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USING TELEHEALTH TO TREAT PANS/PANDAS: HEALTH AND BEHAVIORAL CONSIDERATIONS (Part II)

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Outcome Objectives

- Describe how to use telehealth to better understand the bio-behavioral presentations of PANS/PANDAS
- Identify two family accommodations and two secondary gains in family systems via telehealth.
- Make appropriate behavior therapy recommendations indicated by empirically supported practices

Diagnostic Terminology

- **CPAE**
  Childhood Post-Infectious Autoimmune Encephalopathy

- **PANDAS**
  Pediatric Autoimmune Neuropsychiatric Disorders Associated with Group A Strep

- **PANS**
  Pediatric Autoimmune Neuropsychiatric Syndrome

Current Collaboration - CPAE

Required:

Abrupt-onset (within 72 hours of infection/illness)

Obsessive-Compulsive Disorder (OCD)

+/- Restricted eating (ARFID)

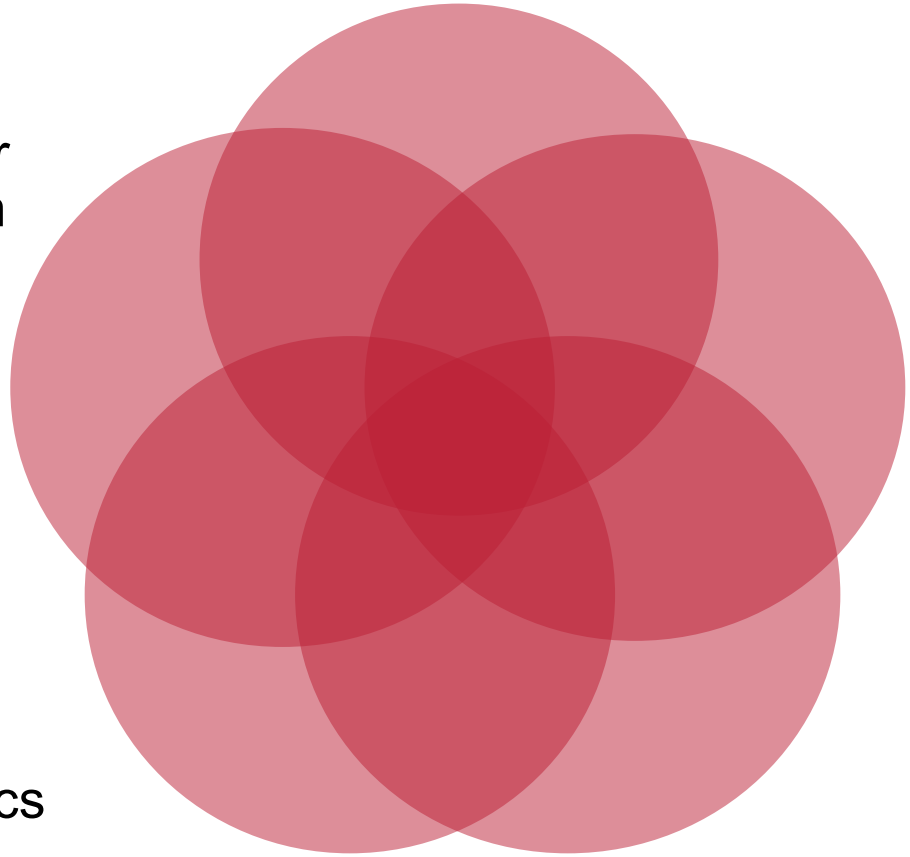
- **PLUS** comorbid symptoms from at least **two** of seven categories:
  - *anxiety* (particularly separation anxiety)
  - *emotional lability* or *depression*
  - *irritability*, *aggression*, and/or *severely oppositional behaviors*
  - *deterioration in school performance* [related to attention-deficit/hyperactivity disorder (*ADHD*)-like behaviors]
  - *memory deficits* and *cognitive changes*
  - *sensory* or *motor* abnormalities
  - *somatic* signs and symptoms (including *sleep* disturbances, *enuresis*, or *urinary frequency)* (Swedo et al. 2012; Chang et al. 2015)

Etiology

Postinfectious autoimmune encephalopathy

Family stress, care giver burden, accommodation

Child secondary gains



Idiopathic psychiatric illness (OCD, anxiety)

Genetics

Neurological conditions

(tics, chorea)

Medical Assessment and Treatment

- **GOAL**: Reduce inflammation
- Tiered treatment:
  - Antibiotics
  - Nonsteroidal medications (ibuprofen, Naprosyn)
  - Prednisone (steroids used to treat inflammation)
  - Intravenous immune globulin (IVIG)

Current Collaboration – CPAE Center of Excellence

- Immunology
- Psychology/Behavior Analysis
- Developmental and Behavioral Pediatrics
- Sleep
- Child & Adolescent Psychiatry
- Gastrointestinal
- Basic Science/lab
- Nursing

Clinical Management of PANS/PANDAS

"While underlying infectious and inflammatory processes in PANS and PANDAS patients are treated, *psychiatric and behavioral symptoms need simultaneous treatment* to decrease suffering and improve adherence to therapeutic intervention."

Thienemann, M., et al. (2017). "Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I-Psychiatric and Behavioral Interventions." J Child Adolesc Psychopharmacol 27(7): 566-573.

Behavioral Assessment and Treatment

- **GOAL**: Reduce challenging behavior & improve appropriate behavior
- Treatments:
  - Empirically Supported Behavioral Interventions
  - Parental Management Training (PMT) and Support

Telehealth Services for CPAE Children and Families

Access to Telehealth Services

- Location:
  - Telehealth services at a specific site with equipment provided (i.e., pediatric practice, outpatient clinic, school district or classroom, etc.)

- Home:
  - Equipment must be available to the family
    - Desktop computer and monitor or laptop (or other device such as a tablet or phone - most effective with enough bandwidth for quality video capability)
    - Webcam
    - Headset (if available)
    - Internet access
    - Video conferencing software (e.g., Skype, Zoom, etc.)

Real-time Coaching and Therapy

- <u>Areas of Services:</u>
  - Play-based language interventions (McDuffie et al, 2013)
  - Skill Acquisition: Teaching ABA principles for therapy via discrete-trial and play-based formats (Fisher et al., 2014)
  - Teaching and coaching parents (homes) and teachers (schools):
    - How to assess and understand challenging behavior (self-injury, aggressive behavior, disruptive behavior, tantrums, etc.) (Functional Analysis or Functional Behavior Assessment)
    - Implementation of behavioral interventions (e.g., Functional Communication Training, etc.)(Gibson et al., 2010; Lindgren et al., 2016; Wacker et al., 2013; Wacker et al., 2016)

Challenges with Telehealth Services

- <u>To Consider:</u>
  - Poor video or sound quality (poor quality, blurred screens, etc.)
  - Technical difficulties (internet stability, lack of technology in rural areas, insufficient speed to transmit video/sound streams)
  - Equipment capabilities (webcam that can pan and zoom to capture child moving and room for data collection as needed)
  - Comfort with the use of technology (parental comfort and ease to use tech and trouble shoot tech issues)
  - Coaching skills (the therapist's ability to effectively vocalize and communicate strategies when unable to be present or model, etc.)
  - Administration issues (policies and permissions, HIPPA compliance, etc., to allow for telehealth)
  - (Frieder et al., 2009; Gibson et al., 2010; Heitzman-Powell et al., 2014; Hay-Hansson & Eldevik, 2013; Wacker et al., 2016)

Treatment Acceptability summary

Treatment Acceptability Rating Form-Revised (Reimers et al. 1992)

Acceptability Data (*n* = 29)

M = 52.97; *SD* = 9.66; Range 31-67

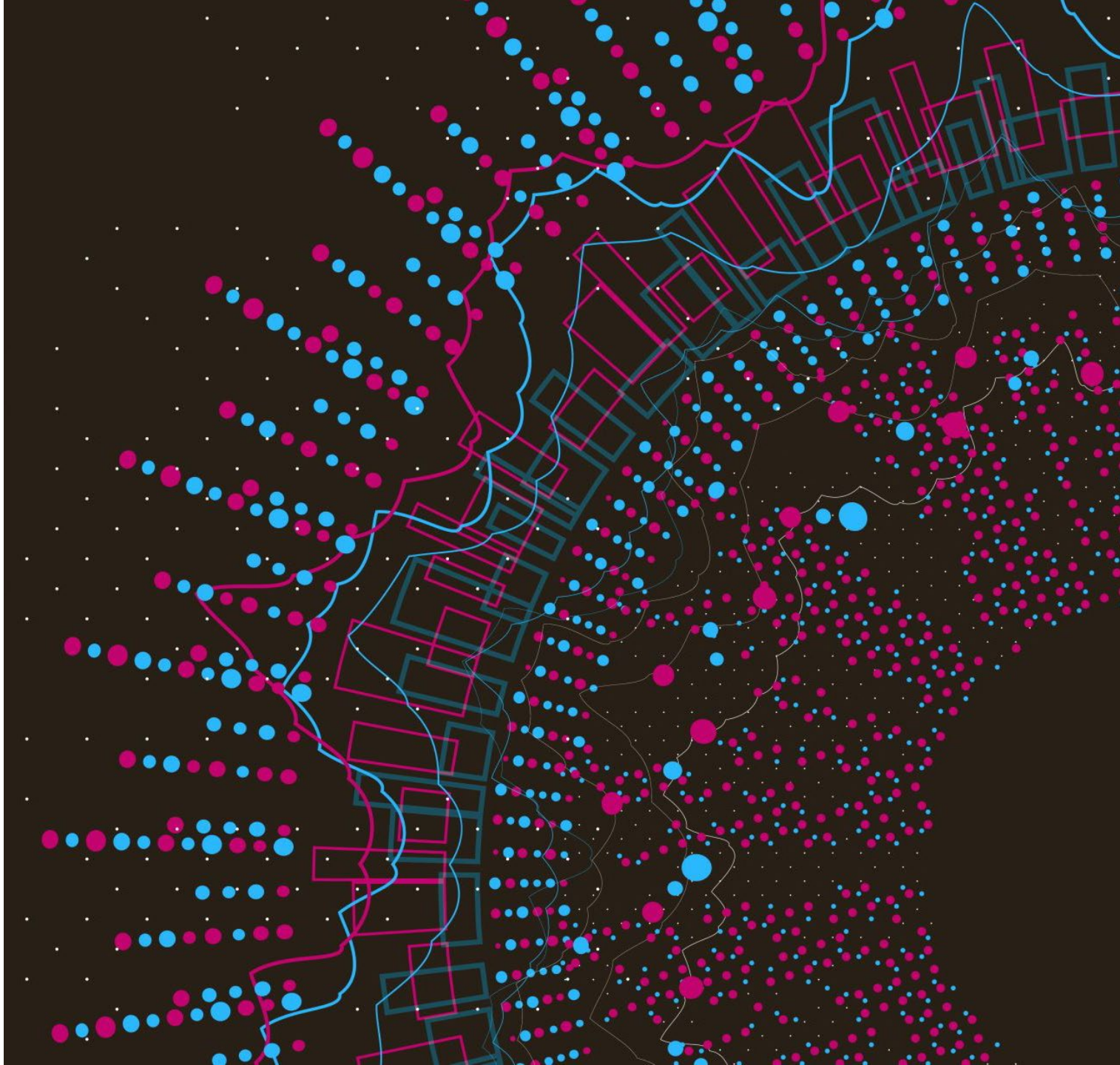
Item	Question	*M*	Range
1	How acceptable do you find the treatment to be regarding your concerns about your child?	5.97	1-7
2	How likely is this treatment to make permanent improvements in your child's behavior?	5.03	1-7
3	How costly will it be to carry out this treatment?*	2.90	1-7
4	How willing are you to carry out this treatment?	6.41	1-7
5	How much time will be needed each day for you to carry out this treatment?*	4.83	1-7
6	How confident are you that the treatment will be effective?	4.93	1-7
7	How willing would you be to change your family routine to carry out this treatment?	6.66	5-7
8	How disruptive will it be to your family (in general) to carry out this treatment?*	2.59	1-5
9	How effective is this treatment likely to be for your child?	5.03	2-7
10	How well will carrying out this treatment fit into the family routine?	5.24	1-7

Note. All items scored 1 (*not at all*) to 7 (*very likely*), * = item was reversed scored for acceptability total

CPAE Behavioral Assessment and Treatment

Biological vs. Behavioral variables?

“Can my child control their own behavior?”



Behavioral Assessment

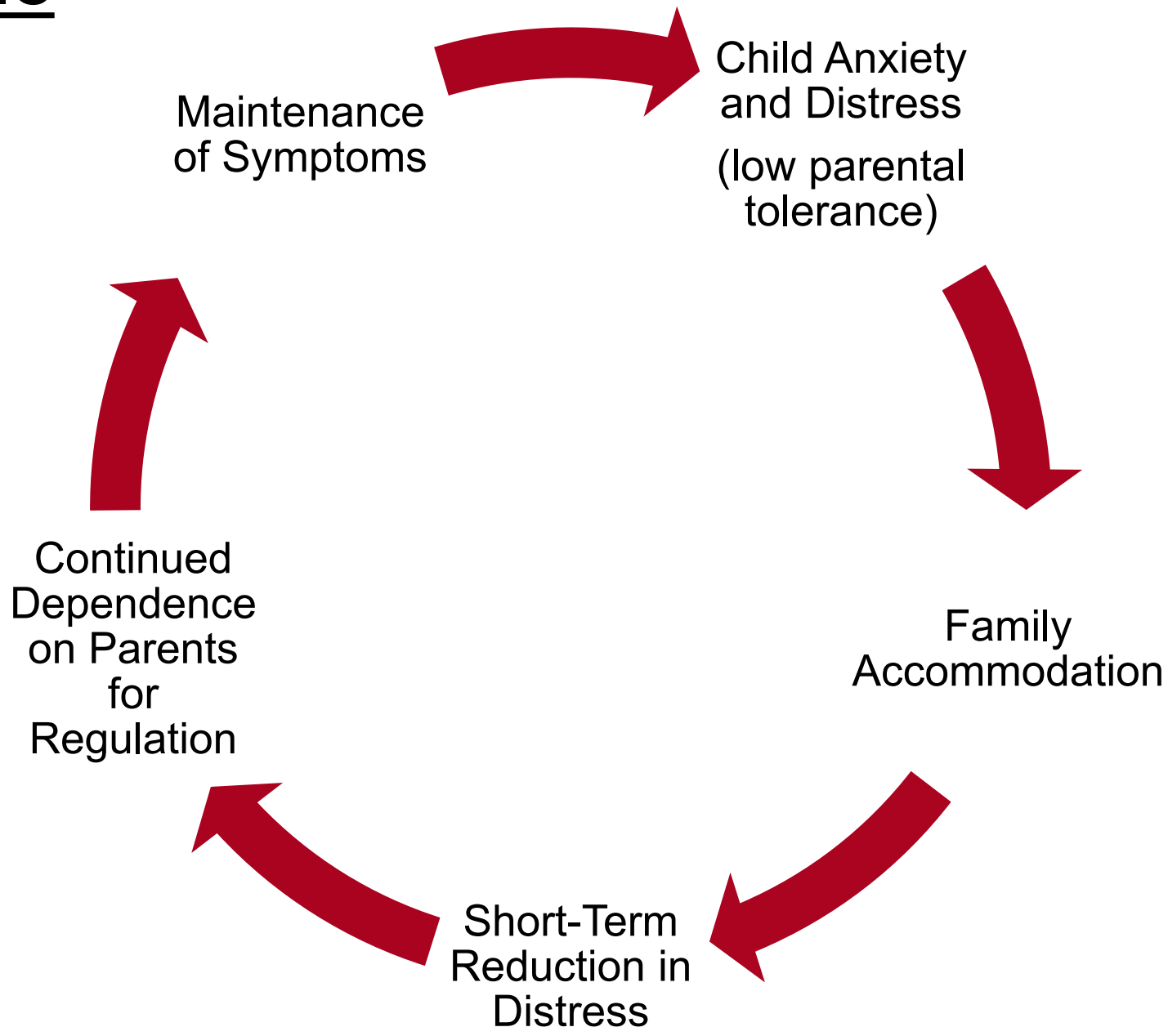
- Baseline assessment
  - *Structural* – daily routine, predictability, rules, requirements
  - *Functional* – consequences for appropriate & inappropriate behavior
- Information gathered from parents, teachers, and other healthcare providers (data sheets, permanent product, technology, etc.)

Family Accommodation and Secondary Gains

- ***Family accommodation*** *= Family involvement in routines that exacerbate and maintain severe problem behavior, anxiety, OCD, etc.*

- Changes in behavior can be related to biology alone, but research indicates that sometimes as children persist in challenging behavior, parental behavior also changes especially when a child is ill (and parents are burdened over time).

Systemic Cycle



Family Accommodation and Secondary Gains

- Parents may:
  - Provide repeated reassurance
  - Allow the child to sleep in parent's bed
  - Facilitate general avoidance and avoidance of social and school engagements
  - Provide items to mitigate anxiety
  - Doing things which fall under the child's responsibility
  - Prepare special meals

Negative Impact of Family Accommodation

PROMOTES AVOIDANCE

REDUCES SELF-REGULATION

REDUCES INSIGHT

REDUCES MOTIVATION FOR TREATMENT

Lebowitz, E. (2019). Addressing Parental Accommodation When Treating Anxiety In Children. New York, NY: Oxford University Press.

30+ YEARS OF RESEARCH ON CHALLENGING BEHAVIOR

Journal of Applied Behavior Analysis

JOURNAL OF APPLIED BEHAVIOR ANALYSIS 2013, **46,** 1–21 NUMBER 1 (SPRING 2013)

THIRTY YEARS OF RESEARCH ON THE FUNCTIONAL ANALYSIS OF PROBLEM BEHAVIOR

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UNIVERSITY OF HOUSTON–CLEAR LAKE

Hanley, Iwata, and McCord (2003) reviewed studies published through 2000 on the functional analysis (FA) of problem behavior. We update that review for 2001 through 2012, including 158 more recent studies that reported data from 445 FAs. Combined with data obtained from Hanley et al., 435 FA studies, with line graphs for 981 FAs, have been published since 1961. We comment on recent trends in FA research and introduce the studies in the 2013 special issue of the *Journal of Applied Behavior Analysis*.

Key words: functional analysis, problem behavior

30 YEARS OF RESEARCH ON PROBLEM BEHAVIOR

Table 5
Summary of Functional Analysis Outcomes

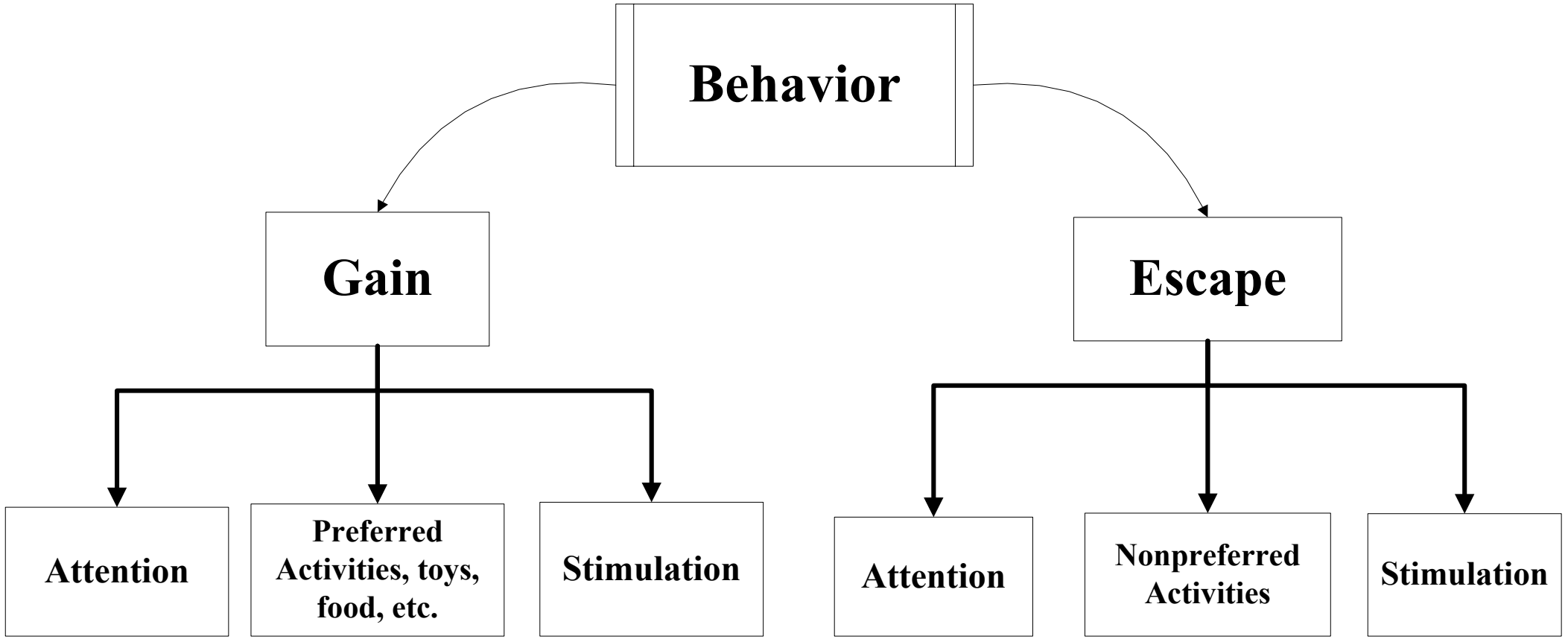
Topography	Undiff	Diff	Esc	Attn	Tang	Auto	Mult
Self-injury	9 (22)	60 (282)	18 (83)	4 (63)	6 (34)	21 (76)	11 (26)
Aggression	10 (12)	45 (95)	17 (41)	12 (21)	10 (16)	1 (2)	5 (15)
Property destruction	0 (0)	7 (9)	2 (2)	2 (2)	0 (2)	1 (1)	2 (2)
Pica	0 (0)	5 (11)	0 (0)	0 (1)	0 (0)	5 (8)	0 (2)
Disruption	0 (0)	10 (26)	0 (11)	0 (3)	0 (1)	6 (7)	4 (4)
Vocalizations	2 (3)	45 (59)	9 (15)	14 (17)	5 (6)	10 (10)	7 (11)
Noncompliance	0 (0)	17 (25)	8 (9)	7 (9)	2 (3)	0 (0)	0 (4)
Elopement	0 (0)	12 (15)	0 (0)	5 (5)	4 (4)	0 (0)	3 (6)
Stereotypy	0 (1)	16 (46)	1 (7)	0 (0)	0 (0)	14 (33)	1 (6)
Tantrums	0 (0)	2 (8)	1 (3)	0 (1)	1 (2)	0 (0)	0 (2)
Other	0 (0)	17 (30)	2 (6)	1 (6)	1 (1)	10 (11)	3 (6)
Aberrant	16 (21)	172 (316)	63 (120)	25 (72)	20 (32)	1 (2)	63 (90)
Total number[a]	37 (59)	408 (922)	121 (297)	70 (200)	49 (101)	69 (150)	99 (174)
Percentage of sample[b]	8.3 (6.0)	91.7 (94.0)	29.7 (32.2)	17.2 (21.7)	12.0 (11.0)	16.9 (16.3)	24.3 (18.9)

Note. Undiff = undifferentiated results, Diff = differentiated results, Esc = maintenance by escape, Attn = maintenance by attention, Tang = maintenance by tangible reinforcers, Auto = maintenance by automatic reinforcement, Mult = multiple sources of control.

[a]Numbers in parentheses indicate current data combined with those from Hanley et al. (2003).

[b]"Sample" refers to all line graphs presented in included studies.

Why does problem behavior occur?



Parents with children who are ill, often let parenting contingencies relax (i.e., *accommodate*)…

Escape function (oppositional/defiance)

- No longer require child to complete tasks/demands

Attention function (separation anxiety/demanding)

- Provide more attention to child than usual due to illness, appointments, home from school, etc.

Tangible function (refusal to transition off items, accept "no," etc.)

- Allow child to have "*free and unlimited access*" to their preferred items (e.g., tablet, phone, video games, television, etc.)

Function of Behavior – MEDICAL Screening Tool (FOB-MED)

Name: Date:
Age: Diagnosis:
Challenging Behavior:_____

	Please Circle:
1. Does your child have difficulty when you pay **ATTENTION** to something or someone else other than them? (*EXAMPLE*: parent making a phone call, parent playing with sibling, parent attending to guests at home, etc.) (*Intensity: **1**—2—3—4—5) (How often: daily #___; weekly #___; monthly #___)	YES / NO
1. (a) *After* you see challenging behavior, do you typically: tell your child to stop (reprimand), try to soothe your child, discuss the behavior, or explain to them why they shouldn't do it? Other:_____	YES / NO
2. Does your child have difficulty when **TANGIBLE** items or preferred activities are taken away, removed, required to share, restricted, or delayed (required to wait) from him/her? (*EXAMPLE*: toys, tablet/phone/computer, going outside, etc.) (*Intensity: **1**—2—3—4—5) (How often: daily #___; weekly #___; monthly #___)	YES / NO
2. (a) *After* you see challenging behavior, is the item ever given back or is your child allowed to participate in the activity (e.g. toy, food, tablet, phone, computer time, go outside, or fun activity)?	YES / NO
3. Does your child have difficulty when you ask them to complete a task or a **DEMAND** is asked of them? (*EXAMPLE*: chores, homework, bed time, get dressed, bath time, etc.) (*Intensity: **1**—2—3—4—5) (How often: daily #___; weekly #___; monthly #___)	YES / NO
3. (a). *After* you see challenging behavior, does your child typically (**Circle all that apply**): leave the area or task, argue with you, go to a calming place, go to time-out, not complete what you asked them to do, go somewhere to be alone, or go play with toys and other preferred items, complete task ONLY if you help? Other:_____	
4. Does your child have difficulty (challenging behavior) when he/she is **ALONE** (when no one else is around)? (*EXAMPLE*: playing in their room, etc.) (*Intensity: **1**—2—3—4—5) (How often: daily #___; weekly #___; monthly #___)	YES / NO

*Intensity:
1 = ***mild*** - challenging behavior – but can manage current behavior
3 = ***moderate*** - challenging for care providers – requires effort to manage behavior
5 = ***severe*** - causing tissue damage to self or hurting others – cannot manage behavior

Function of Behavior – MEDICAL Screening Tool (FOB-MED-TEEN)

Name: Date:
Age: Diagnosis:
Challenging Behavior:_____

	Please Circle:
1. Do you get to spend enough time with **(ATTENTION)** your mother or father (or care provider) during the week? Would you like to spend more time with your Mother or father? (How often: daily #_____; weekly #_____; monthly #_____)	YES / NO
1. (a) How do you typically get their attention? _____ _____	
2. (b) What types of things do you wish you could do more of with your: Mother: _____ Father: _____ (***Q of A**: physical contact, close proximity, vocal enthusiasm, interests, how often*)	
2. Is it hard for you to stop using your favorite items (e.g. Legos or electronics) or stop a favorite activity **(TANGIBLE)?** What about when these things are taken away from you, you have to share, or you have to wait for these things? (*EXAMPLE*: toys, tablet/phone/computer, going outside, etc.) (*Difficulty: **1**—2—**3**—4—**5**) (Access?: daily #___; weekly #___; monthly #___)	YES / NO
2 (a) If you could choose, how long would you use your favorite items and engage in your favorite activities during the day?_____ _____	
3 (b) What are the rules in your home about access to your preferred activities? _____	
3. Do you find it difficult to do your homework, clean your room, complete chores (or follow directions) when your parents ask **(ESCAPE/DEMAND)?** (*EXAMPLE*: chores, homework, bed time routine, get dressed, etc.) (*Difficulty: **1**—2—**3**—4—**5**) (How often: daily #___; weekly #___; monthly #___)	YES / NO
3. (a). ***After*** you are asked to do something at home, do you typically **(Circle all that apply)**: say yes - finish it as quick as possible, try to leave the area or task, argue with your parents, go somewhere else, get upset, continue playing with your favorite things or activities, or complete tasks ONLY if your parents help you? Other:_____	
4. Do you find yourself doing the challenging behavior (e.g. repetitive behavior, skin picking, etc.) when you are **ALONE** (when no one else is around)? (*e.g.* in your room, bathroom, etc.) (How often: daily #___; weekly #___; monthly #___)	YES / NO
3. (a). Do you care if someone else sees you engaging in the behavior?	YES / NO
4. (b). How difficult is it for you to hold yourself back from the behavior? (*Difficulty: **1**—2—**3**—4—**5**)	

*Difficulty scale:
1 = ***mildly difficult*** - challenging – but can manage current behavior daily
3 = ***moderately difficult*** - challenging – requires continual effort to manage behavior
5 = ***very difficult*** – causes Challenging behavior – cannot manage behavior

Treatment Recommendations Based on Behavior and Function

Empirically Supported Strategies

Behavioral Definitions

- Obsessions
  - Compulsions

→ Negative reinforcement

- Tics
  - Vocal tics
  - Motor tics

→ Negative reinforcement

- Stereotypy

→ Automatic reinforcement

- High-preferred activity

→ Positive reinforcement

Individualizing Treatment – Family Support and Therapy

- Minimizing "*family accommodation*" to OCD and other behaviors.
- In turn, decreasing "*secondary gains*"
- Dynamic changes in *Parenting Structure* and *Styles* with fluctuation in symptoms:
  - Acute phases ("*flares" or "Flare-ups*")
  - Absence of infection ("*back to normal?*")

Example of Function-based Treatment

Attention Maintained Behavior

- Promote functional communication (FCT)
- Planned Ignoring
- Tolerating a delay or “wait time” for care giver attention
- Tolerating “No” or “Not right now” when care giver attention is NOT available
- Plan predictable “special times” for individual High-Quality Attention

Treatment Triage Recommendations and Collaborations

- **Mild OCD symptoms**:
  - Cognitive Behavior Therapy (CBT) with Exposure and Response Prevention (ERP) focus

- **Moderate to Severe OCD symptoms**:
  - ERP (Exposure and Response Prevention)
  - Habit Reversal Training (HRT or CBIT) for tics, hair pulling, skin picking, etc.
  - ERP or HRT in combination with Acceptance and Commitment Therapy (ACT)

- **Other Psychiatric Concerns**:
  - ARFID – Feeding therapies/clinics
  - Psychiatry/Neuropsychiatry/Sleep, etc.

Parent Management Training (PMT)

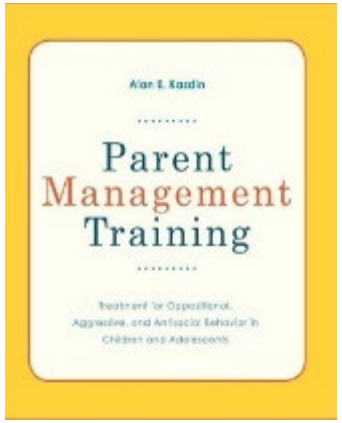
- Encouraging families to not participate in behaviors accommodating the child's avoidance and rituals
- Positively reinforcing desired behaviors
- Setting clear limits, expectations, and consequences
- Establishing reward systems
- Particularly useful when PANS patients are not ready or willing to use CBT themselves (Lebowitz et al. 2014).

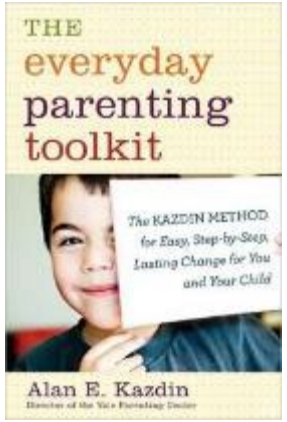
Parent Management Training (PMT)

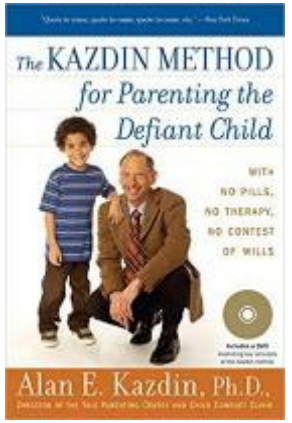
Alan E. Kazdin (2005)

Parent Management Training: Treatment for Oppositional, Aggressive and Antisocial Behavior in Children and Adolescents

Also see: Kazdin, Siegel, & Bass (1992). Problem-Solving Skills Training plus Parent Management Training







Case Example

- Rita – 8 yo female
- Acute onset: 10/4/2018 (positive strep) – symptoms decreased with Motrin

- **<u>Behaviors of Concern</u>**:
  - Disruptive behavior (crying, complaining),
  - Somatic complaints (throat/belly),
  - Tics/rituals (inhaling harshly/rubbing hands), hyperactivity (dancing/constant moving/episodes),
  - Separation anxiety (wants parents next to her constantly),
  - OCD/Fears (constant needing to talk about obsessions - spiders/snakes/bugs – worse with “flares”).

Case Example

- Medical Assessment: 1A (Other Encephalopathy)
  - ***Treatment***: Naproxen (Start Tiered Treatment)

- Behavioral Assessment: FOB-MED results: identified a hypothesized *Attention and Tangible* functions, especially with Mother
  - ***Treatment***: Behavioral Strategies tailored to Family Accommodation (*Attention/Tangible*) and Parent Management Training (PMT)

CPAE Clinic Summary Data

Behavioral Clinical Procedures: Initial Assessment

1. Review records, interview, observation, team collaboration
2. FOB-MED tool used to determine Ho: function of behavior.
3. Provide parents/caregivers with empirically supported practices and resources (e.g., Tx linked to function, PMT, ERP/ACT, HRT/CBIT, etc.)
4. TARF-R measures treatment acceptability.

SCATTERPLOT

Fill in each square that represents when the behavior occurred:

Month: **February/March** Year: **2021** Name: **AA**

Behavior

Mild Behavior: Pouting, non-compliance, talking back

Moderate Behavior: Yelling, screaming, stomping feet, slamming belongings, kicking feet, tantrum

Severe Behavior: Hitting, pushing, grabbing, kicking, property destruction

☐ **No Behavior** / / X ■

Date	2/1 M	2/2 T	2/3 W	2/4 TH	2/5 F		2/8 M	2/9 T	2/10 W	2/11 TH	2/12 F		2/15 M	2/16 T	2/17 W	2/18 TH	2/19 F		2/22 M	2/23 T	2/24 W	2/25 TH	2/26 F		3/1 M	3/2 T	3/3 W	3/4 TH	3/5 F
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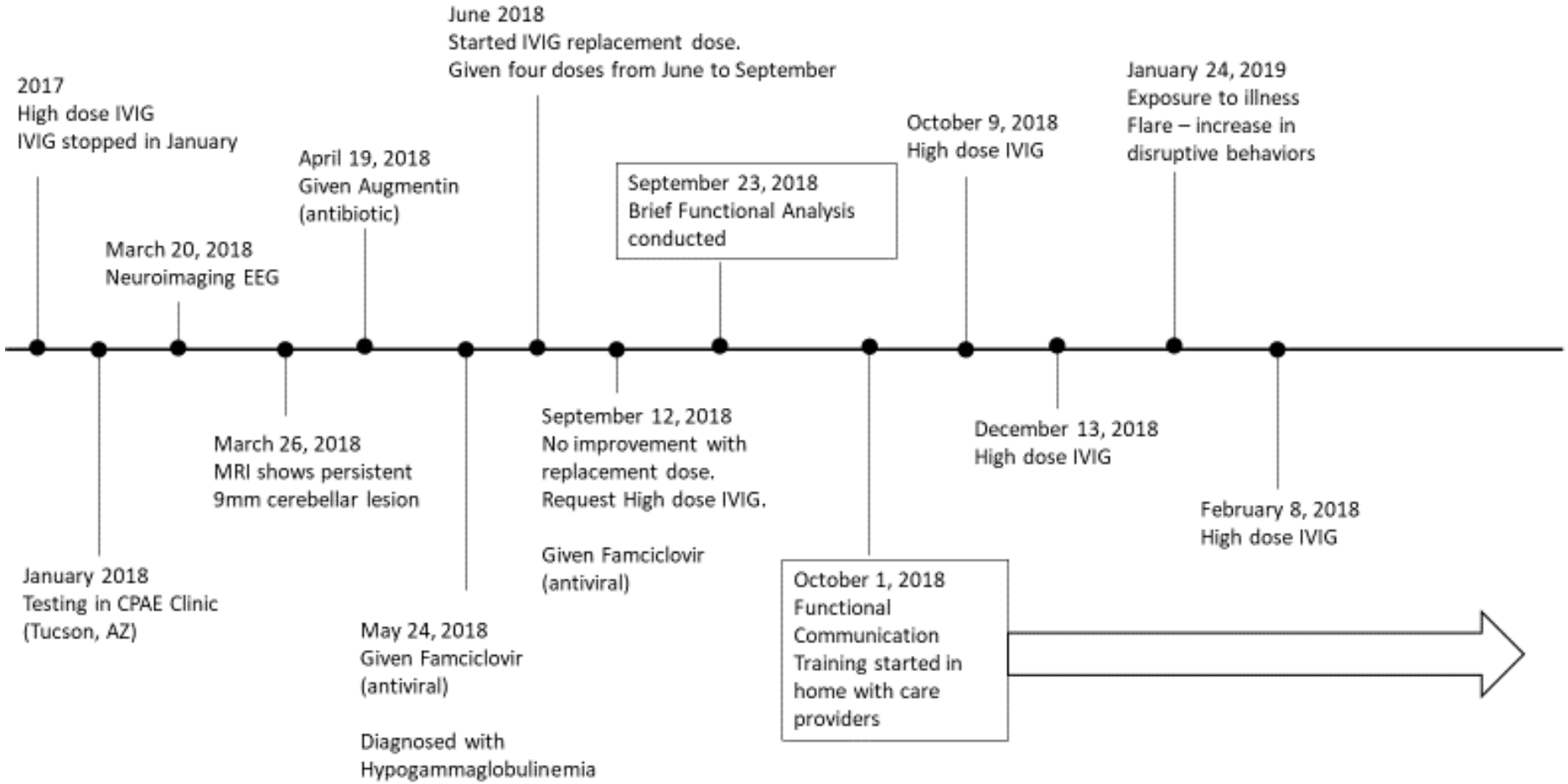
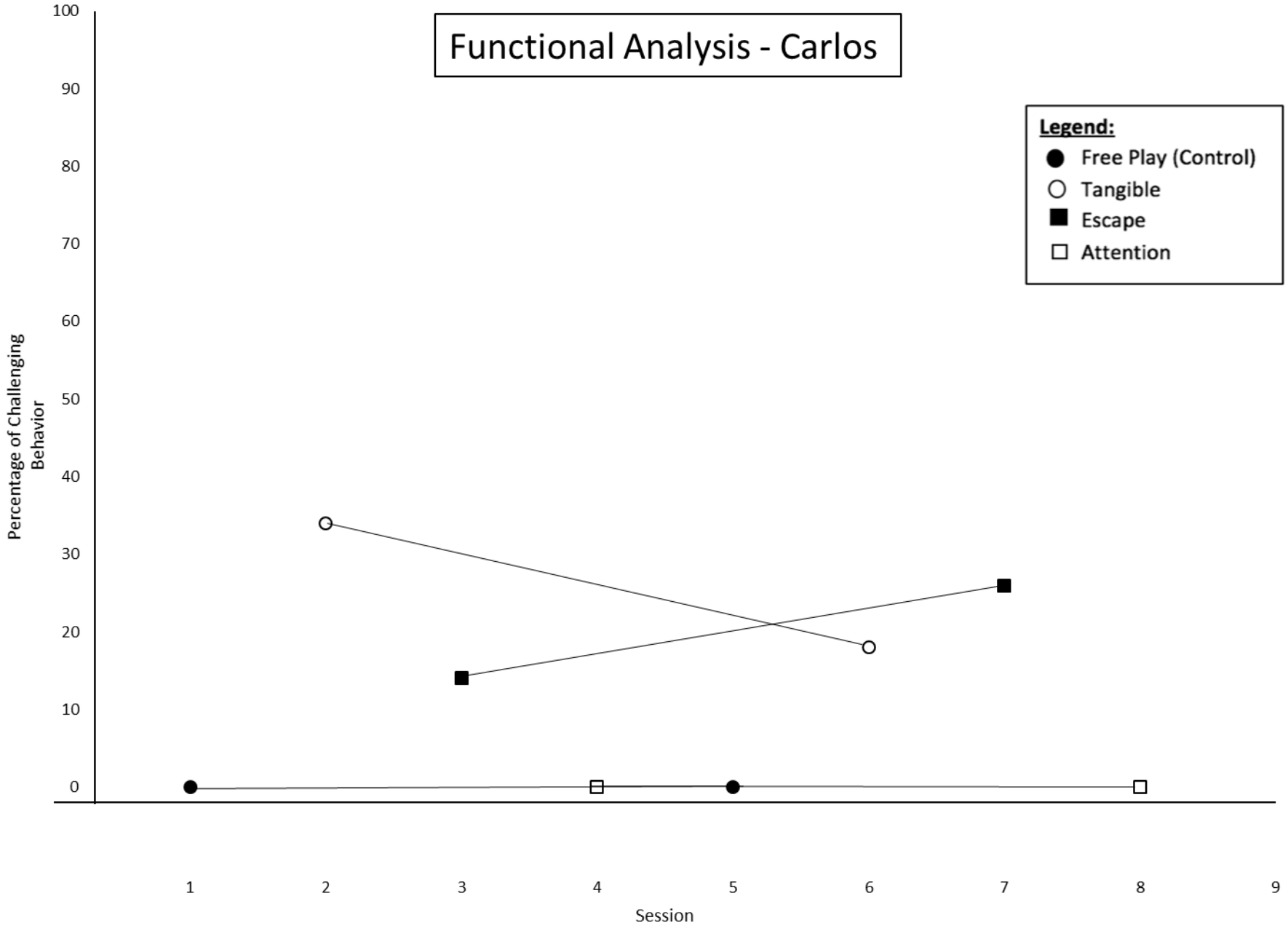
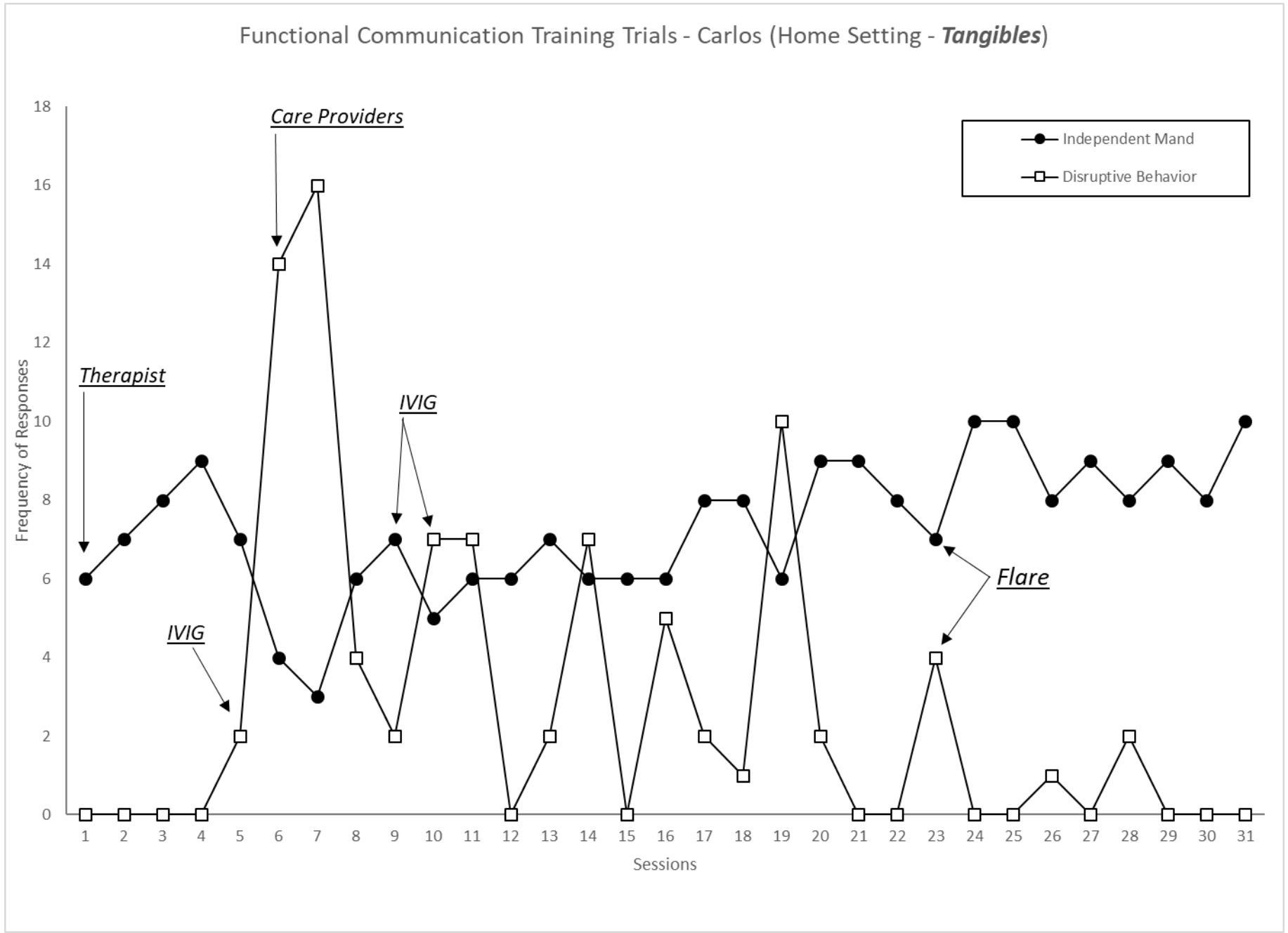
Notes:
Feb 1-5 Generally terrible behavior (has been really bad since he came off Aleve) – defiant, angry, brutally mean to his siblings/parents – especially difficult in any transition and at night
Feb 6 started Naproxen – continued terrible behavior
Feb 7 had to stay home from family get together because of his terrible violence and thrashing in the garage
Feb 8 hard time getting up for school but pretty good today willingly went to Boy Scouts
Feb 9 Andrew was angry that his electronics had been taken away for a while, he stole my cars keys and got his electronics out of the car where he saw I had hidden them

Feb 10 great behavior!
Feb 11 Mostly great but we were late to sister's dance class and that made him on edge
Feb 12 Purposefully annoying to siblings
Feb 13 Good but annoying siblings and getting in their space
Feb 14 Angry for several hours after I wouldn't let him have chips at Subway
Feb 15 Great behavior!
Feb 16 Pretty good but annoying to siblings
Feb 17 Great behavior (said he is starting to count syllables again
Feb 18 A couple minor issues but good *Started 5 day course of Erythromycin upon suggested of primary care doctor
Feb 19 Great!
Feb 20 Was very mean to sister, was mad at brother for telling on him, shoved mother and threw Alexa music device (we let him have gluten today and could be a cause)
Feb 21 Good behavior
Feb 22 Brother bothered Andrew while he was waking up and Andrew slapped Ryan causing lots of bleeding on eyebrow – he didn't mean to but another example of no body control
Good day but he freaked out when he thought he lost his merit badges from scouts and he started throwing stuff in kitchen
Feb 23 Can't seem to stop bothering his sister
Feb 24 Fairly hyper at bedtime – hard time regulating himself but still compliant
Feb 25 Great behavior – a little hyper at bedtime
Feb 26 Fantastic behavior – his sister spit on him for some reason and he remained very calm – previously that would have started WWIII
Feb 27 Had a rough morning, insulted brother and freaked out about his gluten free bagel not being toasted enough – often had food related complaints – food is a hot button for him – we did give him gluten the day before at a family get together and we hypothesize that any gluten contributes to his inflammation causing behavior issues, but he has been primarily gluten free for a year so this is only one factor
Feb 28 Hard time going to sleep but pretty good day – minor argument with cousin about playing Fortnite
March 1 Attended first baseball practice and regular Boy Scout meeting. Went to sleep quickly at night and had a great day.
March 2 Did one hour of homework with Andrew without argument and got it done quickly. Normally this would result in yelling and defiance but it was wonderful!
March 3 Andrew has really transformed – he cares about school, we have had some great conversations, he is happy! Still complains of eyes – mostly when he eats
March 4 Complaining that is syllable counting is getting worse (OCD like behavior) – we are working on Andrew being able to stay home by himself for short periods of time – he has a great deal of anxiety about this – says he thinks we won't come back – I was successful in leaving him home to check the mail while talking to him on the phone
March 5 Great behavior! Andrew is almost a completely different kid right now!

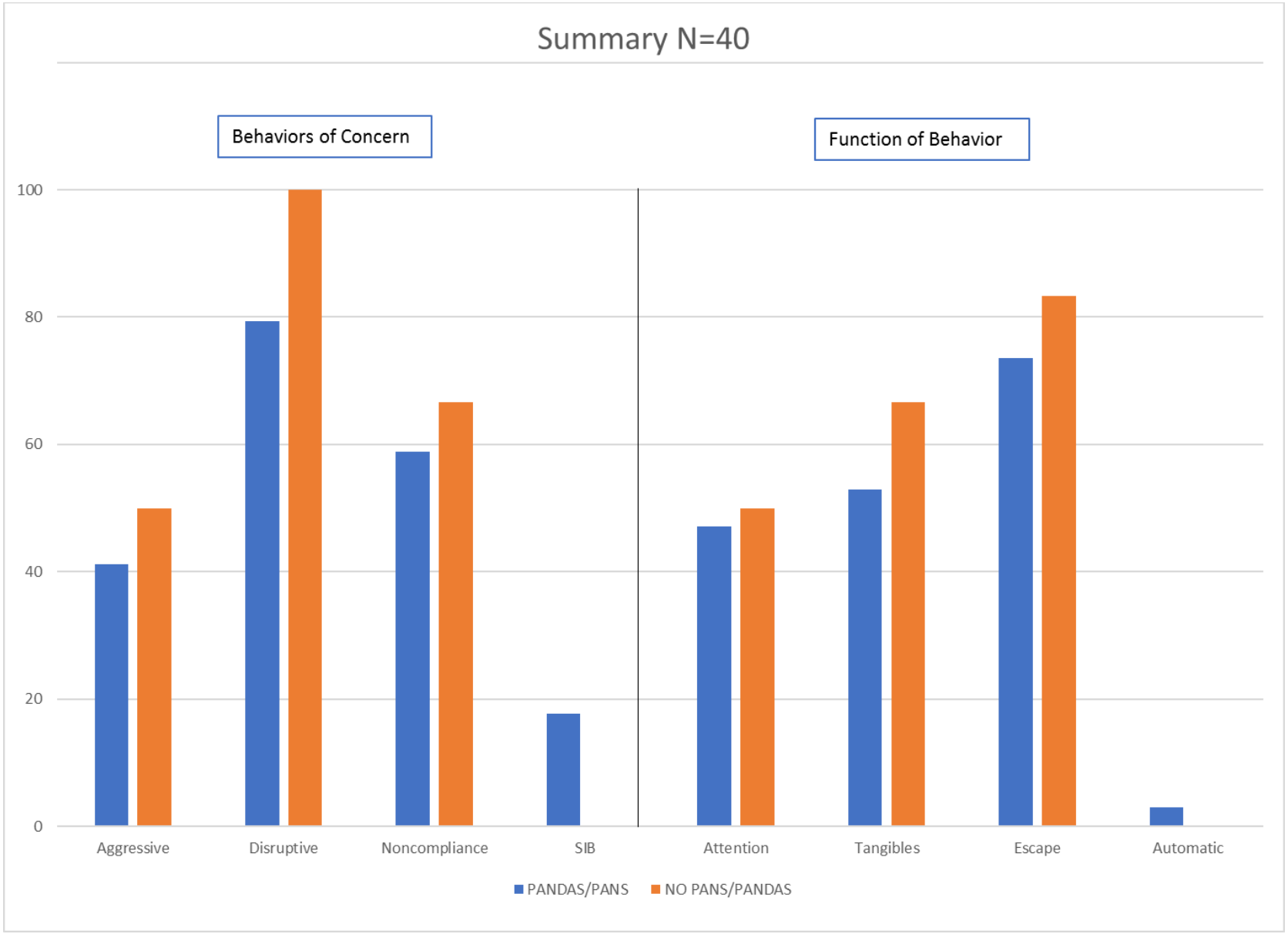
Andrew has a hard time getting to sleep in general, he is now back to smiling and cracking jokes like he used to, he still has a tough time regulating but so much better than before.


2017
High dose IVIG
IVIG stopped in January
January 2018
Testing in CPAE Clinic
(Tucson, AZ)
March 20, 2018
Neuroimaging EEG
March 26, 2018
MRI shows persistent
9mm cerebellar lesion
April 19, 2018
Given Augmentin
(antibiotic)
May 24, 2018
Given Famciclovir
(antiviral)
Diagnosed with
Hypogammaglobulinemia
June 2018
Started IVIG replacement dose.
Given four doses from June to September
September 12, 2018
No improvement with
replacement dose.
Request High dose IVIG.
Given Famciclovir
(antiviral)
September 23, 2018
Brief Functional Analysis
conducted
October 1, 2018
Functional
Communication
Training started in
home with care
providers
October 9, 2018
High dose IVIG
December 13, 2018
High dose IVIG
January 24, 2019
Exposure to illness
Flare – increase in
disruptive behaviors
February 8, 2018
High dose IVIG


Functional Analysis - Carlos
Legend:
Free Play (Control)
Tangible
Escape
Attention
Percentage of Challenging Behavior
100
90
80
70
60
50
40
30
20
10
0
1
2
3
4
5
6
7
8
9
Session

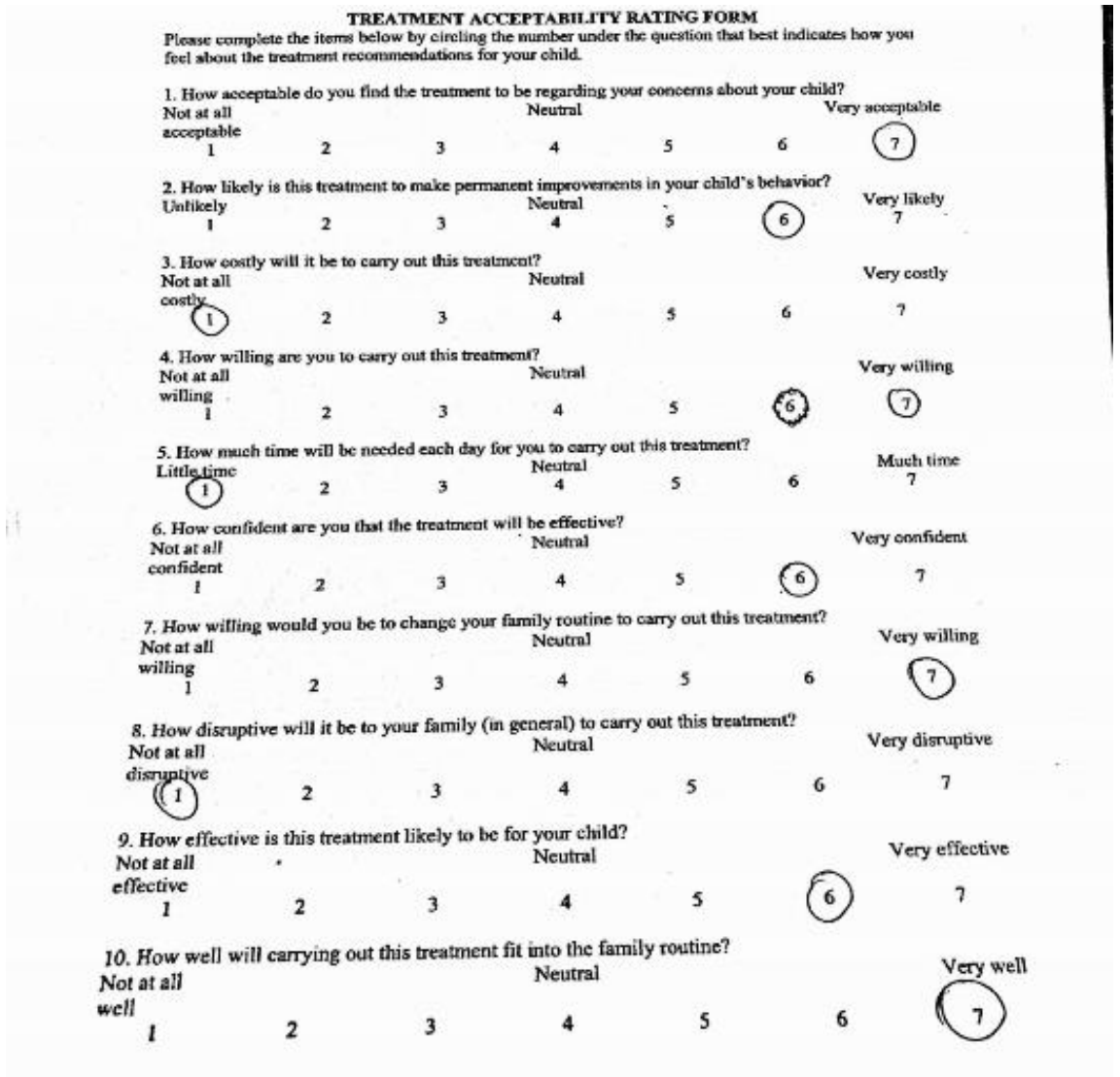

Functional Communication Training Trials - Carlos (Home Setting - Tangibles)
Independent Mand
Disruptive Behavior
Care Providers
Therapist
IVIG
IVIG
Flare
Frequency of Responses
Sessions
0
2
4
6
8
10
12
14
16
18
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31

Summary of 40 Cases



Treatment Acceptability Rating Form (TARF-R)

Reimers, T. M., & Wacker, D. P. (1988). Parents' ratings of the acceptability of behavior treatment recommendations made in an outpatient clinic: A preliminary analysis of the influence of treatment effectiveness. *Behavioral Disorders*, 14, 7-15.



TREATMENT ACCEPTABILITY RATING FORM

Please complete the items below by circling the number under the question that best indicates how you feel about the treatment recommendations for your child.

1. How acceptable do you find the treatment to be regarding your concerns about your child?
Not at all acceptable — Neutral — Very acceptable
1 2 3 4 5 6 (7)

2. How likely is this treatment to make permanent improvements in your child's behavior?
Unlikely — Neutral — Very likely
1 2 3 4 5 (6) 7

3. How costly will it be to carry out this treatment?
Not at all costly — Neutral — Very costly
(1) 2 3 4 5 6 7

4. How willing are you to carry out this treatment?
Not at all willing — Neutral — Very willing
1 2 3 4 5 (6) (7)

5. How much time will be needed each day for you to carry out this treatment?
Little time — Neutral — Much time
(1) 2 3 4 5 6 7

6. How confident are you that the treatment will be effective?
Not at all confident — Neutral — Very confident
1 2 3 4 5 (6) 7

7. How willing would you be to change your family routine to carry out this treatment?
Not at all willing — Neutral — Very willing
1 2 3 4 5 6 (7)

8. How disruptive will it be to your family (in general) to carry out this treatment?
Not at all disruptive — Neutral — Very disruptive
(1) 2 3 4 5 6 7

9. How effective is this treatment likely to be for your child?
Not at all effective — Neutral — Very effective
1 2 3 4 5 (6) 7

10. How well will carrying out this treatment fit into the family routine?
Not at all well — Neutral — Very well
1 2 3 4 5 6 (7)

Treatment Acceptability summary

Treatment Acceptability Rating Form-Revised

(Reimers et al. 1992)

Acceptability Data (*n* = 29)

M = 52.97; *SD* = 9.66; Range 31-67

Item	Question	*M*	Range
1	How acceptable do you find the treatment to be regarding your concerns about your child?	5.97	1-7
2	How likely is this treatment to make permanent improvements in your child's behavior?	5.03	1-7
3	How costly will it be to carry out this treatment?*	2.90	1-7
4	How willing are you to carry out this treatment?	6.41	1-7
5	How much time will be needed each day for you to carry out this treatment?*	4.83	1-7
6	How confident are you that the treatment will be effective?	4.93	1-7
7	How willing would you be to change your family routine to carry out this treatment?	6.66	5-7
8	How disruptive will it be to your family (in general) to carry out this treatment?*	2.59	1-5
9	How effective is this treatment likely to be for your child?	5.03	2-7
10	How well will carrying out this treatment fit into the family routine?	5.24	1-7

Note. All items scored 1 (*not at all*) to 7 (*very likely*), * = item was reversed scored for acceptability total

Research

- **<u>Bio-Behavioral Investigations:</u>**
- **Behavioral Treatment and Therapy**
  - Combinations of Bio and Behavioral Treatments?
  - Dosage? Timing?
  - Control/monitor behavioral therapies along with biological interventions
  - RCT
- **Pediatric Neuroimaging**
  - Accurate imagining using training protocols for CPAE children

Pua, E., Barton, S., Williams, K., Craig, J. M., & Seal, M. L. (2020). Individualised MRI training for paediatric neuroimaging: A child-focused approach. Developmental cognitive neuroscience, 41, 100750. https://doi.org/10.1016/j.dcn.2019.100750

- **Long-term Treatment Variables**
  - How do behavioral treatments and PMT hold up across "Flares" (i.e., exposure to subsequent infection/challenges to structure and consistency – regression and resurgence)

Barfoot Park - Chiricahua Mountains

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