Treating Severe Behavior or Psychiatric Crises in Autistics Admitted to Emergency Medical or Inpatient Psychiatric Settings: It Is More than Just Reducing Behavior

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Outline for Today

1. Brief Background on Acute Psychiatric Needs for ASD/IDD Persons
   - ASD-specific units vs. general psychiatric/ED units
   - Barriers, Strengths, Needs

2. Methods of Assessment/Treatment in Acute Settings

3. Basic Strategies to use in general acute settings that ASD non-specialists can use
Psychiatric Healthcare Crisis

1. The estimated total healthcare costs for ASD community in 2015 was $268 billion (Zuvekas, 2021)

2. 70.8% of ASD persons have problems behaviors/psychiatric needs (Simonff et al., 2008)
   - Approximately 10-15% will need inpatient psych services at least once during lifespan (Mandell, 2008; Tromans et al., 2018)

3. Psych: Increased rates/costs compared to non-ASD
   - Child: 11.9 times as many psych hospital stays; 12.4 times cost (Croen et al., 2006)
   - Adult: More likely to present to ED for psych reasons (12%) vs non-ASD peers (2%) (Kalb et al., 2012)
Common Difficulties in ASD Community that Increase Vulnerability for Behavioral Health Challenges

1. Communication Difficulties
   - Receptive Language
   - Expressive Language

2. Social Difficulties
   - Reduced Interest in Social Approval
   - Theory of Mind Deficits

3. “Co-occurring” Difficulties
   - Inattention
   - Hyperactivity
   - Irritability
   - Anxious/Fearful
   - Undiagnosed/untreated medical concerns

McClintock, Hall, Oliver, 2003; Baghdadli, Pascal, Grisi et al., 2003; LeCavalier, 2006; Matson, Fodstad, Rivet, 2009;
Additional Factors

1. Most often long history of behavioral difficulties
   - 20% of ASD children under age 2 display SIB or aggressive/disruptive behaviors (Fodstad et al., 2012)
   - 40% of ASD children under age 2 display fear, inattentiveness, hyperactivity, or irritable behaviors (Fodstad et al., 2010)

2. Caregiver burden/distress (LeCavalier et al., 2006)

3. Services at all levels (preventative, crisis) are limited compared need

4. Hospitals/Behavioral Healthcare services mis-match
   - 82% of general inpatient psych staff feel unprepared to care for ASD patients, yet 98.5% felt being able to provide acute psych care for ASD patients was necessary (Fodstad et al., 2020)
Predictors of Psychiatric Hospitalization - CHILD

*Mandell, 2008*:
1. Aggressive behavior (odds ratio (OR) = 4.83)
2. Single parent homes (OR = 2.54)
3. Depression (OR = 2.48)
4. Self-injurious Behavior (OR = 2.14)
5. Obsessive Compulsive Disorder (OCD) (OR = 2.35)
** Risk for Hospitalization Increases with Age

*Righi et al., 2018*; - Compared to ASD non-inpatient sample:
1. Mood Disorder (OR = 7.01)
2. Sleep problems (0.27)
3. Others: lower adaptive functioning, greater ASD severity, single parent home, severity of adaptive deficits, severity of ASD symptoms
Predictors of Psychiatric Hospitalization - ADULT

Lunsky et al, 2017:
1. Family distress (OR = 1.4)
2. Negative life events (OR = 2.8)
3. Being on psychotropic medication (OR = 6.7)
4. Aggression – towards self/others, including SI (OR = 4.8)
5. Immigrant-status/immigrant family (OR = 2.8)

Palucka & Lunsky, 2007:
1. Severe autism symptoms
2. Co-occurring ID
3. Mood Disorder
4. Physical Aggression
ASD-specific inpatient psychiatry/behavioral health units
Non-specialized Programs

<table>
<thead>
<tr>
<th>Strengths</th>
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<tbody>
<tr>
<td>• Less wait time than ASD-specific units</td>
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<tr>
<td>• Partnerships with CMHCs</td>
</tr>
<tr>
<td>• Similar struggles as neurotypical peer patients</td>
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<td>• Respite for families in crisis</td>
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<td>• Experienced in broad array of psychiatric disorders which co-occur with ASD</td>
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From Fodstad et al., (2021); Fodstad et al. (in preparation)
## Non-specialized Programs

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<th>Strengths</th>
<th>Barriers</th>
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<tbody>
<tr>
<td>• Less wait time than ASD-specific units</td>
<td>• Patient-specific:</td>
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<tr>
<td>• Partnerships with CMHCs</td>
<td>• Unique communication needs</td>
</tr>
<tr>
<td>• Similar struggles as neurotypical peer patients</td>
<td>• Possible fear/sensory overload</td>
</tr>
<tr>
<td>• Respite for families in crisis</td>
<td>• May need increased staffing</td>
</tr>
<tr>
<td>• Monitor medication changes unlike in outpatient settings</td>
<td>• Safety concerns/behavior problems</td>
</tr>
<tr>
<td>• Experienced in broad array of psychiatric disorders which co-occur with ASD</td>
<td>• Unit-specific:</td>
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<tr>
<td></td>
<td>• Space constraints</td>
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<tr>
<td></td>
<td>• Inability individualize programming</td>
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<td></td>
<td>• Minimal resources</td>
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<td></td>
<td>• High verbal/social demand programming</td>
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<td>• Stay may be too brief</td>
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<td>• Staff-specific:</td>
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<tr>
<td></td>
<td>• Limited ASD training</td>
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<td></td>
<td>• Fear/nervousness</td>
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<td>• Not prepared</td>
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</tbody>
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From Fodstad et al., (2021); Fodstad et al (in preparation)
Needs of Non-specialized Programs

Parents

- Better understanding of ASD and individual needs
- Increase parent involvement and communication
- ASD-friendly resources
- Reduce wait times
- Accommodate sensory needs
- Individualized care approach
- Clear care plan at discharge that encompasses all concerns

From Fodstad et al., (2021); Fodstad et al (in preparation)
# Needs of Non-specialized Programs

<table>
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<tr>
<th>Parents</th>
<th>Staff/Administrators</th>
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<tr>
<td>• Better understanding of ASD and individual needs</td>
<td>• Ongoing training</td>
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<td>• Increase parent involvement and communication</td>
<td>• Consultation with ASD providers</td>
</tr>
<tr>
<td>• ASD-friendly resources</td>
<td>• Better understanding of ASD and individual needs</td>
</tr>
<tr>
<td>• Reduce wait times</td>
<td>• More resources</td>
</tr>
<tr>
<td>• Accommodate sensory needs</td>
<td>• Higher staffing model</td>
</tr>
<tr>
<td>• Individualized care approach</td>
<td>• Therapeutic/sensory</td>
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</tbody>
</table>
<pre><code>                         |     • Visual aids                                          |
                         |     • Communication support                                |
</code></pre>

From Fodstad et al, (2021); Fodstad et al (in preparation)
# Needs of Non-specialized Programs

**Parents**
- Better understanding of ASD and individual needs and strengths
- Increase parent involvement and communication
- ASD-friendly resources
- Reduce wait times
- Accommodate sensory needs
- Individualized care approach
- Assess for contributing factors

**Staff/Administrators**
- Ongoing training
- Consultation with ASD providers
- Better understanding of ASD and individual needs
- More resources
  - Higher staffing model
  - Therapeutic/sensory
  - Visual aids
  - Communication support

**Autistics**
- Better understanding and appreciation of the person
- Accommodations for sensory needs/overload
- Clear support or therapeutic materials
- Involvement in care
- Communication supports
- Reduce waiting/transition
- “Recognition that its not just due to me being autistic”

*From Fodstad et al., (2021); Fodstad et al (in preparation)*
Where To Begin

INCREASE ACCESS TO AUTISM-AWARE PSYCHIATRIC CARE

GUIDELINES OR PROTOCOLS THAT CAN BE IMPLEMENTED IN FAST-PACED HEALTHCARE SYSTEMS

Fodstad et al. (in preparation)
Assessment and Treatment Targets

Adapted from McGuire et al 2015; Fodstad et al (in preparation); Kuriakose et al., 2018
Step 1: Initial Admission

Behavioral Health Intake Questionnaire

Name of parent/caregiver providing information: <free text>
Name your child likes to be called: <free text>
Developmental/Cognitive Level: <free text>
Is your child receiving any services at this time? (Medicaid waiver, therapy, behavioral therapy, first steps, etc.) <free text>
How does your child react to new people/strangers? <free text>
Does your child have difficulty moving between activities, people or new environments? □ Yes □ No
If yes, please explain. <free text>
Does your child get easily agitated, aggressive or engage in self-injurious behavior? □ Yes □ No
Ex. Spitting, hitting, kicking, biting, throwing objects, head banging
If yes, please explain behavior. <free text>
What are your child's triggers and signs of distress? <free text>
What helps calm your child?
□ Weighted blanket □ Electronic tablet □ Other <free text>
□ Music □ Arts/Crafts
□ Action Heroes □ TV/Cartoons
What is the best way to communicate with your child?
□ Pictures □ Sign Language
□ Checklists □ Communication Device
□ Words □ Other <free text>
How does your child tell us what they need?
Step 1: Initial Admission

1. Expeditious Care
2. Reduce Environmental Triggers
   – (See, Hear, Feel, Speak; Samet & Luterman, 2019)
3. Provide Early & Clear Information on Expectations/Options
4. Clearly Communicate Specific Needs to Providers
5. Resource Library
6. Support the Autistic Person’s & Caregiver’s Needs
Step 2: Screen for Medical Etiology

1. High correlation between behavioral health needs and medical concerns (Cohen & Tsiouris, 2020; Courtemanche et al., 2016; Guinchat et al., 2015)

2. Greater prevalence of:
   - Neurological Disorders (10-30% have epilepsy; Pacheva et al., 2019)
   - Sleep difficulties/disorders (80%)
   - GI Problems (46-85% with 5-30% experiencing constipation; Holingue et al., 2018)
   - Metabolic Disorders (Cheng et al., 2017)
   - Immune, Autoimmune, and allergic disorders (25% of ASD children have immune deficiency/dysfunction; Gladysz et al. 2018)
     - The curious case of autoimmune encephalitis
Step 3: Assess for and Treat Co-occurring Psychiatric Disorders

1. High prevalence of psychiatric disorders in ASD and ID

2. Assessment Process
   - Caregiver/patient interview or observation
   - Account and adjust for communication abilities/preferences, cognitive difficulties, developmental level, and features typical of ASD or ID
   - Interpret standardized measures with caution
   - Use evidenced-based pharmacotherapy
   - Contact ASD specialists in system as needed
Step 4: Support Communication, Sensory, Motor, Medical, and Self-Care Needs

CHILL ZONE PASS

Please excuse me. I need a few minutes to take a break and calm down.

Thank you.

My PICC Line

I am sick. I am getting an X-Ray today to feel better. To get my X-ray, I will...

- Lay on my side
- Go into the X-ray room
- Lay on a board
- X-ray my stomach
- Take out the board
- All done ride back to unit

UCLA Tarjan Lecture, 1/24/22
Step 5: Conduct Behavioral Assessment

Indirect Assessment

**Functional Assessment Screening Tool (FAST)**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Age:</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informant:</td>
<td>Interviewer:</td>
<td></td>
</tr>
</tbody>
</table>

*To the interviewer:* The Functional Analysis Screening Tool (FAST) is designed to identify a number of factors that may influence the occurrence of problem behavior. It should be used only as an initial screening tool and as part of a comprehensive functional assessment or analysis of problem behavior. The FAST should be administered to several individuals who interact with the person frequently. Results should then be used as the basis for conducting direct observations in several different contexts to verify likely behavioral functions, clarify ambiguous functions, and identify other relevant factors that may not have been included in this instrument.

**Observation/In Vivo Data Collection**

**Behavior Assessment and Intervention Summary Sheet**

From Gabriels and Barnes, 2012
Step 6: Adapt environment and programming

**My Daily Schedule**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Picture</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00 am</td>
<td>Breakfast Vitas, Medication</td>
<td></td>
</tr>
<tr>
<td>9:00 am</td>
<td>School</td>
<td></td>
</tr>
<tr>
<td>10:00 am</td>
<td>Snack</td>
<td></td>
</tr>
<tr>
<td>11:45 am</td>
<td>Program</td>
<td></td>
</tr>
<tr>
<td>12:30 pm</td>
<td>Lunch</td>
<td></td>
</tr>
<tr>
<td>1:00 pm</td>
<td>Enrichment Activity with Staff</td>
<td></td>
</tr>
<tr>
<td>1:30 pm</td>
<td>Art Therapy</td>
<td></td>
</tr>
<tr>
<td>2:00 pm</td>
<td>Snack</td>
<td></td>
</tr>
<tr>
<td>3:00 pm</td>
<td>Zones Group</td>
<td></td>
</tr>
<tr>
<td>3:30 pm</td>
<td>Snack</td>
<td></td>
</tr>
<tr>
<td>4:00 pm</td>
<td>Zones Group</td>
<td></td>
</tr>
<tr>
<td>4:30 pm</td>
<td>Snack</td>
<td></td>
</tr>
<tr>
<td>5:00 pm</td>
<td>Zones Group</td>
<td></td>
</tr>
<tr>
<td>6:00 pm</td>
<td>Snack, Music</td>
<td></td>
</tr>
<tr>
<td>6:30 pm</td>
<td>Zones Group</td>
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</tbody>
</table>

**My Star Program**

<table>
<thead>
<tr>
<th>Safe Medal</th>
<th>Safe Buck</th>
<th>Safe Team</th>
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UCLA Tarjan Lecture, 1/24/22
Step 7: Additional Considerations

1. Incorporate structured educational services to facilitate transition back to school (if school-age)

2. Outside of ongoing training of staff, provide adaptable resources that can be used as needed upon admission

3. A longer length of stay may be needed to facilitate behavior change, generalization, multidisciplinary, caregiver training, and care coordination work

4. Reconsider medical necessity for inpatient psychiatric care

5. Involvement of autistic patient and/or caregiver in treatment during stay
Summary

1. Acute psychiatric care can be successfully provided in non-specialized medical settings

2. Adaptations must occur to increase access to person- and family-centered care that best meets the needs, co-occurring symptoms, and unique profile of the autistic patient

3. Staff need additional resources and ongoing training and consultation to feel confident in their ability to provide high quality psychiatric care to autistic patient
Questions?

Feel free to email me at: jfodstad@iupui.edu
References


References


