

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

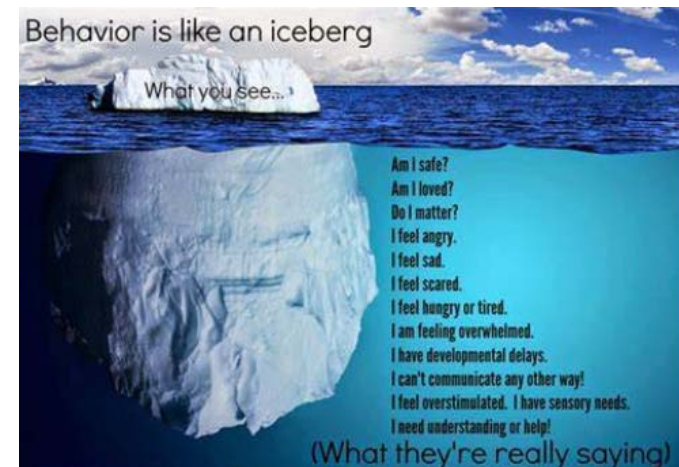
1. Brief Background on Acute Psychiatric Needs for ASD/IDD Persons
 - ASD-specific units vs. general psychiatric/ED units
 - Barriers, Strengths, Needs
2. Methods of Assessment/Treatment in Acute Settings
3. Basic Strategies to use in general acute settings that ASD non-specialists can use

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

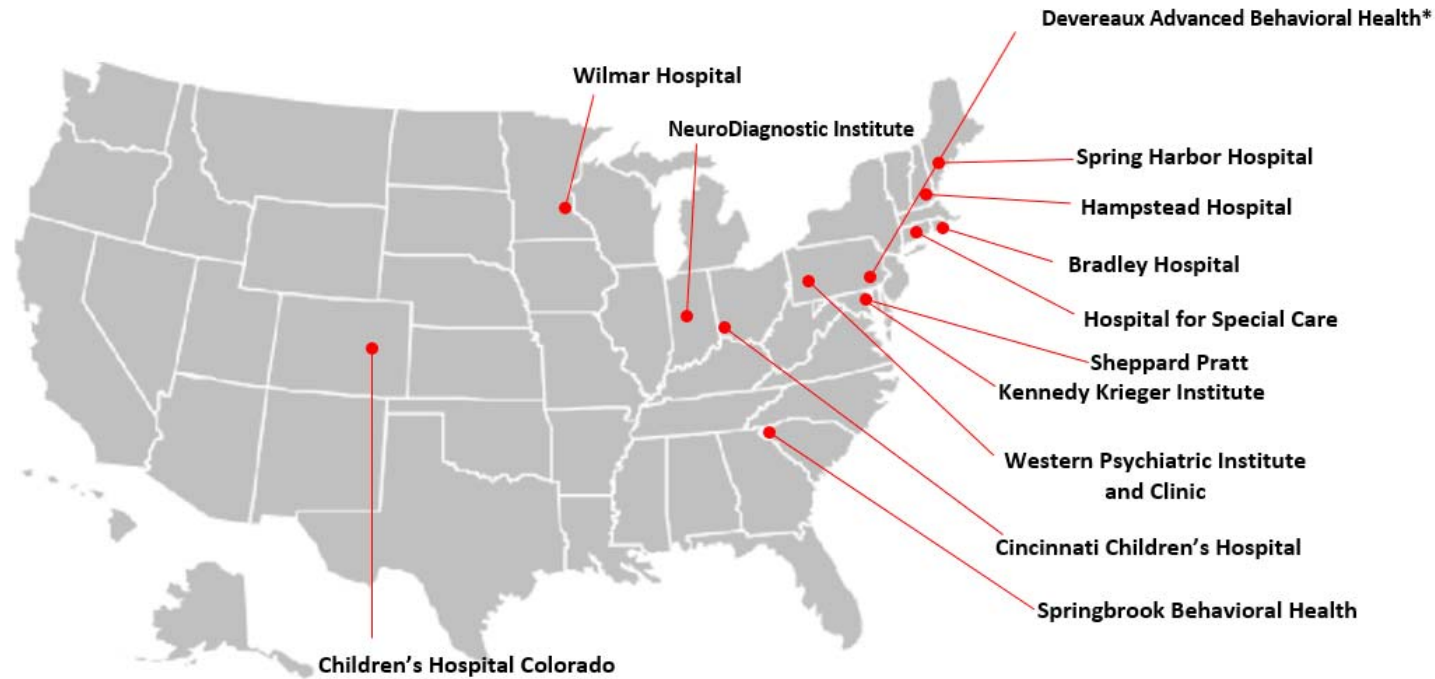
Lunsky et al, 2017:

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

Strengths

- Less wait time than ASD-specific units
- Partnerships with CMHCs
- Similar struggles as neurotypical peer patients
- Respite for families in crisis
- Monitor medication changes unlike in outpatient settings
- Experienced in broad array of psychiatric disorders which co-occur with ASD

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

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Barriers

- Patient-specific:
 - Unique communication needs
 - Possible fear/sensory overload
 - May need increased staffing
 - Safety concerns/behavior problems
- Unit-specific:
 - Space constraints
 - Inability individualize programming
 - Minimal resources
 - High verbal/social demand programming
 - Stay may be too brief
- Staff-specific:
 - Limited ASD training
 - Fear/nervousness
 - Not prepared

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

Parents

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- Individualized care approach

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

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
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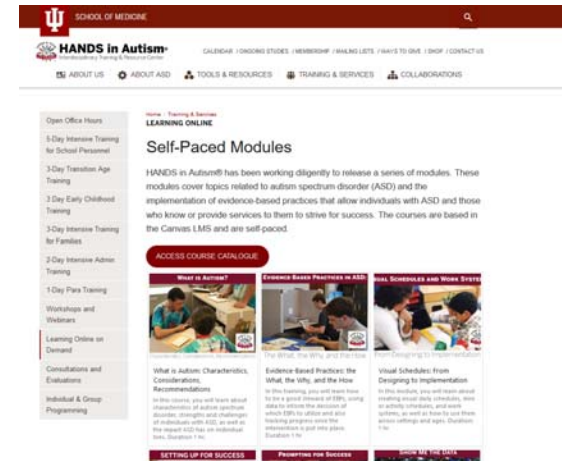
Autistics

- Better understanding and appreciation of the person
- Accommodations for sensory needs/overload
- Clear support or therapeutic materials
- Involvement in care
- Communication supports
- Reduce waiting/transitions
- “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> Date: <date> Time: <time>

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?

<input type="checkbox"/> Weighted blanket	<input type="checkbox"/> Electronic tablet	<input type="checkbox"/> Other <free text>
<input type="checkbox"/> Music	<input type="checkbox"/> Arts/Crafts	
<input type="checkbox"/> Action Heros	<input type="checkbox"/> TV/Cartoons	

What is the best way to communicate with your child?

<input type="checkbox"/> Pictures	<input type="checkbox"/> Sign Language
<input type="checkbox"/> Checklists	<input type="checkbox"/> Communication Device
<input type="checkbox"/> Words	<input type="checkbox"/> Other: <free text>

How does your child tell us what they need?
 Words

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

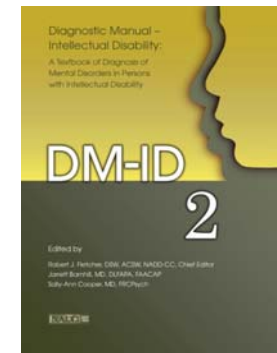
1. High correlation between behavioral health needs and medical concerns (Cohen & Tsiouris, 2020; Courtemanche et al., 2016; Guinchat et al., 2015)
2. Greater prevalence of:
 - Neurological Disorders (10-30% have epilepsy; Pacheva et al., 2019)
 - Sleep difficulties/disorders (80%)
 - GI Problems (46-85% 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



PHARMACOTHERAPY

Original Research Article | [Free Access](#)

Pharmacotherapy of Autism Spectrum Disorder: Results from the Randomized BAART Clinical Trial

C. Lindsay DeVane  Jane M. Charles, Ruth K. Abramson, John E. Williams, Laura A. Carpenter, Sarah Raven, Frampton Gwynette, Craig A. Stuck, Mark E. Geesey, Catherine Bradley ... [See all authors](#) 

Step 4: Support Communication, Sensory, Motor, Medical, and Self-Care Needs

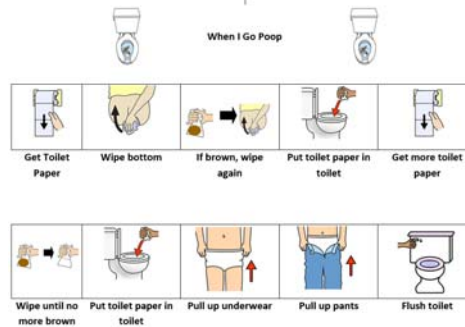
CHILL ZONE PASS

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

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

Step 5: Conduct Behavioral Assessment

Indirect Assessment

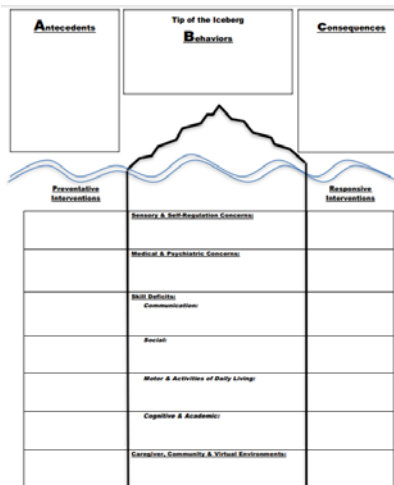
FUNCTIONAL ASSESSMENT SCREENING TOOL (FAST)

Name: _____ Age: _____ Date: _____

Behavior Problem: _____

Informant: _____ Interviewer: _____

To the Interviewer: The Functional Analysis Screening Tool (FAST) is designed to identify a number of factors that may influence the occurrence of problem behaviors. 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.



Behavior Assessment and Intervention Summary Sheet

From Gabriels and Barnes, 2012

Key: Behavior Occurred In: _____
 Did not Occur 30
 No Data If 1

Time		M							T							W							R							F							S						
From	To	M T W R F M T W R F S																																									
7:00	7:30																																										
7:30	8:00																																										
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Observation/In Vivo Data Collection

Date:	Time:	Activity in Progress:	Intensity and Duration
Antecedent: ___ Given direction/task/activity ___ New task or activity ___ Difficult task or activity ___ Waiting ___ Preferred activity interrupted ___ Activity/item denied (told no) ___ Loud and noisy environment ___ Given a correction ___ Transition ___ Attention given to others ___ Presence of specific person ___ Attention not given when wanted ___ Alone (no activity) ___ Alone (no attention) Other: _____	Behaviors: ___ Refusal to follow directions ___ Verbal refusal ___ Making verbal threats ___ Crying/whining ___ Screaming/yelling ___ Scratching ___ Biting ___ Kicking ___ Spitting ___ Flopping ___ Running away ___ Destroying property ___ Flipping furniture ___ Hitting self ___ Hitting others (students) ___ Hitting others (adults)	Consequences: ___ Verbal redirection ___ Physical prompt ___ Ignored problem behavior ___ Kept demand on ___ Used proximity control ___ Verbal reprimand ___ Removed from activity/location ___ Given another task/activity ___ Response block ___ Left alone ___ Loss of privilege ___ Calming spot ___ Peer attention ___ Time out (duration) _____ ___ asked to leave the room	Intensity: ___ Low ___ Medium ___ High Duration: ___ < 1 min. ___ 1-5 min. ___ 5-10 min. ___ 10-15 min. ___ 15-30 min. ___ 30 min.- 1 hr. ___ 1-2 hrs. ___ 3+ hrs.


Step 6: Adapt environment and programming


☆☆ Star Program – Inpatient Zones ☆☆

Patient can earn up to two stars for each time slot. Patient can purchase an activity or reward from his/her "Star Rewards" Menu when the Bank is Open. If Patient is actively having a behavioral episode at the time of reward cash-in, no stars may be redeemed. Points earned in the morning can roll over to the afternoon / evening if they are unused. Each day starts back at zero-star points.

Time	Activity	Follow Directions	Keep my Hands and Feet to Myself
8:00 am – 9:00 am	Breakfast Vitals, Meds Goals with Staff		
9:00 am – 10:00 am	School		
10:00 am – 10:15 am	Snack		
10:15 am – 10:45 am	Zones Group		
10:45 – 11:15 am Reward Time	Total Stars Earned:	Reward Chosen:	










☆☆ MY STAR PROGRAM ☆☆


SAFE HANDS


SAFE FEET

I am working for

My Daily Schedule

Time	Activity	Picture
830A	Vitals	
900A	Goal Group	
9-10A	Enrichment Activity with Staff	
10-11A	Art Therapy	
11A	Snack	
11A-12P	Zones Group	
NOON	Lunch	
1-130P	iPad Time	
130-215P	School	



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

- Baghdadli, A., Pascal, C., Grisi, S., & Aussilloux, C. (2003). Risk factors for self-injurious behaviours among 222 young children with autistic disorders. *Journal of Intellectual Disability Research*, 47(8), 622-627.
- Cheng, N., Rho, J. M., & Masino, S. A. (2017). Metabolic dysfunction underlying autism spectrum disorder and potential treatment approaches. *Frontiers in molecular neuroscience*, 10, 34.
- Cohen, I. L., & Tsiouris, J. A. (2020). Triggers of aggressive behaviors in intellectually disabled adults and their association with autism, medical conditions, psychiatric disorders, age and sex: a large-scale study. *Journal of autism and developmental disorders*, 50(10), 3748-3762.
- Courtmanche, A. B., Black, W. R., & Reese, R. M. (2016). The relationship between pain, self-injury, and other problem behaviors in young children with autism and other developmental disabilities. *American journal on intellectual and developmental disabilities*, 121(3), 194-203.
- Croen, L. A., Najjar, D. V., Ray, G. T., Lotspeich, L., & Bernal, P. (2006). A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics*, 118(4), e1203-e1211.
- Fodstad, J. C., Rojahn, J., & Matson, J. L. (2010). Emergent comorbidity in at risk children with and without autism spectrum disorder—a cross-sectional study. *Journal of Developmental and Physical Disabilities*, 22(4), 381-400.
- Fodstad, J. C., Rojahn, J., & Matson, J. L. (2012). The emergence of challenging behaviors in at-risk toddlers with and without autism spectrum disorder: A cross-sectional study. *Journal of Developmental and Physical Disabilities*, 24(3), 217-234.
- Fodstad, J.C., Mehringer, J., Schieve, N., Saadeh, Y. (2021) , Barriers, and Needs to Improve Acute Psychiatric Care in General Hospital-Based Settings for Autistic Persons: Findings from a Multi-Stakeholder Evaluation, poster presented at the annual Indiana University Undergraduate Research Center showcase. Indianapolis, IN.
- Fodstad, J.C., Neal, T., Mehringer, J., Saadeh, Y., Swiezy, N (in preparation). Outcomes from a pilot of an autism-aware acute psychiatric care package for emergency medical settings.
- Gładysz, D., Krzywdzińska, A., & Hozyasz, K. K. (2018). Immune abnormalities in autism spectrum disorder—could they hold promise for causative treatment?. *Molecular neurobiology*, 55(8), 6387-6435.
- Guinchat, V., Cravero, C., Diaz, L., Périssé, D., Xavier, J., Amiet, C., ... & Consoli, A. (2015). Acute behavioral crises in psychiatric inpatients with autism spectrum disorder (ASD): recognition of concomitant medical or non-ASD psychiatric conditions predicts enhanced improvement. *Research in developmental disabilities*, 38, 242-255.
- Holingue, C., Newill, C., Lee, L. C., Pasricha, P. J., & Daniele Fallin, M. (2018). Gastrointestinal symptoms in autism spectrum disorder: A review of the literature on ascertainment and prevalence. *Autism Research*, 11(1), 24-36.
- Kalb, L. G., Stuart, E. A., Freedman, B., Zablotzky, B., & Vasa, R. (2012). Psychiatric-related emergency department visits among children with an autism spectrum disorder. *Pediatric Emergency Care*, 28(12), 1269-1276.
- Kuriakose, S., Filton, B., Marr, M., Okparaeké, E., Cervantes, P., Siegel, M., ... & Havens, J. (2018). Does an autism spectrum disorder care pathway improve care for children and adolescents with ASD in inpatient psychiatric units?. *Journal of autism and developmental disorders*, 48(12), 4082-4089.
- Lecavalier, L. (2006). Behavioral and emotional problems in young people with pervasive developmental disorders: Relative prevalence, effects of subject characteristics, and empirical classification. *Journal of autism and developmental disorders*, 36(8), 1101-1114.

References

- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of intellectual disability research*, 50(3), 172-183.
- Lunsky, Y., Weiss, J. A., Paquette-Smith, M., Durbin, A., Tint, A., Palucka, A. M., & Bradley, E. (2017). Predictors of emergency department use by adolescents and adults with autism spectrum disorder: a prospective cohort study. *BMJ open*, 7(7), e017377.
- Mandell, D. S. (2008). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of autism and developmental disorders*, 38(6), 1059-1065.
- Matson, J. L., Fodstad, J. C., & Rivet, T. T. (2009). The relationship of social skills and problem behaviors in adults with intellectual disability and autism or PDD-NOS. *Research in Autism Spectrum Disorders*, 3(1), 258-268.
- McClintock, K., Hall, S., & Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study. *Journal of Intellectual Disability Research*, 47(6), 405-416.
- McGuire, K., Erickson, C., Gabriels, R. L., Kaplan, D., Mazefsky, C., McGonigle, J., ... & Siegel, M. (2015). Psychiatric hospitalization of children with autism or intellectual disability: Consensus statements on best practices. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(12), 969.
- Pacheva, I., & Ivanov, I. (2019). Targeted biomedical treatment for autism spectrum disorders. *Current pharmaceutical design*, 25(41), 4430-4453.
- Palucka, A. M., & Lunsky, Y. (2007). Review of inpatient admissions of individuals with autism spectrum disorders to a specialized dual diagnosis program. *Journal on Developmental Disabilities*, 13(1), 205-209.
- Righi, G., Benevides, J., Mazefsky, C., Siegel, M., Sheinkopf, S. J., & Morrow, E. M. (2018). Predictors of inpatient psychiatric hospitalization for children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(11), 3647-3657.
- Samet, D., & Luteran, S. (2019). See-Hear-Feel-Speak: A protocol for improving outcomes in emergency department interactions with patients with autism spectrum disorder. *Pediatric emergency care*, 35(2), 157-159.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(8), 921-929.
- Stark, K. H., Barnes, J. C., Young, N. D., & Gabriels, R. L. (2015). Brief report: understanding crisis behaviors in hospitalized psychiatric patients with autism spectrum disorder—iceberg assessment interview. *Journal of autism and developmental disorders*, 45(11), 3468-3474.
- Tromans, S., Chester, V., Kiani, R., Alexander, R., & Brugha, T. (2018). The prevalence of autism spectrum disorders in adult psychiatric inpatients: a systematic review. *Clinical practice and epidemiology in mental health: CP & EMH*, 14, 177.
- Zuvekas, S. H., Grosse, S. D., Lavelle, T. A., Maenner, M. J., Dietz, P., & Ji, X. (2021). Healthcare costs of pediatric autism spectrum disorder in the United States, 2003–2015. *Journal of autism and developmental disorders*, 51(8), 2950-2958.