## Behavioral Considerations for XY Chromosome Differences

*extraordinary Kids Clinic*

Children's Hospital Colorado

KS&A July 2013

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Jamie Blume, PsyD, Clinical Psychologist

### Clinical Sample of Presenting Concerns by % Behavior

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

### Clinical Sample of Presenting Concerns by % Mood & Social Communication

<table>
<thead>
<tr>
<th>Concerns</th>
<th>XXY %</th>
<th>XYY %</th>
<th>XXXY %</th>
<th>XXXY %</th>
<th>XXX %</th>
<th>Tot %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>60</td>
<td>56</td>
<td>40</td>
<td>29</td>
<td>89</td>
<td>58</td>
</tr>
<tr>
<td>Depression</td>
<td>31</td>
<td>11</td>
<td>5</td>
<td>29</td>
<td>33</td>
<td>24</td>
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<tr>
<td>Social</td>
<td>69</td>
<td>100</td>
<td>55</td>
<td>71</td>
<td>56</td>
<td>66</td>
</tr>
<tr>
<td>Withdrawal</td>
<td>23</td>
<td>0</td>
<td>14</td>
<td>20</td>
<td>44</td>
<td>24</td>
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</table>
### Clinical Sample of Presenting Concerns by %

#### Academic & Learning

<table>
<thead>
<tr>
<th>Concerns</th>
<th>XXY %</th>
<th>XYY %</th>
<th>XXXY %</th>
<th>XXX %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic</td>
<td>74</td>
<td>56</td>
<td>45</td>
<td>71</td>
<td>44</td>
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<tr>
<td>Language</td>
<td>17</td>
<td>33</td>
<td>40</td>
<td>71</td>
<td>39</td>
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</table>

#### Continued …

<table>
<thead>
<tr>
<th>Concerns</th>
<th>XXY %</th>
<th>XYY %</th>
<th>XXXY %</th>
<th>XXX %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory</td>
<td>3</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>17</td>
</tr>
<tr>
<td>Motor</td>
<td>6</td>
<td>11</td>
<td>5</td>
<td>11</td>
<td>28</td>
</tr>
<tr>
<td>Fatigue</td>
<td>41</td>
<td>25</td>
<td>26</td>
<td>40</td>
<td>43</td>
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</tbody>
</table>

### Final Diagnoses of the Clinical Sample by %

<table>
<thead>
<tr>
<th>Diagnoses</th>
<th>XXY %</th>
<th>XYY %</th>
<th>XXXY %</th>
<th>XXX %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD</td>
<td>54.3</td>
<td>55.6</td>
<td>45.0</td>
<td>57.1</td>
<td>16.7</td>
</tr>
<tr>
<td>Conduct Disorder</td>
<td>0</td>
<td>0</td>
<td>5.0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Depression</td>
<td>22.9</td>
<td>11.1</td>
<td>5.0</td>
<td>14.3</td>
<td>11.1</td>
</tr>
<tr>
<td>Anxiety</td>
<td>20.0</td>
<td>22.2</td>
<td>20.0</td>
<td>14.3</td>
<td>27.8</td>
</tr>
<tr>
<td>ASDs</td>
<td>14.3</td>
<td>66.7</td>
<td>35.0</td>
<td>28.6</td>
<td>16.7</td>
</tr>
<tr>
<td>Language Disorder</td>
<td>51.4</td>
<td>33.3</td>
<td>35.0</td>
<td>57.1</td>
<td>50.0</td>
</tr>
<tr>
<td>Learning Disorder</td>
<td>20.0</td>
<td>22.2</td>
<td>25.0</td>
<td>14.3</td>
<td>16.7</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>14.3</td>
<td>11.1</td>
<td>20.0</td>
<td>42.9</td>
<td>0</td>
</tr>
</tbody>
</table>
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

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

**BC 1550 to 1000**
- 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**

Task demands
Parenting relationship
Neuro/biological
Sensory Demands
Environment
Too many words
Hunger
Fatigue
Mood
Anxiety

**Behaviors**

Positive (desirable)
- brushing teeth
- using manners
- doing chores

Neutral

Negative (undesirable)
- Tantrums
- Aggression
- Profanity

**Consequences**

Punishers: reduces behavior

Reinforcers: increases behavior

<table>
<thead>
<tr>
<th>Punisher</th>
<th>Reinforcer</th>
</tr>
</thead>
<tbody>
<tr>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
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....
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

<table>
<thead>
<tr>
<th>Function</th>
<th>Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention?</td>
<td>Ignore, attend to good behavior</td>
</tr>
<tr>
<td>Want Access?</td>
<td>Obtain w/appropriate behavior</td>
</tr>
<tr>
<td>Avoid?</td>
<td>Choices, provide control</td>
</tr>
<tr>
<td>Overwhelmed or “habit”</td>
<td>Calm, redirect, replace</td>
</tr>
</tbody>
</table>
Natural or Logical Consequences

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hit</td>
<td>Sit</td>
</tr>
<tr>
<td>Throw</td>
<td>Lose it</td>
</tr>
<tr>
<td>Break an object</td>
<td>Object is Gone</td>
</tr>
<tr>
<td>Make a mess</td>
<td>Clean it up</td>
</tr>
<tr>
<td>Whine</td>
<td>Ignore</td>
</tr>
<tr>
<td>Don’t get dressed</td>
<td>Go in PJs</td>
</tr>
</tbody>
</table>

Antecedent?

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...
Contact us:

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• *Email is best!