Stuck in Limbo – The Challenges of Caring for Children with Autism and Intellectual Disabilities in the Emergency Department

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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%.[4]
- Up to 50% of youth with DD appear to have comorbid psychiatric disorders.[6]
- 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.[5, 6]

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.[5, 6]
- 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 of ASD, intellectual disability, unspecified anxiety disorder, expressive and receptive language disorder.
Psychiatric History: Multiple ED 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.

November 2017
Seen in ED for aggression
- 5 day stay in the Extended Observation Bed (EOB)
- 14 day psychiatric admission

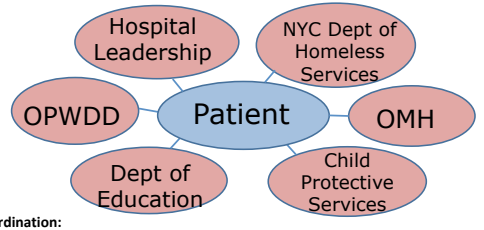
→ **December 2017**
Seen in ED for aggression
- 40 day psychiatric admission

→ **January 2018**
Seen at the Cornell "Rapid Linkage" clinic due to lack of established long-term outpatient provider

→ **February 1st, 2018**
Seen in ED for aggression
- Discharged the following day with plans to follow up at the Cornell Resident Clinic within 24 hours.

→ **February 3rd, 2018**
Pt's mother brought her to the clinic
- Pt ran out of clinic and into the street
- EMS brought pt to the ED
- 10 day inpatient psychiatric admission

→ **February 20th, 2018**
Presented to the ED for aggression
- 90 day psychiatric admission
- OPWDD services were arranged
- Discharged directly to a residential treatment facility for children with DD



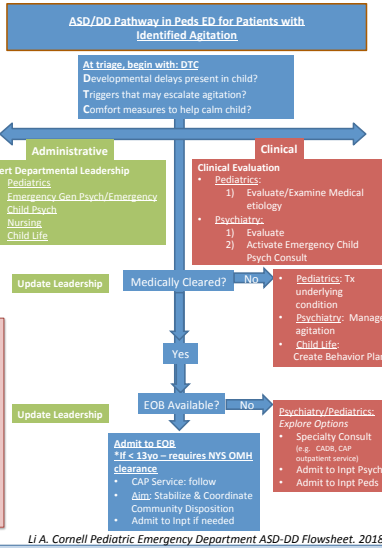
Care coordination:
NYC Dept of Homeless Services: Spoke with shelter case manager to discuss their safety concerns and whether patient would be allowed to return to that shelter setting.
OPWDD: Discussed steps to establish eligibility and services in the absence of citizenship.
Department of Education: Discussed residential school placement options.
Child Protective Services: Discussed preventive services and respite options.
Hospital leadership: Obtained permission for use of extended observation bed, prolonged inpatient stay, and outpatient follow-up plans.
OMH: Notified regarding use of the extended observation bed as well as inpatient hospitalization.

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.[2]
- 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 possible[3, 7] (see Cornell Clinical Pathway for ASD/DD youth in the ED)
- Communicate with hospital administration and involved agencies



Li A. Cornell Pediatric Emergency Department ASD-DD Flowsheet. 2018.

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).

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