Assessment and Treatment of Challenging Behaviors in Children with Autism – Inpatient Approaches

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Disclosure to Audience

No one involved in the planning or presentation of this activity has any relevant financial relationships with a commercial interest to disclose.

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<th>Employee</th>
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Educational Learning Objectives

At the conclusion of this continuing medical education activity, the participant will be able to:

• 1. Evaluate multidisciplinary inpatient approaches to children with autism and other developmental disorders.

• 2. Assess care trends for the inpatient developmental disorders population.
Agenda

• Epidemiology of ASD Inpatient Treatment
• Trends in General and Specialized Inpatient Treatment
• Specialized Treatment Approach
• Evidence for Specialized Inpatient Treatment
• Autism Care Pathway for General Inpatient Units
What Challenges Does the Community ASD Population Have?

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

Predictors of Psychiatric Hospitalization

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

- Risk for hospitalization increases with age.

Children with ASD Have Very High Rates of Psychiatric Hospitalization

- 11% have been psychiatrically hospitalized by age 21.
  (Mandell, Pediatrics, 2008)

- 11.9 times as many inpatient psychiatric hospital days for children with ASD than non-ASD population of children.
  (Croen, Pediatrics, 2006)
Barriers to Inpatient Care

• Insurance rules requiring an additional Axis I diagnosis in order to access care

• Diagnostic overshadowing – ascribing all facets of a child’s presentation as representative of the background ASD diagnosis. (Reiss, 1985.)

• Conclusion: Child has ASD, no other diagnosis, aggressing 50 times a day is part of ASD and is chronic and untreatable, therefore no authorization for care.
Further Barriers

Institutional or clinician resistance to providing care due to lack of experience.

• Most child psychiatry trainees see less than 5 outpatients and 10 inpatients with ASD or intellectual disability (ID) per year during 2 year training.

• Number one predictor of “boarding” in the emergency room was having an ASD diagnosis.
Protective Factors

• Location with higher number of pediatric specialists, female, younger age.

• Each $1,000 increase in spending on respite care during the preceding 60 days resulted in an 8% decrease in the odds of hospitalization in adjusted analysis.

Cost Breakdown

Oswald and Sonenklar, 2007.
High Utilizers within ASD Population

• Similar to other chronic illness populations.

• 10% of children with ASD account for 53% of total annual health care costs.

• Almost all children with ASD who had been psychiatrically hospitalized were in top decile for total annual cost. - Croen, Pediatrics, 2006.
Trends in Inpatient Psychiatry For ASD
Specialized Inpatient Psychiatric Units For Children: Europe

• United Kingdom inpatient services for ASD/ID youth
  – 48 beds, distributed across 5 units, interdisciplinary teams, average length of stay ~ 153 days

• Retrospective study of 96 youth with intellectual disability admitted to a specialized psychiatric unit in England
  – 63% of patients were in need of neuropsychiatric management
  – 37% had mainstream psychiatric issues but had intellectual disabilities that made mainstream services inappropriate
  – No outcome measures

German Study

• Surveyed 136 hospitals with child psychiatry units in Germany

• 8% offered a specialized unit for the ASD and ID populations

• 85% expressed a desire for such a unit

U.S. Study

9 Units - 137 beds in the U.S.

Average length of stay: 42.3 days (30 without outlier)

Bio-Behavioral Approach: 100% of units employ both a child psychiatrist and a psychologist/BCBA.

Multi-disciplinary Teams: 88% of units have teams composed of 4 or more disciplines.

Growth of Specialized Inpatient Psychiatry Units

- National total of specialized inpatient units has increased rapidly in the past decade.
- 5 of the nation’s 9 units originated after the year 2001.
Most Common Chief Complaint at Admission

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

<table>
<thead>
<tr>
<th>Percentage of Units Serving as a Training Site for Clinical Specialty</th>
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<tbody>
<tr>
<td>Nursing Students</td>
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<tr>
<td>Medical Residents, Fellows, or Students</td>
</tr>
<tr>
<td>Psychology Interns or Board Certified Behavior Analysts (BCBAs)</td>
</tr>
<tr>
<td>Occupational Therapists in training</td>
</tr>
<tr>
<td>Speech Language Pathologists in training</td>
</tr>
<tr>
<td>At least one clinical specialty</td>
</tr>
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Follow-up Survey

- August 2012 Survey
- 8 of 10 Units responded

- Children with an autism spectrum disorder are 76% of the inpatient population, totaling over 1,000 inpatient ASD cases per year.
- Average length of stay (LOS) = 30 days (22 days with removal of outlier)
- Recidivism rate = 13.8% (readmission < 1 year)

Siegel, et al., in revision, 2014.
A Severely Affected Population

Full Scale IQ

- IQ < 70
- IQ > 70

Communication Ability

- **non-verbal (<10 words)**, limited verbal (primarily echolalia and scripted speech)
- **verbal (fluent speech)**

- non-verbal (<10 words),
- limited verbal (primarily echolalia and scripted speech)
- verbal (fluent speech).
Most research on autism is on the high functioning, verbal population.

- Accessible
- Who clinicians are familiar with
- You can adapt measures and treatments (CBT) to the verbal, high functioning population

Simons Simplex Collection
5 years, 12 outpatient academic centers
2800 families
Average IQ well above seventy

If we want to understand an entity, we need to look at all forms.
Autism Inpatient Research Collaborative
Parsing Autism

- Multi-site study

Six specialized child psychiatry units
  - 1000 children with ASD per year, weighted toward more severely affected

- Initial 2 year project to perform phenotypic measurement and bio-banking of blood samples from 500 children with ASD.
- Examine domains of communication, intelligence, behavior, medical and psychiatric co-morbidity and emotional regulation.
- Will provide information to begin to sub-type autism across full autism spectrum, including those most severely affected.
Spring Harbor Hospital
Developmental Disorders Program

DD Unit, Spring Harbor Academy, Research Team, Hospital Transition Service
Spring Harbor Hospital Program

- Portland, Maine
- 12 bed self contained unit
- Accepts only children with autism or intellectual disability
- Average length of stay 42 days
- Highly individualized behavioral plan with embedded communication and occupational therapy supports and family and provider training.
- ABA based: 3-5 target behaviors tracked continuously, graphed, and reviewed daily
Multi-Disciplinary Treatment Team

- Child Psychiatry and Pediatrics
- Behavioral Psychologist
- Special Education
- Speech Pathologist
- Occupational Therapist
- Nurse Manager
- Social Work
- Behavioral Coordinator
- Milieu Coordinator
Mission

• To provide **sustained** stabilization for children with autism and other developmental disorders through a multi-disciplinary, evidence-based approach to an individual and their family.

• Ten years ago many Maine children with ASD/ID placed in out of state residential facilities.

• Last 4 years – three out of >200 admitted to Spring Harbor unit sent out of state.
Treatment Philosophy

• Children, family and community systems can be engaged during inpatient stabilization to address both the acute and chronic sources of crisis.

• Positive behavioral reinforcement helps children take the risk to give up old behaviors and learn new ones.

• Diagnosis and treatment of psychiatric comorbidity improves outcomes and reduces polypharmacy.
Causality Model For Admission

- Child with Developmental Disorder with impairment in emotional regulation, communication
  - Non-functional Communication System
    - Communication frustration
      - Family Stress & Dysfunction
        - Lack of School - Home Behavioral Coordination
          - Underdeveloped coping skills
            - High frequency or intensity aggression/SIB
              - Acute Crisis

- Lack of provider training in DD population
  - Misdiagnosed & Undiagnosed Mental Illness
    - Polypharmacy/Sedation
      - Agitation
        - Frequent turn-over of in-home staff
          - Limited lower levels of care
            - Poorly supervised in-home services
              - Unrecognized Sensory Needs
                - Lack of School - Home Behavioral Coordination
### Etiological domains | Examples of potential contributing factors
--- | ---
**Caregiver/community environment** | Environmental inconsistency  
Inadvertent reinforcement of undesired behavior  
Family dynamics/visitation schedules  
Abuse/neglect  
Individuation  
Recent loss or change in the environment  
Challenging social relationships (bullying)  
Inappropriate school setting
**Cognitive** | Intellectual Disability, Learning disability, Slow processing speed
**Communication** | Absence of or inappropriate communication system  
Use of communication system in only one setting
**Genetic** | Fragile X, 22q11.2 deletion syndrome, etc.
**Latrogenic** | Polypharmacy, Sedation, Prompt dependence  
Agitation from prolonged intensive behavioral management
**Medical** | Pain  
Dental  
Vision  
Constipation  
Allergies  
Puberty  
Seizures  
Hearing  
Pica  
Sleep  
Nutrition  
Brain injury
**Psychopathologic** | Anxiety Disorders, including Post-traumatic Stress disorder  
Mood Disorders, ADHD, Obsessive Compulsive Disorder  
Psychosis or Catatonia
**Sensory-Related** | Hyper or hypo-sensitivities to auditory, tactile, oral, visual, vestibular

General Intervention Aims

- Reduce unsafe behaviors
- Improve self-regulation skills
- Increase positive social interactions
- Increase parent management skills
- Acquire adequate school and community supports to sustain gains post-discharge
Foundation Treatment

- Highly individualized behavioral plan with embedded communication and occupational therapy supports
- Targeted psychopharmacology
Additional Treatment Paths

- High Functioning ASD/Mild ID – Social Cognitive Treatment
- Anxiety diathesis – CBT exposure protocols
- Feeding/toileting – Specific protocols
- Inappropriate sexualized behaviors – Circles©, 5 is Against the Law©
- Family dysfunction / ineffective child management – parent-child interaction observation and coaching
Family Education and Training Program

Didactic:
- Understanding diagnosis
- Contingency management approaches
- Sibling education

In vivo:
- Supervised application of individualized behavior plan
- Transfer of stimulus control from therapists to parents

(Abbreviated LOS compromises this element)
Behaviors: Frequent tantrums (30-120 minutes/day total) accompanied by self injury (20-40 times/day).

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

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

Educational: Pre-K level abilities with some splinter skills

Physiologic: Awakening 3-4 times a night

Medications: Risperidone 4mg/day, Benadryl as needed (PRN)
Tantrum Etiology (By History and Early Observations)

- Communication frustration
- Impaired ability to self regulate
- Lack of supports for environmental predictability
- Tiredness
- Inconsistent expectations (even with our staff)
- Reinforcement of behavior by attending to screaming, task avoidance
- Hungry but struggles at mealtime
Strategies/Tools

Pro-active:
- Trazodone for sleep, removal of other meds
- Visual schedule
- Visual count down to start of transition
- Picture Exchange Communication System (PECS) implemented throughout day
- Build earned times into schedule (task, earn, task)
- Motor breaks built into schedule
- Eating protocol implemented at snacks and meals

Reactive:
- Quiet voice icon presented/withdraw other attention
A Broad and Deep Intervention

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

- Behavioral Tracking
  - Behavior Plan – Reinforce non tantrums
  - Parents shadow and run plan

- Sleep Deficit
  - 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
Evidence for Specialized Inpatient Treatment Effectiveness

Children’s Hospital Colorado
Retrospective Study

Compared children with ASD in a psychiatric unit from general era (2001) vs. specialized era (2009)

◆ Decreased length of stay (45 to 26 days)
◆ Decreased recidivism rate (33% to 12%)

Prospective Study

- Spring Harbor Hospital Developmental Disorders Unit
- Aberrant Behavior Checklist by primary caregiver at admission, discharge and 2 months post-discharge
- Clinical Global Impression of Improvement (CGI-I), clinician rated
- Discharge Diagnoses
- Medications at admission, discharge and 2 months post discharge

Siegel M, et al., Submitted, 2014
<table>
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<tr>
<th>Comorbid Diagnosis</th>
<th>Total Sample N=38</th>
<th>ASD Group N=19</th>
<th>Non-ASD Group N=19</th>
<th>Statistic</th>
<th>DF</th>
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<td>Any Disrupt. Behav. DO</td>
<td><strong>22 (58%)</strong></td>
<td><strong>3 (16%)</strong></td>
<td><strong>19 (100%)</strong></td>
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<td>Any Anxiety Disorder</td>
<td><strong>25 (66%)</strong></td>
<td><strong>12 (63%)</strong></td>
<td><strong>13 (68%)</strong></td>
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<td>Any Mood Disorder</td>
<td><strong>6 (16%)</strong></td>
<td><strong>2 (10%)</strong></td>
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<td>Tic Disorder NOS</td>
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<tr>
<td>Tourette’s Syndrome</td>
<td>4</td>
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<td>3</td>
<td>( \chi^2=1.11 )</td>
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<td>0.29</td>
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<td>Any DO of Infancy/EC</td>
<td><strong>9 (24%)</strong></td>
<td><strong>4 (21%)</strong></td>
<td><strong>4 (21%)</strong></td>
<td>( \chi^2=0.00 )</td>
<td>1</td>
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DO: disorder; EC: early childhood
Significant treatment by time effect, $F(3, 26) = 57.19, p<0.001$

No significant difference between ASD and Non-ASD groups, $F(3, 26) = 0.15, p=0.71$
CGI-I

- Clinician-rated

- 84% of ASD group much/very much improved

- 72% of non-ASD group (primarily ID) much/very much improved
Psychotropic Medications at Admission, Discharge and 2 Month Follow Up

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<tr>
<td>7</td>
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<td>1</td>
<td>2</td>
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Further Questions

• What is the trajectory further out and what predicts outcome?

• How do our outcomes compare to those for same population admitted to a general child psychiatry unit?

• What is the effect of a low-cost, post-hospital transition service?

• Can we develop an efficient, low burden intervention (a care pathway) to improve outcomes in the 100’s of non-specialized units in the country?
Developing an ASD Pathway for General Inpatient Unit Admissions

- Use of clinical pathways in other areas of medicine have led to significant quality improvements: congestive heart failure, diabetes, wound care.

- Common elements: standardized evaluation tasks, checklists for treatment components and institutional benchmarks to track performance.

- Mental health settings have been relatively slow to adopt.
Autism Care Pathway Elements

- Increased information at admission
- Basic support tools for communication
- Basic positive behavior plan
- Staff training
- Environmental modifications
Autism Inpatient Care Pathway

### Additional Patient Information to Collect
- Food, object and activity preference and aversions
- Calming items / techniques
- Level of assistance with activities of daily living (ADL’s)
- Communication strategies
- Does child have communication system with them?
- Response to restraint in past
- Early signs of agitation (e.g. pacing)
- Specific information on dangerous behaviors
- Produce a tip sheet with this information for unit staff

### Interventions to Apply
- Define two problem behaviors
- Utilize a behavior plan:
  - Reinforce desired behaviors
- Reduce polypharmacy
- Provide visual supports for:
  - Schedules and routines alternating preferred/less preferred activities
- Teach feeling states and coping strategies (deep breaths/space) with designated quiet calming areas on the unit
- Convey successful strategies to parents

### Staff Structure
- Identify a consistent subset of staff for this patient
- Train staff to:
  - Minimize verbal directions
  - Simplify language
  - Use visual cues
  - Allow child time to process
  - Do not move toward an agitated child – give space.
- Model self-regulation strategies such as taking deep breaths
- Be aware of patients’ individual preferences and aversions

Children with ASD can develop serious behavioral disturbances = risk for polypharmacy, hospitalization and residential placement

Hospitalization of children with ASD is prevalent.

There is preliminary evidence for the effectiveness of specialized inpatient psychiatry units designed for the ASD and ID population, and a lack of studies of general child psychiatric hospital treatment for this population.

Successful treatment requires a broad multi-disciplinary diagnostic approach that manages acute symptoms and ameliorates key perpetuating factors, such as sleep deprivation, communication inefficiency, or environmental reinforcement of maladaptive behaviors.
Acknowledgements

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- Amy Stedman
Thank you

Matthew Siegel, M.D.

siegem@springharbor.org
Date: 05/02/2014
Starting Time: 12:00 pm
Ending Time: 1:00 pm

Topic: Assessment and Treatment of Challenging Behaviors in Children with Autism – Inpatient Approaches
Presenter(s): Matthew Siegel, MD

At the conclusion of this activity, participants should be able to:

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<th>Not at All</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Mostly</th>
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<tr>
<td>Evaluate multidisciplinary inpatient approaches to children with autism and other developmental disorders</td>
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<tr>
<td>Assess care trends for the inpatient developmental disorders population</td>
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Was the presentation commercially biased in any manner? Yes [ ] No [ ]

Based on this activity, what will you do differently in your practice? ______________________________________________________

Topics of Interest for future Seminars: ________________________________________________________________

Printed Name of CME participant: ____________________________ Physician Yes [ ] No [ ]

Signature of CME participant: ____________________________

Agency/Organization: ____________________________________________

Email: _______________________________________________________

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