Developmental; Construct (Principal Components Analysis); Criterion (e.g., Vineland, IQ, CARS, Aberrant Behavior Checklist, etc.); Clinical (e.g., ADI-R, ADOS-G, ADOS-2, Seizure History)
- Shows consistent results across DSM IV and 5 diagnoses
- Widely used in research (>560 references on Google Scholar as of 12/24/2023)
- Reading Level: Flesch-Kincaid Reading Level – Grade 4.7; Gunning Fog Index – 7.8 ("Reader's Digest" level)
- Translated into 8 different languages (on-line Spanish version available)
- Sensitive to a variety of **clinically and research relevant** variables (see references from our group in Appendix)

Final Comments on The ACD Findings

- The ACD is charged with assessing outcome
- They can't assess causality as currently designed
- For all we know, the static cases may have benefitted from intervention by not worsening over time (e.g., increases in aggression or self-injury)
- A properly designed research study would be helpful with this cohort for recommendations on efficacy of ABA, as well as other common therapies such as Occupational, Physical, Speech, Sensory Integration, etc.
- Here, informed consent would be required indicating the duties and responsibilities of all parties; and families would not be prevented from getting intervention if they decided to not participate or complete any required forms
- The data analyses in these reports were simply inadequate and cannot answer causative factors
- Averages are not that informative if you don't ask the right questions

Thank you for your attention



Appendix

1. PDDBI assessments and manuals
2. Background references for the PDDBI
3. Peer-reviewed publications on the PDDBI from our group
4. “Why Knowing Goals Is Important” Table
5. Case graphs and cluster score example
6. Relation between the ADOS-2 Comparison Score and PDDBI Composite T-scores

PDDBI Assessments and Manuals

PDD Behavior Inventory (PDDBI; 2005)

Ages 1.5 – 12.5 years

PDD Behavior Inventory Screening Version (PDDBI-SV; 2011) - 5 to 10 minutes to complete. For screening at-risk children and assessing severity

Level 1

Ages 1.5-12.5 years

PDDBI Adolescent Normative Data (2017) –

For follow-up assessments

Ages 12.6 – 18.5 years

Autism Spectrum Disorder Decision Tree (ASD-DT; 2011) – For assisting with diagnosis (Level 2), subtyping, and assessment recommendations

Ages 1.5 – 12.5 years

PDDBI Professional Manual Supplement (2023)

Ages 1.5-12.5 years

For providing statistical significance of parent-teacher T-score differences and the statistical significance of change over time for individual cases using the Reliable Change Index

Background References

Field Test Version

Cohen, I.L., Schmidt-Lackner, S., Romanczyk, R., and Sudhalter, V. (2003). The PDD Behavior Inventory: A rating scale for assessing response to intervention in children with PDD. Journal of Autism and Developmental Disorders, 33(1), 31-45.

Cohen, I.L. (2003). Criterion-related validity of the PDD Behavior Inventory. Journal of Autism and Developmental Disorders, 33(1), 47-53.

Published Versions and Supplements by Psychological Assessment Resources, Inc.

Cohen, I.L. and Sudhalter, V. (2005). **The PDD Behavior Inventory.** Lutz, FL: Psychological Assessment Resources, Inc.

Cohen, I.L. (2011). **The PDD Behavior Inventory-Screening Version (PDDBI-SV).** Lutz, FL: Psychological Assessment Resources, Inc.

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Cohen, I.L. and Sady, M.D. (2023). **PDDBI Professional Manual Supplement: Advanced Score, Multirater, and Progress Monitoring Interpretation.** Lutz, FL: Psychological Assessment Resources, Inc.

Peer-Reviewed References on the PDDBI from Our Group

- Cohen, I.L., Schmidt-Lackner, S., Romanczyk, R., and Sudhalter, V. (2003). The PDD Behavior Inventory: A rating scale for assessing response to intervention in children with PDD. **Journal of Autism and Developmental Disorders, 33(1), 31-45.**
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- Cohen, I.L., Rovito-Gomez, T., Gonzalez, M., Lennon, E.M., Karmel, B.Z., and Gardner, J.M. (2010). Parent PDD Behavior Inventory profiles of young children classified according to Autism Diagnostic Observation Schedule-Generic and Autism Diagnostic Interview-Revised criteria. **Journal of Autism and Developmental Disorders**, 40, 246-254.
- Karmel, B.Z., Gardner, J.M., Swensen, L.D., Cohen, I.L., London, E., Flory, M.J., Lennon, E.M., Rabinowitz, S., Parab, S., Barone, A., and Harin, A. (2010). Early medical and behavioral characteristics of NICU infants later diagnosed with Autism Spectrum Disorder (ASD). **Pediatrics**, 126*,* 457-467.
- Cohen, I.L., Liu, X., Lewis, M.E., Chudley, A., Forster-Gibson, C., Gonzalez, M., Jenkins, E.C., Brown, W.T., and Holden, J.J.A. (2011). Autism severity is associated with child and maternal MAOA genotypes. **Clinical Genetics**, 79, 355-362. Epub 2010, May 22.
- Cohen, I.L., Gardner, J.M., Karmel, B.Z., Phan, H.T.T., Kittler, P.M., Rovito-Gomez, T., Gonzalez, M., Lennon, E.M., Parab, S.L., and Barone, A.L. (2012). Neonatal brainstem function and four-month Arousal−Modulated Attention are jointly associated with autism. **Autism Research**, 6, 11-22.
- Cohen IL**.** (2013). Behaviour profiles of children with attention deficit hyperactivity disorder and autism spectrum disorder on the parent PDD Behaviour Inventory. **OA Autism**, 1(1),10.
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- Cohen, I. L., Liu, X., Hudson, M., Gillis, J., Cavalari, R. N., Romanczyk, R. G. et al. (2017). Level 2 screening with the PDD Behavior Inventory: Subgroup profiles and implications for differential diagnosis (invited article). **Canadian Journal of School Psychology,** 32 (3/4), 299-315.
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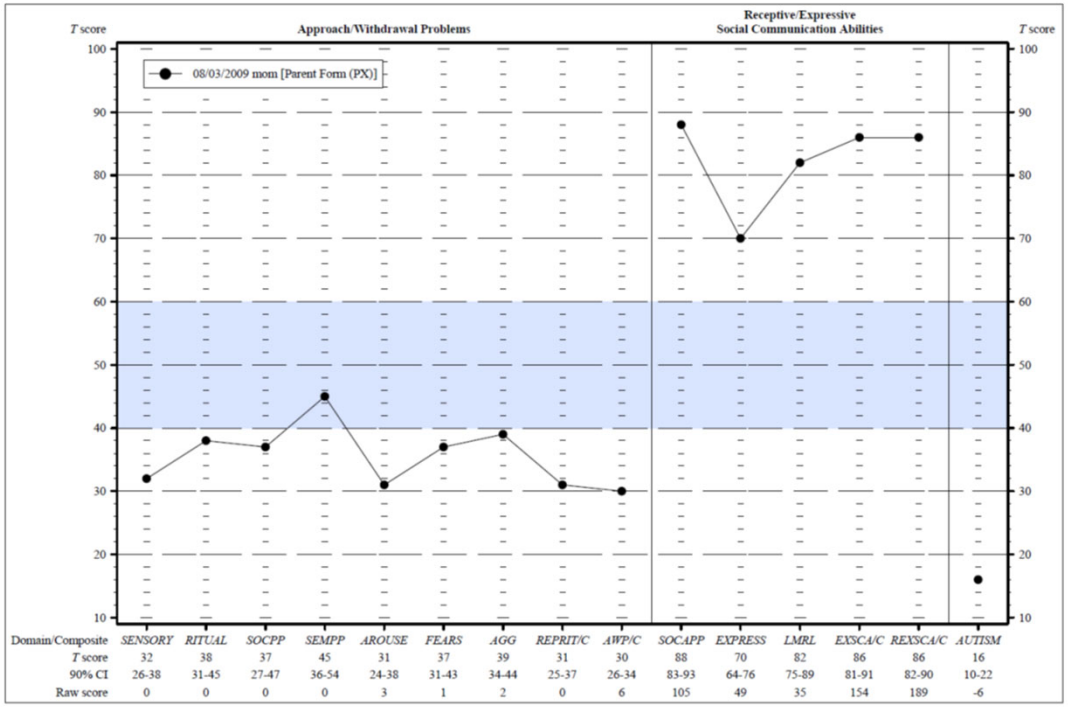
Why Knowing Goals Are Important
Hypothetical Average Baseline – Follow-Up Differences According to Goals
Results Match the Goals and Effect Sizes are Medium to Large
But the Groups Are Matched to Have the Same AUTISM/C Effect Size

	CASES GROUPED BY GOALS							
	UNKNOWN VARIETY OF GOALS				***IMPROVE SOCIAL AND LANGUAGE SKILLS***			
CORE DOMAINS	**BASELINE**	**FOLLOW-UP**	**COHEN'S D**	**EFFECT SIZE**	**BASELINE**	**FOLLOW-UP**	**COHEN'S D**	**EFFECT SIZE**
SENSORY	50	48	-0.2	SMALL	50	48	-0.3	SMALL
RITUAL	50	50	0.0	N/A	50	53	+0.3	SMALL
SOCPP	50	48	-0.2	SMALL	50	48	-0.2	SMALL
SEMPP	50	48	-0.2	SMALL	**50**	**55**	**+0.5**	**MEDIUM***
REPRIT SUM (1)	200	194			200	204		
SOCAPP	50	51	+0.1	N/A	**50**	**58**	**+0.8**	**LARGE***
EXPRESS	50	51	+0.1	N/A	**50**	**55**	**+0.5**	**MEDIUM***
EXSCA SUM (2)	100	103			100	113		
AUTISM RAW SCORE ((1) - (2))	100	91			100	91		
AUTISM/C T-SCORE	*50*	*47*	*-.3*	***SMALL***	*50*	*47*	*-.3*	***SMALL***

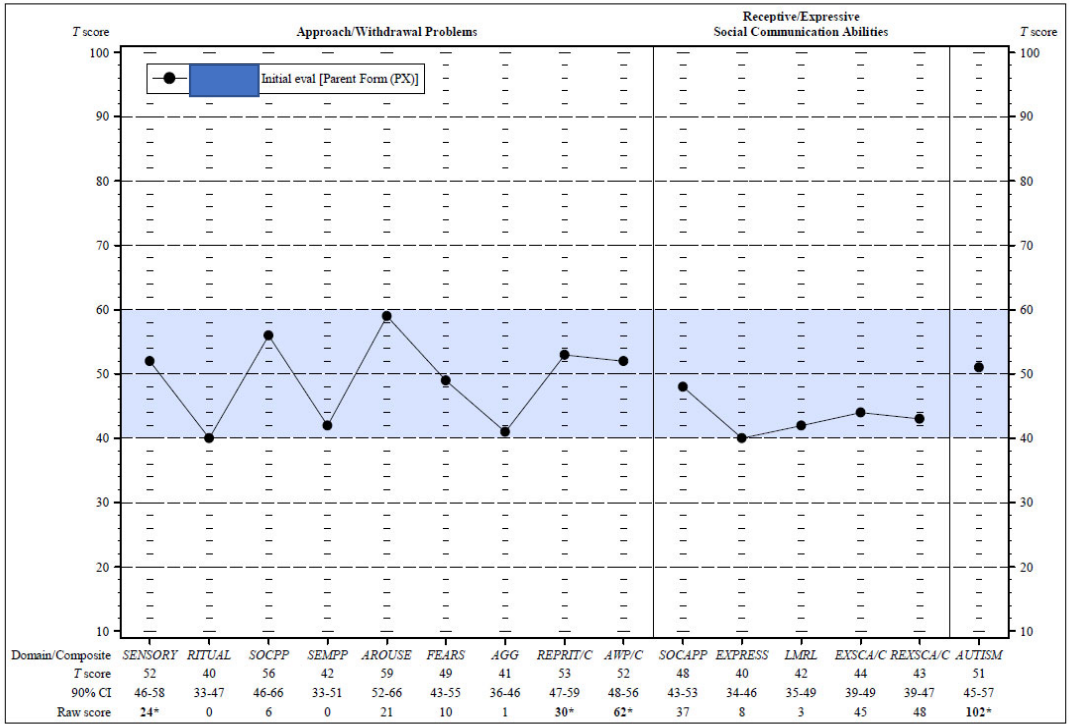
Profile of “Typically Developing” 2-Year-Old on the PDDBI-PX

Note the low Autism Composite

For typicals, the Autism/C T-score averages about 20 (+/- 3) or 3 SDs from ASD cases)



2-year-old with Autism



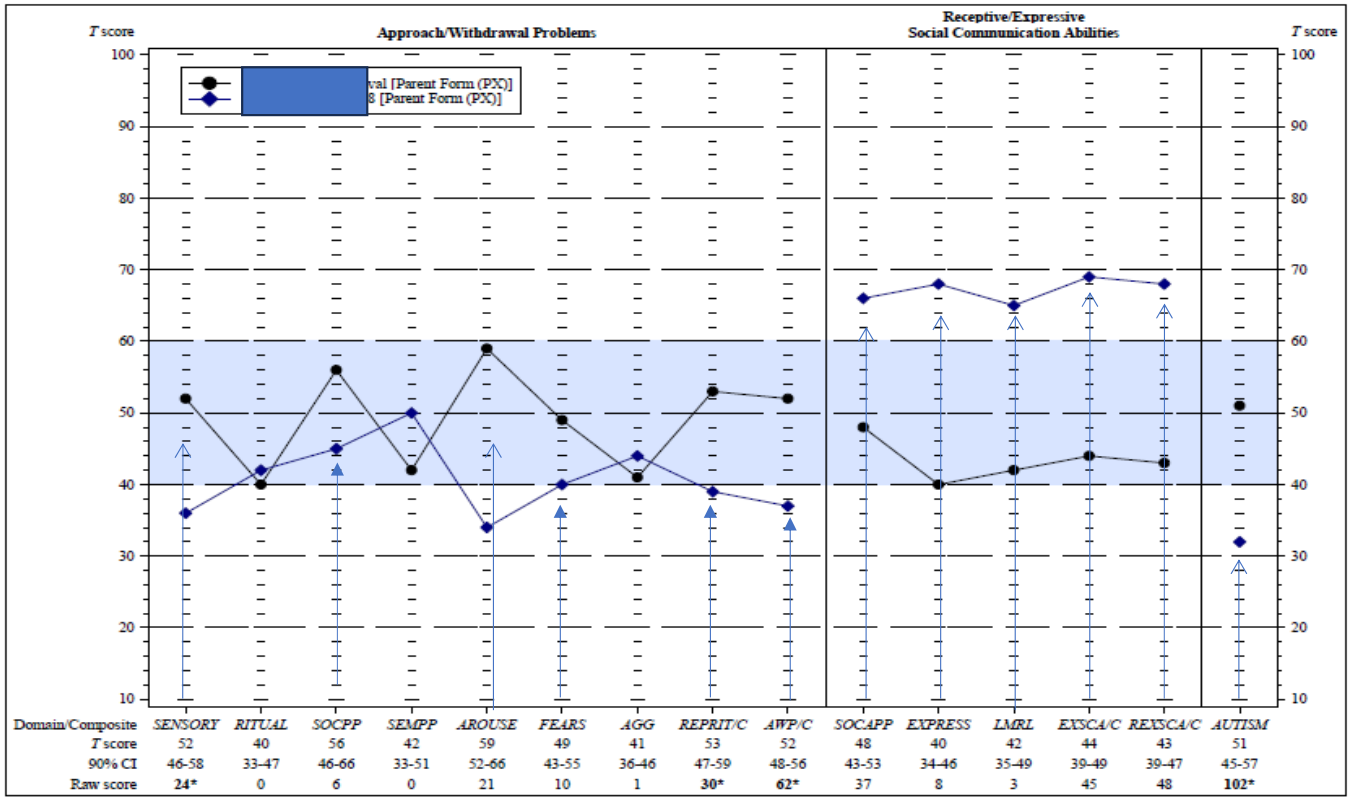
Domain/Composite	SENSORY	RITUAL	SOCPP	SEMPP	AROUSE	FEARS	AGG	REPRIT/C	AWP/C	SOCAPP	EXPRESS	LMRL	EXSCA/C	REXSCA/C	AUTISM
T score	52	40	56	42	59	49	41	53	52	48	40	42	44	43	51
90% CI	46-58	33-47	46-66	33-51	52-66	43-55	36-46	47-59	48-56	43-53	34-46	35-49	39-49	39-47	45-57
Raw score	**24***	0	6	0	21	10	1	**30***	**62***	37	8	3	45	48	**102***

Same Child

2 years and at 4 years

Before (black) and After (blue) Intensive ABA Therapy

Arrows Highlght Follow-Up T-Scores Beyond the 90% CI at Baseline



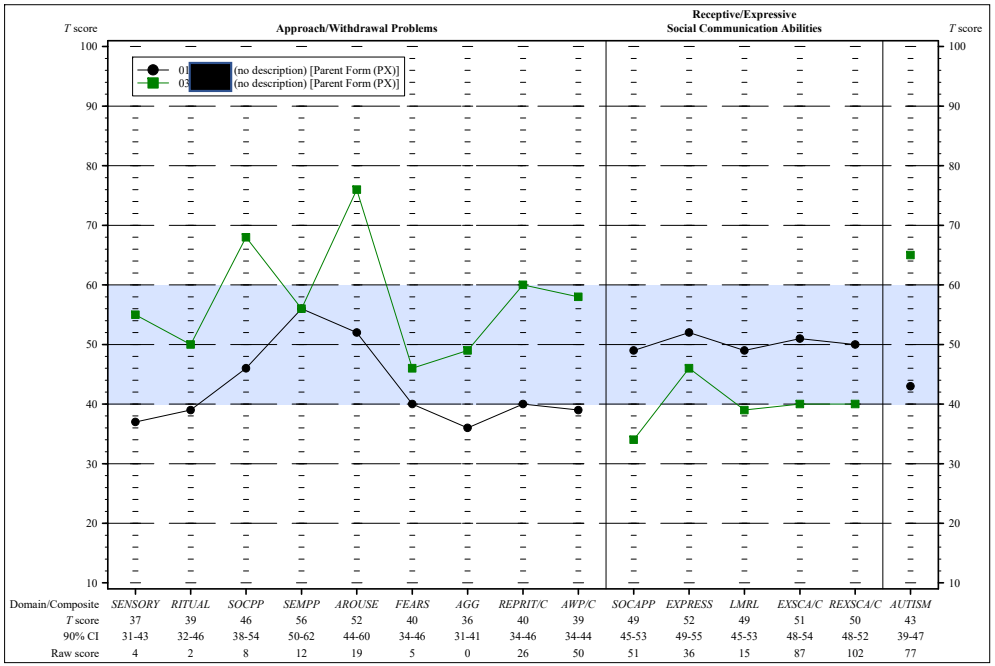
Three-Year-Old Male With ASD Followed One Year Later

His T-Scores Worsened

Follow-Up T-Scores (in green) greater than the 90% CI in SENSORY, RITUAL, SOCPP, AROUSE, and AGG Domains and composite scores. Worse than the 90% CI in SOCAPP, EXPRESS, and LMRL domains and composite scores.

Neurological Evaluation Revealed He Had Epileptic Aphasia.

Autism/C Increased to >60



Domain/Composite	*SENSORY*	*RITUAL*	*SOCPP*	*SEMPP*	*AROUSE*	*FEARS*	*AGG*	*REPRIT/C*	*AWP/C*	*SOCAPP*	*EXPRESS*	*LMRL*	*EXSCA/C*	*REXSCA/C*	*AUTISM*
T score	37	39	46	56	52	40	36	40	39	49	52	49	51	50	43
90% CI	31-43	32-46	38-54	50-62	44-60	34-46	31-41	34-46	34-44	45-53	49-55	45-53	48-54	48-52	39-47
Raw score	4	2	8	12	19	5	0	26	50	51	36	15	87	102	77

Cluster Scores For a Male with Fragile X Syndrome
His Social "Approach/Withdrawal" Cluster Profile is Classic

Inappropriate Reactions.. Others	Very High
Verbal Pragmatic Deficits	Very High
Visual Social Approach	Very High
Positive Affect	Very High
Gestural Approach	Very High
Imaginative Play	Very High
Empathy	High
Social Imitative	High
Social Interaction	Moderate
Social Play	Low

Full Mutation: Behavioral Phenotype

Classic Gaze Aversion of Fragile X

www.fragilex.org

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Cincinnati Children's

The EXSCA Composite T-Score Agrees With Observations of Autism Severity on the ADOS-2 More Than the REPRIT Composite T-Score for Both Parent and Teacher Informants in Children Diagnosed with ASD (see text)

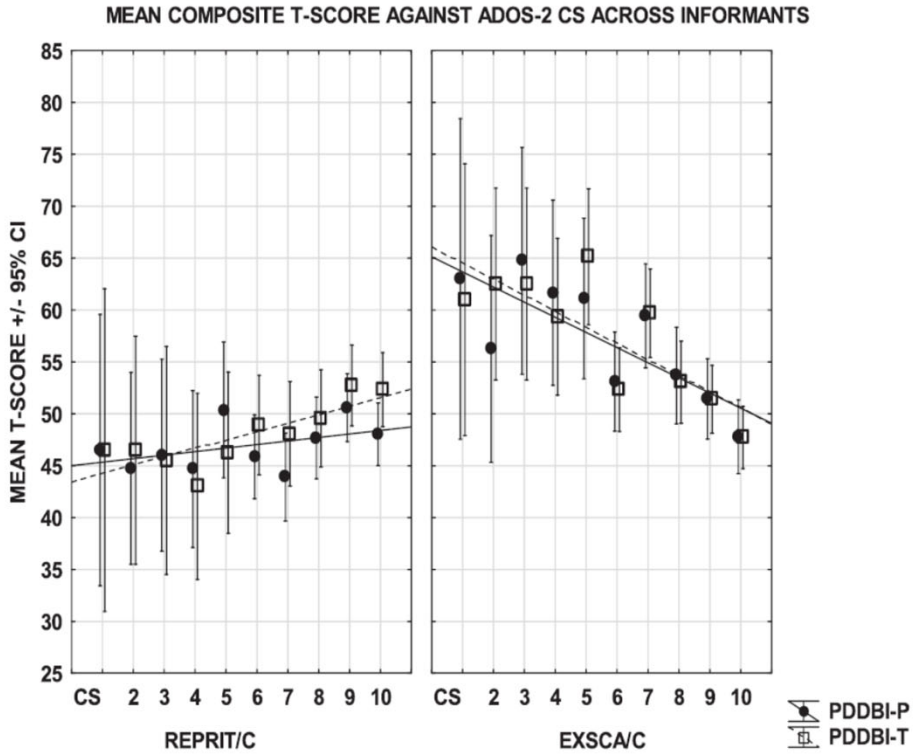

Fig. 1. This figure shows the linear relationship between the mean (± 95 % CI) REPRIT/C T-score (left) and EXSCA/C T-score (right) at each ADOS-2 Comparison Score level for both parent (PDDBI-P) and teacher (PDDBI-T) forms. For REPRIT/C, higher scores indicate increased severity. For EXSCA/C, higher scores indicate increased ability. See text.