
Georgina Hartzell, MD
NewYork-Presbyterian/Columbia University/Weill Cornell Medicine

Background

Prevalence and Comorbidities of Autism Spectrum Disorder (ASD)/Developmental Disabilities (DD) in the U.S.: - ASD prevalence estimated at 1 in 68.1 - DD prevalence (including Intellectual Disability) is estimated at over 10%.2 - Up to 50% of youth with DD appear to have comorbid psychiatric disorders.3 - Up to 80% of youth with ASD appear to have a comorbid psychiatric disorder.4 - Psychiatric problems include ADHD, self-harming and aggressive behavior, and anxiety.1,5

Psychiatric Disorders and Emergency Department (ED) Visits in ASD/DD Youth: - Youth with ASD are 6x as likely to have an ER visit for psychiatric reasons compared with youth without ASD.1 - Youth with ASD and DD have longer inpatient hospital stays and are more likely to use the pediatric ED for “boarding”.5

Systems of Care for ASD/DD Youth: - In many states, psychiatric services for individuals with ASD and DD are administered through a separate entity than those without these conditions.

In New York: - Office of Persons With Developmental Disabilities (OPWDD) = Services for ASD/DD (outpatient treatment, respite, etc.) - Office of Mental Hygiene (OMH) = Psychiatric services for general population (including inpatient psychiatric hospitals) - Separate agencies within these entities are involved in determining eligibility/provision of services - Increasing complexity of care coordination.

Case Report

Patient: 11 yo East African girl (moved to the US 2 years prior, was undocumented), domiciled in NYC shelter with mother, with history of ASD, intellectual disability, unspecified anxiety disorder, expressive and receptive language disorder.

Psychiatric History: Multiple visits for aggression and behavioral dysregulation. Suspected remote history of physical abuse. Not eligible for OPWDD services at presentation and did not have a psychiatrist.

Discussion

Challenges to care specific to this patient: - Patient’s immigration status. - Language barrier/cultural barrier. - Lack of stable housing. - Lack of access to state-funded service agencies.

Challenges of emergency care in the ASD/DD population: - Excessive stimulation (bright light, constant noise, interviews with new providers, painful procedures) and disruption to the patient’s routine can exacerbate symptoms.2 - Receptive and expressive language problems are common in ASD/DD. - Inadequate disposition options exist for patients who aren’t ready to return home but are not appropriate for an inpatient psychiatric unit. - Complex systems of care with several different entities/shareholders.

Key Points for working with ASD/DD Youth in the ED: - Minimize interactions that are perceived as threatening (standing over patient, approaching with a large group, interrupting self-soothing behavior, taking away comforting items).4 - Use a calm voice, speak slowly, inform the patient and family about changes in location and caregivers, provide positive reinforcement and rewards for desired behavior. Give warnings/explanations before procedures. - Involve Child Life or other specialists. - Use established protocols and clinical pathways whenever possible4 (see Cornell Clinical Pathway for ASD/DD youth in the ED) - Communicate with hospital administration and involved agencies.

Future Directions: - Expanded training for ED personnel, including ED physicians, pediatricians, nurses, technicians, and security. - Improvement in collaboration between different systems of care (for example in NY State, integration of OMH and OPWDD.) - Increase availability of low-stimulation, short-term stabilization options (such as extended observation beds). - Address psychiatric needs of ASD/DD youth BEFORE emergency develops (outpatient providers, in-home crisis services, respite services).

REFERENCES


Special thanks to Dr. Annie Li and Dr. Fortuna for their mentorship!