Psychiatric Hospitalization for Serious Emotional and Behavioral Challenges in Autism

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AGENDA

- Autism & Behavioral Challenges
- Psychiatric Hospitalization
- Spring Harbor Specialized Inpatient Unit
- Inpatient Research Collaborative
- Care Pathway for General Psychiatric Units
- Consensus Recommendations
## Common Problems in ASD

- Survey of 487 school children identified as ASD in their IEP – parent report

- Easy frustration   (60%)
- Inattention       (50%)
- Hyperactivity     (40%)
- Temper tantrums   (30%)
- Irritable         (20%)
- Fearful / anxious (13%)
- Harming self      (11%)
- Destroying property (11%)
- Physical aggression (5%)

- Lecavalier, 2006
PREVALENCE OF SERIOUS CHALLENGING BEHAVIOR

Aggression:

- Kanne & Mazurek, 2011 1380 youth using the ADI-R
  Aggression Items
  68% definite towards parents
  49% definite towards non-caregiver

- Mazurek et al., 2013 1584 youth - ATN Parent Survey
  Is child currently demonstrating physical aggression?
  53% Yes
# Prevalence of Serious Challenging Behavior

## Self Injury:

- **Soke et al., 2016**
  - 8065 children from the Autism and Developmental Disabilities Monitoring Network (ADDM)
  - Record review
  - 27.7% Yes

- **Steenfeldt-Kristensen et al., 2020**
  - 14,379 children, Meta-analysis
  - Multiple measures
  - 42% Yes
Families report that aggression is often of greater concern and negative impact than the core social and communicative deficits that define ASD, as it increases their stress, isolation, and financial burden, and decreases available support options.

Developmental Trajectory

Development

Age
Etiology

Aggression / Self-injury

- Psychiatric Co-Morbidity
- Behavioral Function, Reinforcement & Skill Deficits
- Functional Communication Deficits
- Family Changes
- Dysregulated Sensory System
- Demand:Ability Mismatch
- Side Effects
- Medical Illness/Pain
- Emotion Regulation Deficits
- Trauma
- Genetically Linked
- Sleep Disorders
- Bullying/Social Challenges
Leyfer, 2006: 109 children, at least some spoken language. Modified the K-SADS to account for symptoms typical of ASD.

**Lifetime Prevalence (by Adolescence):**

<table>
<thead>
<tr>
<th>Anxiety Disorders</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Specific Phobia</td>
<td>44%</td>
</tr>
<tr>
<td>OCD</td>
<td>37%</td>
</tr>
<tr>
<td>Separation anx. d/o</td>
<td>12%</td>
</tr>
<tr>
<td>Social phobia</td>
<td>7%</td>
</tr>
<tr>
<td>Generalized anxiety</td>
<td>2%</td>
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</tbody>
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| ADHD                            | 31%        |
| Depressive Disorder             | 13%        |
| ODD                             | 7%         |
| Bipolar Disorder                | 2.4%       |
| Psychotic Disorder              | 0%         |
How do we “make sense” of challenging behaviors?

Big Question: What is the function of the behavior?
- That is ...
  - What is s/he getting be engaging in the behavior?
  - What is reinforcing the behavior?
  - What is the outcome of the behavior?

Four Primary Functions of challenging behavior
- Social attention
- Access to preferred (getting something desired)
- Escape / Avoidance (of non-preferred)
- Automatic Reinforcement (self-stimulatory)
COMMON MEDICAL PROBLEMS IN ASD

- Seizures (10-20%)
  Two peaks of incidence: early childhood, adolescence
- GI Problems
  - Constipation / Encopresis
  - GERD (acid reflux)
- Dental problems
- Sleep deficit
- Environmental allergies
- Food allergies
- Minor injuries
- Ear infections
- Headaches

Therapeutic Approaches For Challenging Behaviors

- Applied Behavior Analysis
- Communication strategies
  (AAC/Functional Communication/Visual supports)
- Social skills / social cognitive strategies
- Treatment of Psychiatric Co-morbidity
- Psychotherapy approaches – CBT / Emotion regulation
- Sensory regulation strategies
- Treat Medical Problems
- Family treatment / Parent Management Training (RUBI)
PSYCHIATRIC HOSPITALIZATION
Massachusetts ER study:
- Diagnosis of Autism #1 predictor of ED boarding
- Diagnosis of Intellectual Disability #2
  (Wharff et al, 2011)

13% of children with ASD present to the ER for mental health concerns, compared to 2% without ASD
  (Kalb et al., 2012)
11% have been psychiatrically hospitalized by age 21 (Mandell, *Pediatrics*, 2008)

Study of 33,000 children with ASD. Youth with ASD psychiatrically hospitalized at a ratio of 6:1 compared to non-ASD children. (Croen, *Pediatrics*, 2006)
Barriers to Psychiatric Hospitalization for People with ASD

- Limited number of specialized units and geographic maldistribution
- Almost all units are for youth. Vanishingly few for adults (Pittsburgh, Michigan, a few others)
- Lack of knowledge, expertise and relevant treatment approaches in many general units.
- Insurance rules in some states that require a primary psychiatric diagnosis for admission, and declare ASD not to be one.
- Denial of care due to misunderstanding of autism symptoms
- Institutional fear and stigma
RISK FACTORS FOR PSYCHIATRIC HOSPITALIZATION

- Aggressive behavior (odds ratio (OR) = 4.83)
- Single parent homes (OR = 2.54)
- Depression (OR = 2.48)
- Obsessive compulsive disorder (OCD) (OR = 2.35)
- Self Injurious Behavior (OR = 2.14)

Risk for hospitalization increases with age.

(Mandell, JADD, 2008)
Comparison of two age, gender and geographically matched ASD cohorts:

- Inpatients - Autism Inpatient Consortium (AIC)
- Outpatients - Rhode Island Consortium for Autism Research and Treatment (RI-CART)

Lower adaptive functioning, greater ASD symptom severity, single primary caregiver, and presence of a mood disorder or sleep problems each independently increased risk of psychiatric hospitalization.

CHIEF COMPLAINT FOR PSYCHIATRIC HOSPITALIZATION

- SIB: 23%
- Sexualized Behavior: 4%
- Tantrums: 16%
- Elopment: 4%
- Decreased functioning: 8%
- Property destruction: 17%
- Aggression: 28%

Siegel M, JADD, 2011
## Different Needs

<table>
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<tr>
<th>Common Elements of Psychiatric Units</th>
<th>People with ASD/ID</th>
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<tr>
<td>Developed for internalizing/psychiatric problems</td>
<td>Have primarily externalizing, behavioral symptoms</td>
</tr>
<tr>
<td>Rely on verbal interventions: Talking with staff, discussing events, family meetings</td>
<td>May struggle to understand or become agitated with verbal interventions</td>
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<tr>
<td>Group programming with high social interaction demands</td>
<td>May not be able to participate in groups or meet social interaction demands</td>
</tr>
<tr>
<td>Frequent staff transitions, shifting schedules</td>
<td>Removed from preferred routines &amp; caregivers, thrive on consistency</td>
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| Unit point or level reinforcement systems  
  - Infrequent: daily to weekly reinforcement  
  - General reinforcers: unit store, hospital privileges | Are used to much higher frequency of reinforcement that is child-specific  
  - Agitated, excluded, non-reinforced, in room > aggression > seclusion/restraint |
Spring Harbor Hospital DD Unit, Spring Harbor Academy, Partial Hospital Program, K-12 and Preschool Day Treatment, Toddler In-home Program, Outpatient Clinic, Clinical Research Program
Children, family and community systems can be engaged during inpatient stabilization to address the key acute and chronic sources of crisis.

Opportunity for intensive assessment and treatment of challenging behavior, teaching new skills and setting children up for success.

Rigorous diagnosis and treatment of psychiatric comorbidity improves outcomes and reduces polypharmacy.
Multidisciplinary Treatment Team

- Child Psychiatry
- Behavioral Psychologist
- Behavior Analyst (BCBA)
- Special Education
- Speech Language Pathologist
- Occupational Therapist
- Nursing
- Social Work
- Milieu Coordinator
FOUNDATION OF TREATMENT

- Individualized positive behavior support plan with embedded communication and occupational therapy supports
- Targeted psychopharmacology
- Transfer of management skills to parents, local school, in-home staff
Behaviors: Frequent tantrums (30-120 minutes/day total) accompanied by aggression (20-40 times/day).

Communication: Non-verbal (<10 single words), reported to use PECS at school and not at home.

Motor: Impaired fine and gross motor skills, unable to use utensils effectively.

Educational: Pre-K level abilities, with some splinter skills.

Physiologic: Awakening 3-4 times a night.

Medication: Risperidone 4 mg/day, Benadryl PRN.
Tantrum Etiology
(By History & Early Observation)

- Tired & Sedated
- Communication frustration
- Confused / disoriented:
  Lack of supports for environmental predictability
- Inconsistent expectations (even with our staff)
- FBA: Reinforcement of behavior by attending to screaming (attention function), allowing task avoidance (escape function)
- Hungry but struggles at mealtime
### A Broad and Deep Intervention:

#### Tantrums +/- Aggression

**Communication**
- PECS trials in class (slp)
- PECS use 24/7
- Train parents/in-home

**Behavioral Response**
- Weaned off Risperidone
- **Behavior Plan**
  - Reinforce Non Tantrums
  - Deny Escape
- Parents shadow and run plan

**Sleep Deficit**
- Sleep Hygiene
  - Trazodone
- Sleep hygiene training with parents

**Structure Environment**
- **Visual Schedule**
- **Visual Transition Countdown**
- Motor Breaks
- Table Top Learning
- Transfer to School/Parents

**Eating Protocol**
- Adaptive Utensils
- Parent/School Training

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- Adaptive Utensils
- Parent/School Training
Patient X Aggression Over Stay
Emotional Dysregulation Over Stay

Days

# of Occurrences
Figure 1. Estimated Marginal Means of Abberant Behavior Checklist Irritability (ABC-I) Subscale Between Children with and without Autism Spectrum Disorder (ASD) Over Time.

Siegel M, et al., JADD, July, 2014
**Autism Inpatient Collection**

- **Goals:** Standardized assessment, description of the population, resource for all investigators, research platform for measure development, mechanistic studies and treatment studies.

- To date, enrolled over 1450 youth with ASD and their biological parents through six-site research network of specialized child psychiatry units.

- Rigorous core assessment battery and ASD diagnostic reliability.

- 48% minimally verbal, 42% Intellectual Disability (Molec Aut, 2015).

- Biosamples stored, gene sequencing of complete trios.

- Dataset of n=1354 available to approved investigators through SFARIBase.

- SPARK AIC
ABC-I Scores, n=350

- Significant reduction in problem behavior scores from admission to discharge, and 2-month follow-up ($p \leq 0.05$)
- Admission: 29.7(9.6)
- Discharge: 15.0(10.3)
- 2-Month Follow Up: 19.3(10.3)

Care Pathway for Youth with Autism Admitted to General Psychiatric Units

Implemented in a low resource, public psychiatric hospital. Bellevue Hospital in Lower Manhattan.

Development of pathway, staff training, pre-post data collection.

Compared 18 months pre-implementation ($n=17$) vs 18 months post implementation ($n=20$).

ASD-ID Care Pathway Elements

1. Key information at admission
2. Address the basics
3. Support predictability and activity
4. Positive behavior reinforcement plan
5. Concrete coping strategies
6. Enhance communication

Slides & Pathway developed with Sarah Kuriakose, Ph.D., NYU and Mollie Marr, BFA, Bellevue Hospital
### 1. Collect Key Information

- **Tip Sheet contains key information**
  - Communication style
  - Early warning signs of agitation
  - Preferred activities and rewards

### Communication

- **How does the child communicate with people?**
  - talks  □ writes  □ sign language  □ pictures  □ voice device  □ gestures

  *Non-verbal but will pull on hand to guide adult. Uses a lot of echoing.*

- **What communication does the child understand?**
  - ☑ single words  ☑ short sentences  □ long sentences  □ written  □ pictures  □ sign language

  *Knows “stop”, “prize” – keep sentences very short. Uses pictures at school*

### Behavior

- **What are warning signs that the child is becoming upset?**
  - ☑ crying  □ pacing  □ withdrawing  □ not answering  □ echoing/noises  ☑ rocking
  - □ tense body  □ refusing  □ other (specify)

  *Gets very upset if separated from pokemon object*

  **BRING TO TOILET every 90 minutes**

- **What unsafe behaviors does the child have?**
  - □ grabbing  ☑ hitting  □ throwing  □ kicking  □ spitting  □ pinching  □ scratching
  - □ hair pull  □ eating inedible objects  □ biting  □ self-injury  □ eloping

### Helps the child calm down?

- ☑ taking space  □ deep breaths  ☑ physical activity  ☑ fidget  □ food/drink  □ choices
  - □ humor  □ talking to staff  □ phrase  □ object **Pokemon**

*Do NOT try to talk to him when he is upset. Bouncing on ball can help.
If he is calming down, can tell him that pokemon is happy he is calm*

### Activities and Rewards

- **What activities does the child enjoy doing?**
  - □ coloring  □ reading  □ videos  □ physical activity  □ fidget toy  □ music  □ other (specify)

  *Running around, basketball*
2. **Address the Basics**

- Is the child **eating** and **drinking** enough?
- Is the child **sleeping** enough?
- Is the child in **pain**?
- Is the child **toileting**?
3. Support Predictability

- Increasing predictability reduces problem behaviors in patients with ASD or ID

- Hospital is a new environment

- All people, including our patients, need to know
  - What am I doing now?
  - What am I doing next?
  - When will I get to eat?
  - When will I get to do something I like doing?

- They need some predictability
4. **Positive Reinforcement Behavior Plan**

**High Frequency, Specific Reward**

- Using rewards decreases problem behaviors.
- The more delayed or distressed a child is, the higher the frequency (could be every 5 minutes).
- For kids with ASD, reward can be highly specific to their interest (might be repeatedly watching 5 minutes of Barney video).
5. **Concrete Coping Strategies**

**Agitation Management**

- **Baseline - Prevention**
- **Early Warning Signs**
- **Loss of control**
- **Safety Management**
- **De-escalation**
- **Alert Zone**
- **Give Space, then Coping Card**

**Agitation**

**Time**
All of our ASD and ID patients require support to communicate effectively.

Total Communication means helping patients to communicate through any and all modes available to them.

- Verbal
- Sign language/gestures
- Written/visual aids
- Technological devices/programs
Effectiveness of the ASD-CP in a public hospital child psychiatric service compared 18 months pre-implementation ($n=17$) vs 18 months post implementation ($n=20$).

- Average length of hospital stay decreased 40% (22.4 days to 13.4 days) $p=0.07$

- Use of physical holds/restraints decreased 77% (0.65/day to 0.15/day) $p=0.057$

Summary of Consensus Recommendations

- Obtain information specific to child with ASD/ID
- Screen for medical etiology of challenging behaviors
- Assess for co-occurring psychiatric disorders and target the psychopharmacology
- Assess and support communication and occupational therapy needs
- Perform functional behavioral assessment and take behavioral data

- Create therapeutic spaces and appropriate activities
- Provide structured educational services
- Provide direct care staff specific training
- A longer length of stay to change behavior
- Interpret standard medical necessity criteria in context of the developmental disorder
Youth with ASD can develop serious emotional and behavioral challenges. Puts them at risk for polypharmacy, community/educational exclusion, hospitalization and residential placement.

The work of a single discipline is often not enough for a multi-factorial problem.

Successful treatment of refractory challenges may require a broad multi-disciplinary approach that manages acute symptoms and ameliorates key perpetuating factors, such as sleep deprivation, psychiatric co-morbidity, communication inefficiency, and environmental reinforcement.
AUTISM SPECTRUM DISORDER:
Parents’ Medication Guide

Download for free at: www.aacap.org
RESOURCES


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