

Behavioral Considerations for XY Chromosome Differences

eXtraordinary Kids Clinic
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Clinical Sample of Presenting Concerns by % Behavior

Concerns (N=Number)	XXY % (35)	XYY % (9)	XXYY % (20)	XXXY % (7)	XXX % (18)	Total % (89)
Behavioral	54	78	60	86	67	63
Poor Attention	57	56	30	86	17	45
Hyperactivity	6	11	5	43	6	9
Aggression	6	33	15	14	11	12
Conduct	3	0	0	0	17	5

Clinical Sample of Presenting Concerns by % Mood & Social Communication

Concerns	XXY %	XYY %	XXYY %	XXXY %	XXX %	Tot %
Anxiety	60	56	40	29	89	58
Depression	31	11	5	29	33	24
Social	69	100	55	71	56	66
Withdrawal	23	0	14	20	44	24

**Clinical Sample of Presenting Concerns by %
Academic & Learning**

Concerns	XXY %	XYY %	XXYY %	XXXYY %	XXX %	Total %
Academic	74	56	45	71	44	60
Language	17	33	40	71	39	33

**Clinical Sample of Presenting Concerns by %
Continued ...**

Concerns	XXY %	XYY %	XXYY %	XXXYY %	XXX %	Total %
Sensory	3	0	5	0	17	6
Motor	6	11	5	11	28	10
Fatigue	41	25	26	40	43	36

Final Diagnoses of the Clinical Sample by %

Diagnoses	XXY	XYY	XXYY	XXXYY	XXX	Total
ADHD	54.3	55.6	45.0	57.1	16.7	44.9
Conduct Disorder	0	0	5.0	0	0	1.1
Depression	22.9	11.1	5.0	14.3	11.1	14.6
Anxiety	20.0	22.2	20.0	14.3	27.8	21.3
ASDs	14.3	66.7	35.0	28.6	16.7	38.2
Language Disorder	51.4	33.3	35.0	57.1	50.0	53.9
Learning Disorder	20.0	22.2	25.0	14.3	16.7	20.2
Intellectual Disability	14.3	11.1	20.0	42.9	0	14.6

What we have learned from clinic...





A-B-Cs

Antecedent...happens before a behavior

Behavior...what we do or say

Consequence...happens immediately after a behavior

Relationship

XY chromosomes

We have been thinking about the ABCs for awhile....

BC 1550 to 100

- The Ebers Papyrus
- Hippocrates
- Plato
- Aristotle

CE 1650 to 1950

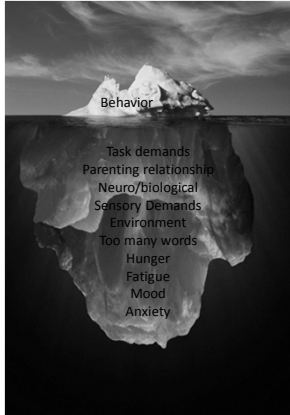
- Descartes
- Pavlov
- Freud
- Piaget
- Skinner
- Rogers
- Kanner
- Maslow

1965 to Present

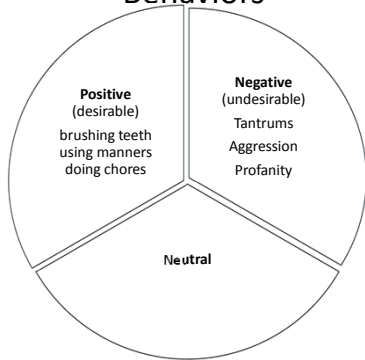
- Beck
- Bowlby
- Harlow
- Erikson



Antecedents



Behaviors



Consequences

Punishers: reduces behavior

Reinforcers: increases behavior

Punisher	Reinforcer
+	+
-	-



The ABC Snowball



Trigger seems insignificant
Behavior starts...*"oh no, I'm going to be upset..."*
Executive function diminishes...*"uh oh, I'm stuck!"*

Meltdown!

Tantrum snowballs, dysregulation builds....

"Now I'm really upset!"


"I hate this feeling!"

MELTDOWN! (what trigger?)

The ABCs of Habit

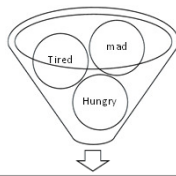
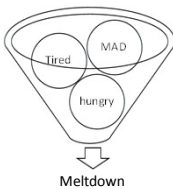
When Triggers and Behaviors become linked
Habit is broken when:

Antecedent  Negative Behavior

Antecedent  Neutral/positive behavior

Practice calming, coping, mastering a difficulty
Catch 'em calming!

Breaking the Habit....



Anticipate
Modify Sensory, Neurological Maturation, Reduce
Impulses, Remove Irritants

Cope

Behaviors as... EXPRESSION!

Words give you power

Behavior IS Power



A visual approach to ABCs

Reduce language

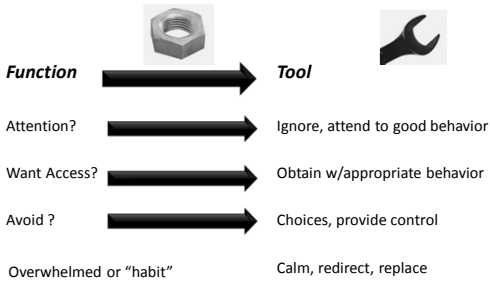
Give warnings (visual and verbal)

Discuss prior to high risk situations (older kids)

Build a "visual" vocabulary



Different tools for different behaviors



Natural or Logical Consequences



<u>Behavior</u>	<u>Consequence</u>
Hit	Sit
Throw	Lose it
Break an object	Object is Gone
Make a mess	Clean it up
Whine	Ignore
Don't get dressed	Go in PJs

Behaviors from Senses

- Anticipate a sensory setup
- What can change, what can't
 - Lengthen the fuse
 - Label without blaming
 - Offer sensory competition
 - Limit number of challenges



- ▶ Sensory diet
- ▶ Limit exposure
- ▶ Teach calming

Behaviors from Frustration

- Allow "trying and failing"
- Offer to help
- Don't ignore (support)
- "Practice" versus "do"
- Do half, let them finish
- Language (for all ages)
- Choices
- Fill in the blank
- Early on- sign, modified signs, PECS Alternatives to talking



Behaviors from Anxiety

Panic attacks associated with actual physiological changes (heart rate, sweating, rapid breathing, dizziness)

Teach relaxation tricks

Shorten exposure until success, lengthen once successful

Give a second chance

Redirect.. Works even for adults



Spectrum of Severity and Care



Spectrum of the conditions

- Healthy expression
- Minor behaviors, developmentally appropriate
- Moderate behaviors, escalation
- Severe, concern for safety

Levels of care/ treatment

- Parent/family support
- Medication
- Outpatient
- Day treatment
- Inpatient/hospitalization

Severe Behaviors

Multiple times a day
More than 30-45 minutes

Triggers are minor
Destructive
Disoriented
Injury to self/others
Threat to harm

Severely withdrawn
Not eating

A change in personality or hygiene
Worsening into young adulthood



Practical strategies

Make a diary/chart of the behaviors
 Across all environments and care providers
 Measure intensity, time, frequency, impairment
 A-B-C's
 Evaluation
 Medication
 Hospitalization

ABC Toolbox for XY

Remember the ABCs
 Know your triggers/hotspots
 Less language, more visuals
 Redirect, ignore, distract, humor
 Give choices, break down tasks
 Lower expectations, shorten time
 Structure, routines, prepare
 Ease transitions, allow processing
 Build special, positive relationships
 Catch em being awesome!
 Positive, positive, positive!!!!



....A most sincere thank you

- To the families and their children with XY SCA that have emailed, called, visited, worked with us and taught us so very much.
- Your courage and persistence continues to encourage and inspire us...

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