BEHAVIORS IN INTELLECTUAL DISABILITIES AND AUTISM
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NEUROBEHAVIORAL UNIT
- Kennedy Krieger
  - Department of Behavioral Psychology in 1975
    - Dr. Michael Cataldo
- Neurobehavioral Unit (NBU) was established in 1980
  - Leading programs in the nation for providing intensive behavioral treatment to individuals with severe and highly treatment-resistant behavioral disorders
  - Inpatient = 16 bed hospital unit
  - Outpatient = day treatment
  - Integrate clinical service, research, education and advocacy

OUTLINE
- Problem Behavior in Intellectual and Developmental Disabilities (IDD)
- Behavioral Phenotyping
- Functional Behavioral Phenotyping
- Current Findings
- Practical Advice
BEHAVIORS IN INTELLECTUAL DISABILITIES AND AUTISM

PROBLEM BEHAVIORS

- DANGEROUS BEHAVIORS
  - SELF-INJURIOUS BEHAVIOR (SIB)
  - AGGRESSIVE BEHAVIOR
  - DISRUPTIVE BEHAVIOR
  - ELOPEMENT

- INTERFERING BEHAVIORS
  - NONCOMPLIANCE
  - RESTRICTED AND REPEATED BEHAVIOR (RRB)

- BEHAVIORS ARE MORE COMMON IN THE IDD POPULATION
  - MORE COMMON IN DUALLY DIAGNOSED INDIVIDUALS (E.G., AUTISM AND ID)

ABSENCE OF BEHAVIOR

- DANGEROUS BEHAVIORS
  - SELF-INJURIOUS BEHAVIOR (SIB)
  - AGGRESSIVE BEHAVIOR
  - DISRUPTIVE BEHAVIOR
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PROBLEM BEHAVIORS

- DANGEROUS BEHAVIORS
  - SELF-INJURIOUS BEHAVIOR (SIB)
  - BEHAVIOR THAT CAUSES PHYSICAL INJURY TO THE SELF
  - AGGRESSIVE BEHAVIOR
  - BEHAVIOR THAT CAUSES PHYSICAL INJURY TO OTHERS
  - DISRUPTIVE BEHAVIOR
    - BEHAVIOR THAT UPSET THE ENVIRONMENT
  - ELOPEMENT
    - LEAVING SUPERVISED CARE WITHOUT PERMISSION
SIB NOT NONSUICIDAL SELF-INJURY (NSSI)

- **Not talking about NSSI**
  - For example, cutting in typically developing individuals
  - Occurs in the typically developing population
  - Has its own DSM designation
  - It is a different condition

SIB FACTS

- Across intellectual and developmental disabilities ~15% of individuals
- Autism: 30% – 50% of individuals
- Greater in other syndromes
  - Prader-Willi Syndrome > 90%
  - Lesch-Nyhan Syndrome ~ 100%

SELF-INJURIOUS BEHAVIOR (SIB)

- Behavior that causes injury to self
AGGRESSION FACTS

- Covaries with level of disability
- More likely with individuals with greater deficits
- Occurs in ~ 45% to 50% of people with IDD
- Common in Fragile-X

AGGRESSION

- Behavior that causes injury to others

DISRUPTION

- Covaries with level of disability
- Hard to know the prevalence
- Has been used to define a number of behaviors
  - Behavior that damages the environment
  - Behavior that disrupts others in the environment
Behaviors in Intellectual Disabilities and Autism

**Disruption**

- Behavior that disrupts or damages the environment

**Disruption**

- Dangerous Acts

**Elopeement**

- Leaving an area of supervision
  - Running away
  - Major safety concern
- Prevalence
  - ~50% of children with ASD
  - Kids with ASD are at a significantly higher risk for death from accident (drowning)
  - Of the kids with ASD who drown, ~75% reported to elope
IMPACT OF PROBLEM BEHAVIOR

- Risk of injury to self and others
  - Life altering SIB
  - Death (elopement)
- Strains educational systems
  - Schools are not set up to treat very challenging behaviors
- May necessitate residential or hospital care
  - Leading to prolonged separation from caregivers and community

RESTRICTED AND REPETITIVE BEHAVIOR (RRB)

- Persistent repeated acts (motor or vocal) that have no obvious purpose
  - Hand-flapping
  - Rocking
  - Repetitive statements
  - Arranging and ordering
RRB FACTS

• Extremely high prevalence in IDD
  • > 80% in ID
  • > 90% in ASD

• Impact of repetitive behavior
  • Interferes with adaptive behavior
  • Interferes with social/community engagement
    - Socially stigmatizing

BEHAVIORAL PHENOTYPE

• The prevalence of these behaviors contributes to a behavioral phenotype
  • Characteristic pattern that comes to define a disorder or condition

• Clinically relevant information
  • For example, in Prader-Willi Syndrome
    • Chronic skin-picking
    • Food-stealing ➔ Gastric Necrosis
  • Tells us: what to expect, what to plan for

PREVALENCE OF THESE BEHAVIORS IN SYNGAP1

• 5 studies (Ns = 10 – 56, M = 20)
  • SIB: 33% – 73%
  • Aggression: 33%
  • Disruption: 10% – 73%
  • Elopement: ?
  • RRB: 62.5% – 90%

• Issues
  • Wide ranges
  • Aggregating dissimilar behaviors
  • Manner in which the data were collected
PHENOTYPICAL BEHAVIOR

- However, this information is also limited
  - Only tells us what behaviors are likely to occur
  - Limited strategies to treat them

- My premise:
  Understanding characteristic patterns of behavior is exponentially more informative, if we understand why these behaviors occur

FUNCTIONAL BEHAVIORAL PHENOTYPIC (FBP)

- Unique behavioral sensitivities to the environment that give rise to common behaviors in a disorder or condition

- Questions
  - How is this information useful?
  - How do we find out why problem behaviors occur?

THE USEFULNESS QUESTION

- Provides a rich source of information on predispositions to respond in particular ways in particular contexts
  - A model for successful treatment can be developed given the population’s predisposition to respond in particular ways in particular contexts
  - Types of behavioral treatments that are successful with individuals with the disorder and subgroups within that disorder can be identified
    - Direct, actionable, information for clinical care
EASY EXAMPLE: ATTENTION DEFICIT HYPERACTIVITY DISORDER

- First off you might say: BEHAVIORAL TREATMENTS FOR ADHD?
  DON’T DRUGS WORK?
  - Yes and no
  - Northrup et al. (1995)

DRUG EFFECTS ARE CONTEXTUAL
EASY EXAMPLE: ATTENTION DEFICIT HYPERACTIVITY DISORDER

  - Examined how people with ADHD responded to different aspects of rewards (how big the reward was vs. how quick the reward came)
  - Conclusion: The immediacy of the reward mattered most to individuals with ADHD
  - Use in future care: Teaching individuals with ADHD to tolerate delays is going to be a crucial aspect of any behavioral treatment for an individual with ADHD

THE WHY IS IMPORTANT

- How do we determine why a behavior is occurring?

FUNCTIONAL ANALYSIS

- Dr. Brian Iwata
  - Experimental method to assess why behavior may be occurring as related to the current environment and local history
  - Not denying that biological factors may be the source of, or a contributing factor in, the occurrence of, problem behavior
  - Goal: Identify the controlling antecedent and consequent events in the environment
  - The things that come before and the things that come after
ALLERGY TEST ANALOGY

- In an allergy test, we expose the individual’s skin to a series of common environmental stimuli and look for reactions
  - Done in a controlled manner
- In an FA, we expose an individual’s behavior to a series of environmental contexts and look for where behavior occurs and is maintained
  - Done in a controlled manner

WHAT DOES AN FA PHYSICALLY LOOK LIKE?

- 3-4 test conditions run during a series of brief sessions (e.g., 5 mins of Test 1, followed by 5 mins of Test 2, etc.)
- Patient, therapist in a room away from other individuals
- Define problem behavior and collect data
- Test for sensitivity to “common” consequences
  - For example: Tangibles – objects, items, toys, food
- Control condition
  - Designed to be a control for all the test conditions
- Test conditions conducted until a pattern of responding emerges

ONE OUTCOME: SOCIALLY REINFORCED SIB

- Reinforcer is mediated by another person
  - Access to attention
  - Escape from demands
  - Access to objects
- Makes sense for a population with communication difficulties
ANOTHER OUTCOME: AUTOMATICALLY REINFORCED SIB

- **Automatic Reinforcement:** Reinforcement that occurs independent of others
  - Jumping on a trampoline
  - Hitting a drum
  - Candy Crush
  
*Vaughn & Michael, 1982*

NON-ClinICAL INDIVIDUALS AND AUTOMATICALLY REINFORCED SIB

- Recruited people from a farmers market and church
- Shocked everyone
- How much of $ to not get shocked again?
- Left alone in a barren environment for 15 mins with device that produced shock
- 65% of men and 25% of women chose to administer shock to themselves during the waiting period (some up to 9 times)
- Didn’t agree to research at the farmers market
- Bad stimulation can be > No stimulation

AUTOMATICALLY REINFORCED SIB

- **SIB Produces Reinforcement directly via a biological process**
  - Sensory Stimulation
  - Production of opioids (Thompson et al., 2004)
  - Pain attenuation (Kennedy & Thompson, 2000)
UTILITY OF FA ON AN INDIVIDUAL LEVEL
IWATA ET AL., 1994

- FA outcomes for 152 cases
- Socially reinforced SIB was common
  - Access to attention, escape, and tangibles
  - 60% - 75% of cases historically are socially reinforced
- Automatically reinforced in most of the remaining cases
- Undifferentiated (i.e., no result) in a small percentage of case (~5%)

EFFECTIVENESS OF FUNCTION-BASED TREATMENT

- Treatment for 121 cases
- 2 most common treatments were effective in over 90% of cases
- 35 years of behavioral treatment literature assessing function of problem behavior
  - A large variety of behavioral treatment options
  - The most effective treatments for problem behavior address reinforcing function

UTILITY OF FA ON A POPULATION LEVEL
BACK TO FBP

- FA allows us to build a FBP
  - Identifying common reasons why problem behavior occurs
  - A model for successful treatment can be developed given the population's predisposition to respond in particular ways in particular contexts
  - Reactive treatment
  - If we know there are common reasons why people with a particular condition engage in particular problem behavior we can focus on preventing problem behavior
  - Proactive treatment
CURRENT RESEARCH

GOAL

• ESTABLISH THE BEHAVIORAL PHENOTYPE IN SYNGAP1
  • USING WELL VALIDATED BEHAVIORAL MEASURES
    • REPETITIVE BEHAVIOR SCALE
    • FAST
• INVESTIGATE THE FUNCTIONAL BEHAVIORAL PHENOTYPE
  • DETERMINE THE FUNCTION OF PROBLEM BEHAVIOR THROUGH DIRECT MEASUREMENT OF PROBLEM BEHAVIOR THE CONTEXT IN WHICH IT OCCURS
  • TELI-FUNCTIONAL ANALYSIS

BEHAVIORAL PHENOTYPE

<table>
<thead>
<tr>
<th>First author (year)</th>
<th>Number of Individuals</th>
<th>SIB</th>
<th>Aggression</th>
<th>Disruption</th>
<th>Elopement</th>
<th>RRB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berryer (2012)</td>
<td>12</td>
<td>33%</td>
<td>33.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jimenez-Gomez (2019)</td>
<td>15</td>
<td>33%</td>
<td>60%</td>
<td>33%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mignot (2016)</td>
<td>16</td>
<td>43.8%</td>
<td>62.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parker (2015)</td>
<td>10</td>
<td>50%</td>
<td>60%</td>
<td>10%</td>
<td>90%</td>
<td></td>
</tr>
<tr>
<td>Vlaskamp (2018)</td>
<td>56</td>
<td>73%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Our findings</strong></td>
<td><strong>8</strong></td>
<td><strong>66.7%</strong></td>
<td><strong>62.5%</strong></td>
<td><strong>100%</strong></td>
<td><strong>62.5%</strong></td>
<td><strong>87.5%</strong></td>
</tr>
</tbody>
</table>
### MORE SPECIFIC BEHAVIORAL PHENOTYPE

<table>
<thead>
<tr>
<th>Disturbance</th>
<th>Proportion of population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Throwing object/property destruction</td>
<td>37.5%</td>
</tr>
<tr>
<td>Dangerous Acts</td>
<td>25%</td>
</tr>
<tr>
<td>Agitated vocalizations</td>
<td>25%</td>
</tr>
<tr>
<td>Dropping to the ground</td>
<td>12.5%</td>
</tr>
<tr>
<td>Food stealing</td>
<td>12.5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RRB</th>
<th>Proportion of population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor stereotypy (hand flapping, toy play)</td>
<td>62.5%</td>
</tr>
<tr>
<td>Vocal stereotypy (verbal statements)</td>
<td>25%</td>
</tr>
</tbody>
</table>

### FUNCTIONAL BEHAVIORAL PHENOTYPE BY PERSON

<table>
<thead>
<tr>
<th>Dangerous Behaviors</th>
<th>Proportion of the population (n = 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>25%</td>
</tr>
<tr>
<td>Escape</td>
<td>25%</td>
</tr>
<tr>
<td>Tangible</td>
<td>100%</td>
</tr>
</tbody>
</table>

### FUNCTIONAL BEHAVIORAL PHENOTYPE BY BEHAVIOR - ELOPEMENT

<table>
<thead>
<tr>
<th>Elopement</th>
<th>Proportion of the behaviors (n = 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>33.3%</td>
</tr>
<tr>
<td>Escape</td>
<td>0%</td>
</tr>
<tr>
<td>Tangible</td>
<td>100%</td>
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</table>
FUNCTIONAL BEHAVIORAL PHENOTYPE BY BEHAVIOR - ELOPEMENT

<table>
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<th>Elopement</th>
<th>Proportion of the behaviors (n = 3)</th>
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<tbody>
<tr>
<td>Tangible</td>
<td>100%</td>
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</table>

PRACTICAL ADVICE

PRACTICAL ADVICE - ACCESS TO TANGIBLES

- Tangible function seems likely
  - Problem behavior occurs to get access to objects the individual wants
- Recommended treatments: Extinction
  - Deny access to objects when problem behavior occurs

<table>
<thead>
<tr>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highly Effective</td>
<td>Behavior gets worse first</td>
</tr>
<tr>
<td>Requires very little maintenance in the long run</td>
<td>Giving in, after denying access, will make behavior worse in the long run</td>
</tr>
<tr>
<td>May engender appropriate behavior</td>
<td>Other behaviors may emerge</td>
</tr>
</tbody>
</table>
Behaviors in Intellectual Disabilities and Autism

PRACTICAL ADVICE - ACCESS TO TANGIBLES

- Tangible function seems likely
- Problem behavior occurs to get access to objects the individual wants
- Recommended treatments
  - Functional communication training: Teach the individual to ask for things rather than engage in problem behavior

<table>
<thead>
<tr>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>New skill is taught</td>
<td>Unlikely to be effective in the absence of extinction</td>
</tr>
<tr>
<td>Should quickly replace problem behavior (provided the person has the ability)</td>
<td>Require you to give the person access to desired things a lot (interfering)</td>
</tr>
<tr>
<td></td>
<td>May not be sustainable in the long run (see tolerance training)</td>
</tr>
</tbody>
</table>

Pros Cons

- Immediately stops problem behavior with very little effort
- Requires you to give the person access to desired things all the time (interfering)
- May not be sustainable in the long run (see tolerance training)

PRACTICAL ADVICE - ACCESS TO TANGIBLES

- Tangible function seems likely
- Problem behavior occurs to get access to objects the individual wants
- Recommended treatments
  - Noncontingent reinforcement: Simply provide the item freely

PRACTICAL ADVICE - ACCESS TO TANGIBLES

- Tangible function seems likely
- Problem behavior occurs to get access to objects the individual wants
- Recommended treatments
  - Teach tolerance of delays to objects through progressive fading – Needs to be combined with one of the other treatments
PRACTICAL ADVICE - ACCESS TO TANGIBLES

- All of the treatments have pros and cons, but...
- You can mitigate the cons by combining the treatments:
  Functional Communication Training, with Extinction, with Tolerance Training

Make the person ask, don't allow access for problem behavior, eventually build in delays

Greer et al., 2015

CONTACT

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