## Psychiatric Hospital Treatment of Children with Autism and Serious Behavioral Disturbance

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## **KEYWORDS**

• Inpatient • Autism • Intellectual disability • Hospitalization • Psychiatric

## **KEY POINTS**

- Eleven percent of children with autism spectrum disorder (ASD) are admitted to a psychiatric hospital unit before adulthood.
- Children with ASD are admitted primarily because of externalizing behaviors: aggression, self-injury, and tantrums.
- Externalizing behaviors frequently represent a manifestation of impaired emotion regulation or acute exacerbation of a comorbid psychiatric disorder.
- Successful management requires a broad multidisciplinary diagnostic approach that manages acute symptoms and ameliorates key perpetuating factors, such as sleep deprivation, communication inefficiency, or environmental reinforcement of maladaptive behaviors.
- There is preliminary evidence for the effectiveness of specialized hospital psychiatry units designed for the ASD and intellectual disability population, and there is a lack of studies of general psychiatric hospital treatment of this population.

## INTRODUCTION

Children with an autism spectrum disorder (ASD) are admitted to psychiatric hospitals at high rates, but some institutions refuse or are unable to serve them. This paradox springs from the application of a brief inpatient intervention model initially developed for the neurotypical population to children with ASD. The ASD population has unique abilities and needs and typically presents with externalizing behaviors that require intensive assessment and intervention methods to tease out the underlying issues fueling the crisis presentation.

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Admission to psychiatric hospitals of children with ASD or intellectual disability (ID) creates a separation from family, educational services, and therapeutic programming, as well as substantial financial costs. Despite the impacts of frequent admissions on public health and caregivers, there is little information in the scientific literature regarding psychiatric hospital treatment of this population. Hospitalization is usually based on acutely unsafe behaviors, which can be generated by impaired emotion regulation, behavioral excesses, and/or comorbid psychiatric illness. Children with ASD and/or ID have higher rates of comorbid psychiatric illness than the general pediatric population.<sup>1,2</sup> Children with ASD and ID also show delays in social communication skills and the development of emotion regulation. These characteristics can lead to bullying or exclusion from peer groups, social isolation, suspension from school and communication frustration, all of which can increase the risk of developing comorbid psychiatric illness and/or acute behavioral disturbance.

To facilitate best practices for this population, this article (1) presents the evidence for inpatient treatment of ASD in both general and specialized child psychiatry units, (2) outlines approaches to inpatient treatment of this population, and (3) describes 2 specialized hospital programs designed for the ASD and ID populations.

## EPIDEMIOLOGY, COSTS, AND ACCESS

Eleven percent of children with ASD are reported by their parents to have been psychiatrically hospitalized in the United States by 21 years of age.<sup>3</sup> The 1-year prevalence of psychiatric hospitalization of children with ASD is 1.3% to 7.0%.<sup>3,4</sup> By comparison, only 0.23% of privately insured children in the United States were psychiatrically hospitalized in the year 2000.<sup>5</sup>

Two large studies have examined psychiatric hospital admission rates for children with ASD. Among 760 children with ASD aged 5 to 21 years, the strongest predictors of psychiatric hospitalization were the following:<sup>3</sup>

- Aggressive behavior (odds ratio [OR] = 4.83)
- Coming from a single-parent home (OR = 2.54)
- Depression (OR = 2.48)
- Obsessive compulsive disorder (OCD) (OR = 2.35)
- Self-injurious behavior (OR = 2.14)

Risk for hospitalization increased over time and with patient age. Additionally, caregivers of psychiatrically hospitalized youth had a lower socioeconomic status and educational attainment than those whose children had not experienced hospitalization. Another large study of 33,000 children aged 2 to 18 years revealed a ratio of 6.6 ASD psychiatric admissions to every one non-ASD psychiatric admission. Even more striking, the children with ASD incurred 11.9 times more psychiatric hospital days, indicating that children with ASD also have longer hospital stays on average. A recent study of almost 4 million emergency department visits in the United States found that 13% of children with ASD who presented to the emergency department were there for mental health problems; comparatively, only 2% of non-ASD children came for such problems.<sup>6</sup>

A few protective factors associated with a lower risk of psychiatric hospitalization in the ASD population have been identified; these factors include living in an area with a high number of pediatric specialists, being female, younger age, and using respite care.<sup>7</sup> In particular, every \$1000 increase in spending on respite care during the preceding 60 days resulted in an 8% decrease in the odds of hospitalization. However, as the investigators point out, aggressive or self-injurious behaviors, the primary reasons

for psychiatric hospitalization, may disqualify children from receiving respite care. Because respite care is not typically thought of as a treatment for children with ASD, it is not yet known if providing respite care lowers total psychiatric hospitalization over time or simply delays it.

The cost of psychiatric hospitalization is a large component of the total health care costs for individuals with ASD. In a comparison study, children with ASD incurred 12.4 times the cost for psychiatric hospitalization than children without ASD.<sup>4</sup> Additionally, 10% of the children with ASD accounted for 53% of the total annual cost of medical care, and almost all of the children with ASD who had been psychiatrically hospitalized were in the highest decile for total health care costs.

If we extrapolate a conservative 1.3% 1-year prevalence of psychiatric hospitalization to the estimated 760,000 children with ASD in the United States (1% of 76 million children), up to 10,000 children with ASD are psychiatrically hospitalized each year. As children with ASD have been identified in increasing numbers by the Centers for Disease Control and Prevention<sup>8</sup> and psychiatric hospitalization costs for ASD increase with age.<sup>9,10</sup> psychiatric hospitalization costs will likely swell over the coming decade.

Although the psychiatric hospitalization of children with ASD is prevalent, there are multiple barriers to care that can perpetuate a state of crisis for this population. Stigma associated with developmental disorders is reflected in the rules of some health insurers, which require that an individual with ASD must also have a comorbid psychiatric illness in order to access psychiatric hospital care. The logic of such rule making is difficult to discern, considering that no other group with a *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition, Text Revision)<sup>11</sup> axis I psychiatric disorder is required to have an additional axis I disorder to access treatment.

Conversely, insurers and some practitioners can fall victim to diagnostic overshadowing,<sup>12</sup> ascribing all facets of a child's presentation (aggression, self-injury, and change in sleep patterns) to the background ASD or ID diagnosis rather than to a possible comorbid disorder. This error of attribution is then conflated with a presumption that the symptoms are chronic and untreatable, leading to a circular justification for denial of care. It is simply not normal or typical, however, for children with ASD to repeatedly strike themselves or others and to suggest otherwise represents a lack of knowledge and/or an ethical failure in the service of cost containment.

Stigma can also affect the willingness of institutions and clinicians to provide psychiatric hospital care to individuals with ASD or ID; therefore, access to inpatient care varies widely across institutions. Notably, a study of *boarding* in a pediatric emergency department, a term for staying in the emergency department while awaiting a psychiatric hospital bed, found that having a diagnosis of ASD was the number one predictor of boarding, followed by having an ID diagnosis.<sup>13</sup> In addition, most child psychiatry trainees see less than 5 outpatients and 10 inpatients with ASD or ID per year during their 2 years of training.<sup>14</sup> This very limited clinical exposure has particularly concerning implications for inpatient treatment, given that child psychiatric hospital units are almost universally led by child psychiatrists.

### RECENT DEVELOPMENTS IN PSYCHIATRIC HOSPITAL CARE FOR CHILDREN WITH ASD

Psychiatric hospital treatment of individuals with ASD and/or ID has developed from the earlier twentieth century era of long-term institutionalization, through the movement for deinstitutionalization and normalization of the 1970s and 1980s, to the current era of short-stay acute admissions.

Most hospitalized children with ASD in the United States are treated in general child psychiatry units. However, over the last decade, the number of *specialized* hospital

psychiatry units (those that exclusively serve children with ASD or ID) has doubled in the United States.<sup>15</sup> A recent survey identified 9 of these units in the United States. These units universally used a combined pharmacologic and behavioral therapy approach, used large multidisciplinary treatment teams (average of 4.6 disciplines), and had an average length of stay of 42.3 days. The most common chief admission complaint was aggression, followed by self-injurious behavior, property destruction, and emotional dysregulation.

A follow-up survey<sup>16</sup> of these specialized units identified high rates of ASD, communication impairment, and self-injury in the hospitalized population. Children with ASD made up 76% of the specialized inpatient population, totaling more than 1000 ASD cases per year. Most patients (88%) had a full-scale IQ of less than 75, and 25% exhibited self-injurious behaviors. The patients with ASD had particularly high rates of expressive communication impairment, with 27% classified as nonverbal (less than 10 words), 26% as limited verbal (primarily echolalia and scripting), and 45% as verbal (phrase speech). The median length of hospital stay was 30.5 days, and 13.8% of patients were readmitted within 1 year. All the specialized units used a combination of intervention approaches, including psychopharmacology, applied behavioral analysis, and individualized behavior plans. In addition to these core therapies, 63% of the units offered speech therapy, 50% offered occupational therapy, and 50% used family therapy.

Other countries, particularly England, Germany, and Canada, have also developed a small number of specialized units that serve the child ASD and ID populations. A survey of 136 hospitals with child psychiatry units in Germany found that 8% of these hospitals offered a specialized unit for the ASD and ID populations. Eighty-five percent of the respondents expressed a desire for a specialized unit.<sup>17</sup>

# GENERAL CONSIDERATIONS FOR PSYCHIATRIC HOSPITAL CARE OF CHILDREN WITH ASD

The psychiatric hospital care of children with ASD requires consideration of the unique learning styles and needs of this population to guide the assessment and intervention process.

## Assessment of Presenting Crisis Behaviors

The key initial treatment step is to accurately assess the issues underlying the presenting tip-of-the-iceberg crisis behaviors of patients with ASD.<sup>18–20</sup> This assessment process can be quite challenging, however, because typical psychiatric interview methods may not be reliable. Individuals with ASD, regardless of their language level, tend to have an impaired ability to reflect on and effectively communicate their internal experiences.<sup>21</sup> This challenge increases the risk that individuals with ASD will garner clinical attention for their unsafe behaviors, leaving the underlying cause of the behaviors underappreciated.

The Child and Caregiver Information Form, developed for use with the ASD and ID population, can provide a quick screen for etiologic domains of problem behaviors.<sup>22</sup> Successful treatment of problem behaviors in the ASD population is likely to increase if a broad differential diagnostic approach is used based on a multidisciplinary consideration of cause (**Table 1** and McGonigle and colleagues in this issue). At a general level, symptoms should be analyzed in terms of whether environmental (operant) conditions or intrinsic factors are responsible for the maintenance of the behavioral presentation. For example, one can consider whether the symptoms are best explained by environmental reinforcement, such as the removal of task demands

Table 1 Differential diagnosis of presenting problem behaviors in ASD/ID	
Etiologic Domains	Examples of Potential Contributing Factors
Caregiver/community environment	<ul> <li>Environmental inconsistency</li> <li>Inadvertent reinforcement of undesired behavior</li> <li>Family dynamics/visitation schedules</li> <li>Abuse/neglect</li> <li>Individuation</li> <li>Recent loss or change in the environment</li> <li>Challenging social relationships (bullying)</li> <li>Inappropriate school setting</li> </ul>
Cognitive	<ul><li>ID</li><li>Learning disability</li><li>Slow processing speed</li></ul>
Communication	<ul> <li>Absence of or inappropriate communication system</li> <li>Use of communication system in only one setting</li> </ul>
Genetic	<ul> <li>Fragile X, 22q11.2 deletion syndrome</li> </ul>
latrogenic	<ul> <li>Polypharmacy</li> <li>Sedation</li> <li>Prompt dependence</li> <li>Agitation from prolonged intensive behavioral management</li> </ul>
Medical	<ul> <li>Pain</li> <li>Seizures</li> <li>Dental</li> <li>Hearing</li> <li>Vision</li> <li>Pica</li> <li>Constipation</li> <li>Sleep</li> <li>Allergies</li> <li>Nutrition</li> <li>Puberty</li> <li>Brain injury</li> </ul>
Psychopathologic	<ul> <li>Anxiety disorders, including posttraumatic stress disorder</li> <li>Mood disorders</li> <li>Attention-deficit/hyperactivity disorder, obsessive compulsive disorder</li> <li>Psychosis or catatonia</li> </ul>
Sensory-related	<ul> <li>Hypersensitivities or hyposensitivities to auditory, tactile, oral, visual, vestibular</li> </ul>

Adapted from Siegel M. Psychopharmacology of autism spectrum disorder: evidence and practice. Child Adolesc Psychiatr Clin N Am 2012;21(4):962; with permission.

when a child strikes their educational aide, versus being neurobiologically mediated, such as aggression that arises when a severely anxious child experiences stimuli flooding. Inpatient admission also presents a unique opportunity to assess medical or environmental factors that may be contributing to a behavioral disturbance. For example, in the authors' experience, many children with ASD who were presumed to have a primary sleep disorder at home prove to sleep well in the hospital, suggesting an environmental cause. Additionally, **Case 1** provides an example of medical issues underlying a severe behavioral presentation in a nonverbal child with ASD.

#### CASE VIGNETTE 1: MEDICAL ISSUES IN CHILD WITH ASD

Sarah was a 12-year-old girl diagnosed with autistic disorder, ID, seizure disorder and mood disorder not otherwise specified. On admission to the neuropsychiatric special care (NSC) program at the Children's Hospital Colorado (formerly The Children's Hospital), Sarah was wearing a helmet because of her frequent head-banging behaviors. In addition, Sarah was nonverbal with no communication system, was not toilet trained, and frequently held her hand to her ear while making a very loud grunting/vibration noise and grimacing. Sarah routinely engaged in dangerous behaviors, including overturning furniture, aggression toward others, and selfinjury (eg, head banging to the point of causing soft tissue damage, biting herself, and pinching and scratching herself). Several providers had told Sarah's parents that they needed to consider long-term institutionalization for Sarah because of the severity of her self-injurious behavior. Sarah had already been in a residential facility for 2.5 months, during which time she had refused to eat and lost 25 pounds. Sarah was then admitted to a general psychiatric unit where she had multiple staff and multiple psychotropic medications to manage her behaviors. Because of a lack of progress, Sarah was then transferred to the NSC program. On admission, Sarah's parents expressed concern that she had never seen a dentist. Previous institutions had not provided dental assessment because her providers and her insurance company determined that it was not medically necessary to see a dentist during a psychiatric hospitalization.

On admission to the NSC program, Sarah was immediately referred for a dental consultation within the hospital setting. Because of this consult, it was determined that Sarah had a black molar and a life-threatening jaw infection, which were quickly addressed. Almost immediately, Sarah's self-injurious behaviors disappeared; she no longer needed to wear a helmet, and she was calm and easily directed. Since Sarah's pain had been addressed, Milieu staff, including a speech therapist, were able to engage Sarah in learning to use simple signs to make requests, which she quickly learned and generalized to using with a variety of staff and with her father. Sarah's treatment team also began to question whether her hearing was impaired because of her insistence on seeking loud sounds. Sarah was then seen by the audiology department and found to be partially deaf in both ears. A hearing device was tried on Sarah, and she immediately responded by smiling and turning to look at her father when he called her name.

After 22 days, Sarah was discharged from the NSC program. She had learned to sit at a table and feed herself, give objects, and use some sign language to communicate her needs, as well as attend to individual work, social group, and toileting activities. After discharge, Sarah's father reported that Sarah had begun to say a few words and that he had learned that Sarah tends to have a calm disposition unless she is experiencing some kind of pain.

## Psychiatric Comorbidity

Diagnosing comorbid psychopathology in children with ASD, particularly children with significant communication impairment, is a complex endeavor. Assessment must take into account whether a child's symptoms are typical of ASD, normal for developmental age, serve a specified adaptive function, and/or are modeled or reinforced in their environment, among other considerations. Children with ASD usually perform in an aberrant fashion on standard psychiatric diagnostic instruments that are designed for the neurotypical population, which can lead to the overidentification of comorbid psychiatric disorders. To address this, Leyfer and colleagues<sup>2</sup> (2006) modified the Kaufmann Schedule for Affective Disorders & Schizophrenia (K-SADS)<sup>23</sup> to account for symptoms typical of autism and for how psychiatric symptoms may present in children with ASD, producing the Autism Comorbidity Interview – Present and Lifetime Version (ACI-PL). The most frequently identified comorbid disorders were the following:

- Specific phobia (44%)
- OCD (37%)
- Attention-deficit/hyperactivity disorder (31%)

- Separation anxiety disorder (12%)
- Major depressive disorder (10%)

Clinicians should be wary of community-acquired comorbid psychiatric diagnoses as Mazefsky and colleagues<sup>24</sup> (2012) found that 60% of prior psychiatric diagnoses in a group of high-functioning adolescents with ASD were not supported by a psychiatric interview with the ACI-PL.

## Verifying ASD Diagnosis and Cognitive Ability

A community diagnosis or the absence of a diagnosis of ASD or ID should not be taken at face value by the inpatient team. Verification of an ASD and/or ID diagnosis can allow for better-targeted interventions and recommendations for follow-up care in the community. A previously assigned diagnosis of ASD can be supported using a screening tool, such as the Social Communication Questionnaire.<sup>25</sup> A suspected new diagnosis of an ASD should be evaluated by the following:

- Gathering developmental history about the patient from a primary caregiver using a standardized measure, such as the Autism Diagnostic Interview-Revised<sup>26</sup>
- Using a standardized observational assessment of patients, such as the Autism Diagnostic Observation Schedule, Second Edition<sup>27</sup>

Using a standardized observational assessment administered by a trained evaluator can effectively tease out whether the patients' presenting social-communication difficulties are caused by ASD or another cause, such as an anxiety disorder or psychosis.

Obtaining reports from community providers regarding the patients' levels of intelligence, achievement, and adaptive functioning can assist in clarifying assessment issues and identifying appropriate interventions. Caregivers may tend to overestimate or underestimate the ability levels of their child with ASD because of the variability and inconsistent profile of adaptive and cognitive abilities common in this population.<sup>28</sup> Verbally based intelligence tests may not be reliable estimates of true problemsolving ability, particularly if the individual has coexisting language production, processing, or pragmatic impairments. In such cases, the Leiter International Performance Test, Revised<sup>29</sup> is a reliable cognitive screening tool for patients aged 2 to 21 years, and the brief IQ version takes approximately 30 minutes to administer.

### **Considering Communication**

#### Receptive communication

Psychiatric settings typically rely on verbal instructions and intervention strategies. Individuals with ASD and ID, however, tend to process auditory information slowly. When they are provided with rapid or multiple pieces of verbal information, they can become agitated or unresponsive, which can be misinterpreted as resistant behaviors. The ASD population tends to think concretely, which can result in a tendency to follow directions in a literal manner.<sup>30,31</sup> The ASD population also has particular difficulty integrating and interpreting multiple pieces of social information (eg, tone of voice, facial expression, eye contact, and gestures).<sup>32</sup> This limitation can lead to the misperception of staff intentions and resultant agitation.

Strategies to increase comprehension include providing clear visual cues that have enough clarity for patients to understand and answer the following critical questions: What do I need to do? How much or how long do I do something? How do I know when I am finished? What do I do next? Strategies of visual clarity, schedules, and routines have empiric support for reducing behavior problems related to a lack of predictability and understanding of expectations.  $^{33,34}$ 

## Expressive communication

Impaired ability to communicate even a basic need can cause great frustration for individuals with ASD and ID, and this can often be a sole cause for a resulting behavior problem. Helping patients communicate at any level can provide a prosocial means to getting their needs met.<sup>35</sup> It is recommended that psychiatric programs admitting ASD and ID populations routinely consult with speech language pathologists to identify and facilitate appropriate expressive communication strategies.

## Hospital Environment

General psychiatric hospital environments are not typically adapted for the unique learning styles, needs, and abilities of the pediatric ASD or ID populations. Staff typically expect social and verbal initiations from patients, thus making it easy for individuals with ASD or ID to be ignored or forgotten in the regular daily operations of a busy psychiatric unit. Children with ASD may have abnormal responses to sensory stimuli, such as light, sound, touch and smells, that can make the hospital environment uncomfortable or even intolerable for some children. Minor modifications, such as dimming bright lights, choosing a patient room at a quieter end of the unit, providing noise-cancelling headphones, and access to fidget toys and quiet play spaces can significantly lessen agitation. It is recommended that psychiatric programs that admit the ASD/ID population routinely consult with occupational therapists to help assess and address sensory needs.

Structuring the environment can help individuals with ASD increase their attending behaviors and reduce challenging behaviors.<sup>36</sup> Environmental structure can range from providing picture schedules of routines, labeling containers, and designating routine locations with visual boundaries to having consistent routines paired with visual cues for activities and transitions. In addition to modifying the physical environment, patients' motivation can increase and challenging behaviors can be reduced when daily schedules alternate preferred and less-preferred activities.

## Staff Training

General psychiatric hospital staff are not routinely trained to understand and effectively respond to this population.<sup>37</sup> Individuals with ASD or ID do not typically respond positively to the verbal strategies (eg, repetitive coaxing, verbal reassurance, or long explanations) or lengthy time-out procedures typically used with the neurotypical patient population. Additionally, not all staff prefer to work with the unique demands of patients with special needs. Training staff, including providing hands-on experience with the variety of functioning levels of patients with ASD and ID, is critical to reduce the risk for harm. Staff can be taught to alter their communication styles and management approaches, paying attention to their tone of voice and the complexity and amount of words used. Staff should be encouraged to allow patients extra time to process auditory information before repeating a direction or expecting a response. It is equally important for staff to resist the human urge to move in close to an individual who is in distress. Moving into close proximity or touching a distressed child with ASD or ID can be perceived as an intolerable sensory or emotional threat by the child. Backing away and giving patients time and space to process and deescalate is rarely the wrong thing to do.

# EVIDENCE BASE FOR TREATMENT OF CHILDREN WITH ASD IN GENERAL PSYCHIATRIC HOSPITAL UNITS

There is very limited evidence for the treatment of children with ASD in general psychiatric hospital units. One retrospective case series described 29 adolescents with ASD hospitalized for acute behavioral regression in a French general adolescent psychiatry unit.<sup>38</sup> All the patients with ASD exhibited severe autistic symptoms and intellectual disability, two-thirds had no functional verbal language, and 48% had epilepsy. The average length of stay was 44 days, and a lower IQ was associated with longer length of stay.

The investigators assessed the cause of the disruptive behavior as adjustment disorder (24%), epilepsy (21%), inadequate outpatient therapy or educational services (21%), pain (10%), depression (7%) or catatonia (7%). The investigators concluded that adolescents with ASD need to be examined and treated with a multidisciplinary approach.

Some investigators have proposed concerns regarding the treatment of individuals with ASD or ID in general psychiatry units, such as exposing a vulnerable population to more able peers<sup>39</sup> or that staff typically lack training and experience in the assessment and treatment of comorbid psychopathology in this population.<sup>40</sup> One study reported that specialized units are perceived to provide a higher standard of care for individuals with ID.<sup>41</sup>

# EVIDENCE BASE FOR SPECIALIZED PSYCHIATRIC HOSPITAL TREATMENT OF CHILDREN WITH ASD

There is a small and growing body of literature on the treatment effects of specialized inpatient psychiatry units for the adult and child populations with ASD and ID, although most studies have been retrospective and/or uncontrolled.

## Adult Studies

A Finnish prospective study of 31 adult patients with borderline to mild ID and psychiatric symptoms described the treatment in a specialized psychiatric inpatient unit.<sup>42</sup> The treatment consisted of occupational therapy; group therapy; training in activities of daily living (ADL) skills; pharmacotherapy; financial guidance; psychoeducation; and other treatments, including music therapy; the average length of stay was almost 90 days. Psychotic symptoms were reduced on the Brief Psychiatric Rating Scale during hospitalization and at the 6-month follow-up, but nonpsychotic symptoms were reduced only at the follow-up.

A retrospective chart review of 13 adults with ASD admitted to a Canadian specialized inpatient psychiatry program showed an average length of stay of 295 days, 77% admitted with aggression, 15% with unmanageable behaviors, and 8% with selfharm/suicidality.<sup>43</sup> Another Canadian retrospective study of an adult specialized psychiatry unit with an average length of stay of 119 days compared outcomes for patients with mild ID with those with moderate/severe ID and found clinical improvement for both groups, but changes in standardized outcome measures did not reach significance.<sup>44</sup>

One descriptive study in the United Kingdom prospectively compared adults with ID admitted to a specialized psychiatric unit and a similar group admitted to a general psychiatric unit. The specialized unit cohort had a longer length of stay on average but demonstrated greater improvements on global measures of mental illness severity and was less likely to be discharged to a residential placement.<sup>45</sup>

## Child and Adolescent Studies

The child literature begins with a report from 1972 describing an inpatient treatment program for children with autism or schizophrenia.<sup>46</sup> Children ranged from 4 to 12 years old, and the median length of stay was 2.25 years. The report describes the then-novel application of a daily routine of tasks and systematized reinforcement techniques, with positive results. Only 19 of the 57 children, however, were discharged to their homes.

In 1992, Barrett and colleagues<sup>47</sup> published an article describing a hospital program serving children with ASD or ID at Bradley Hospital. The program used applied behavioral analysis techniques and operant behavioral management principles in the context of a multidisciplinary intervention. The report stressed the importance of detecting and treating comorbid psychopathology. In a retrospective review of 50 serial admissions, they found an age range of 4 to 22 years, a 3:2 male/female ratio, 34% with ASD, and a wide range of comorbid axis I disorders. Characteristics of irritability and oppositionality were present in 80%.

In the United Kingdom, another case series identified 96 children with ID admitted to a specialized unit. The population was found to contain 2 subgroups: two-thirds had more severe disability and were admitted for neuropsychiatric management; one-third had problems more typical of mainstream psychiatry, but their ID was a barrier to mainstream psychiatric services.<sup>44</sup>

Gabriels and colleagues<sup>48</sup> provided the first support for the effectiveness of introducing a specialized inpatient psychiatric program for the treatment of children with ASD/ID. This retrospective chart review covered 2 eras of a psychiatric unit at the Children's Hospital Colorado. In the first era, children with ASD or ID were treated in a general child psychiatry unit, whereas, in the later era, a specialized unit was developed that included a step-down day treatment component. Twelve cases from the general treatment era and 26 cases from the specialized treatment era were compared. A dramatic decrease in the average length of stay from 45 days to 26 days and a decline in the recidivism rate (defined as readmission within 1 year) from 33% to 12% correlated with the change from the general to the specialized care era. In addition, the investigators found a significant decline from admission to discharge on the Aberrant Behavior Checklist<sup>49</sup>–Irritability and Hyperactivity subscales for children admitted to the specialized treatment program.

Recently, Siegel and colleagues<sup>50</sup> reported the first prospective study of a specialized inpatient psychiatry unit for children with ASD or ID using standardized outcome measures. Thirty-eight children, aged 5 to 18 years, were assessed by a consistent caregiver at admission, discharge, and 2 months after discharge on the Aberrant Behavior Checklist – Irritability (ABC-I) subscale. The ABC-I is a measure of behavioral functioning, evaluating aggression, self-injury, and tantrums, which has been shown to be valid and reliable for children with developmental disabilities. There was a substantial main treatment effect for time on the mean ABC-I score, which decreased from 27.3 (SD 7.4) at admission to 11.9 (SD 8.8) at discharge with slight regression to 14.8 (SD 9.3) at the 2-month follow-up (F [2, 36] = 52.57, P<.001). Seventy-eight percent of the patients were rated as *much improved* or *very much improved* on a clinician-rated Clinical Global Impression - Improvement (CGI-I).

### SPECIALIZED PSYCHIATRIC HOSPITAL TREATMENT MODELS Model 1: Specialized Inpatient Treatment Unit

The Spring Harbor Hospital Developmental Disorders Unit (DDU) is a 12-bed specialized inpatient psychiatry program that performs assessment and treatment of comorbid psychopathology and acute behavioral disturbance in children with ASD and ID. Most patients present with unsafe behaviors toward themselves or others, and a small minority present with acute deterioration in functioning. Daily counts of physical aggression in the double digits and self-injurious behavior in the hundreds are common. The average length of stay is 42 days; 66% of the patients have ASD; greater than 80% have ID; and the average staffing ratio is 3 staff to 4 patients. Most children entering the program are at risk for out-of-home placement (residential or group home) and have been failed by multiple modes of prior treatment, including pharmacology, day treatment, in-home therapeutic services, and admission to general child psychiatry units. After treatment in the DDU, two-thirds of the children are discharged back to their home.

The treatment team consists of child psychiatry, pediatrics, behavioral psychology, a physician assistant, occupational therapy, speech and language pathology, social work, nursing, special education, and behavioral and educational technicians. Consultation from physical therapy, neurology, nutrition, genetics, and other specialties is available.

Treatment begins with an intensive multidisciplinary diagnostic assessment, typically aided by the removal of psychotropic medications. Details of the assessment approach are illustrated (**Case 2**). Treatment modalities include behavioral treatment based on principles of applied behavior analysis and positive reinforcement schema,

### CASE VIGNETTE 2: CHILD BEHAVIORAL CHANGE OVER HOSPITAL STAY

Alana was a 7-year-old girl with autistic disorder, ID (mild to moderate), and significantly impaired communication (<50 words, primarily echolalia). Alana was admitted to the Spring Harbor Hospital Developmental Disorders Unit because of an acute increase in self-injurious behavior, tantrums, and aggression over the prior 2 months. Her mother estimated that Alana was emotionally dysregulated 50% of the time and engaged in self-injurious behavior more than 100 times a day, primarily by biting her hand or hitting her head with her hand. In the past, Alana had not responded to outpatient trials of clonazepam, risperidone, quetiapine, naltrexone, sertraline (5 mg/d), fluoxetine (5 mg/d), melatonin, and clonidine. Alana was awake for several hours nightly, which was highly disruptive for the family. Provision of 16 hours per week of in-home behavioral services, consisting of bachelor- and master-level providers, had been unsuccessful.

Initial multidisciplinary assessment revealed a tired girl who engaged in aggression and selfinjury across home and school settings, primarily during tantrum episodes. Alana used a Picture Exchange Communication System (PECS)<sup>51</sup> at school but not outside that environment, and her independence with the system was minimal. Her tantrums were observed to occur primarily in relation to task demands or when denied preferred items. Alana's parents were assessed as being engaged with her treatment but were using minimal structure at home, relying mostly on psychopharmacology to attempt to decrease her aggression and self-injury.

Alana's initial hospital treatment focused on weaning her off clonidine and introducing a sleep routine, which included minimal attention during awake periods at night. This treatment resulted in much more consistent sleep, improved alertness, and reduced irritability. Target behaviors of emotional dysregulation, self-injury, and aggression were defined and operationalized and were tracked by the unit staff 24 hours a day. A positive behavioral support plan, utilizing a task:token economy, was developed to reinforce non-performance of target behaviors. PECS trials were initiated to assess and improve her communication efficiency.

Midway through her stay, it was determined that the token economy was too abstract for Alana, and she was changed to direct (ie, cause and effect) reinforcement of task completion. Alana was prepared for the end of each reinforcing activity by placing a visual countdown graphic next to her. A reduction in the frequency and duration of Alana's tantrums was obtained by creating a response routine whereby staff used a first/then visual card to reduce language demands and show her "first quiet voice," then (next activity). It was noted that her tantrums also occurred when she moved from one setting to another, which was addressed by using a preferred object as a transitional reinforcer, which was removed when tantrums occurred during the transition and returned when forward motion reinitiated.

Concurrently, a psychiatric assessment after a medication-free period diagnosed a generalized anxiety disorder, based on a consistent fear of elevators and entering group situations. Her anxiety decreased after initiation of sertraline at 25 mg/d (5 times the prior outpatient dosage). Occupational therapy and special education services provided Alana with sensory supports and academic task demands. Constipation was detected and treated with polyethylene glycol 3350 (MiraLax).

In the final phase of her hospitalization, Alana's parents were taught how to implement her behavioral plan, which included the first/then instruction card and other interventions described earlier. They then shadowed her staff and finally were coached by staff as they implemented the plan with Alana. Attendance by parents at a community PECS training course was facilitated by the unit social worker. Alana's parents were assisted in modifying the home environment to be more conducive to sleep and to implement visual supports. Alana's local school staff came into the hospital to observe the implementation of her behavior plan and supports. Outpatient services with a behavioral psychologist were arranged, and all supporting materials were transferred to her parents, the psychologist, and her school staff.

At discharge, Alana evidenced a 92% reduction in her daily number of self-injurious behaviors, a 66% decrease in her daily minutes of emotional dysregulation, and a 258% increase in her daily PECS exchanges (Fig. 1). After a 35-day hospital stay, Alana was discharged to her home.



Fig. 1. Case 2 behavioral change over stay.

targeted psychopharmacology, treatment of acute medical issues, speech/language and occupational therapy, milieu therapy, special education, family therapy, and parent behavioral management training. Treatment is highly individualized; a verbal child with ASD and average IQ with explosive outbursts caused by social pragmatic deficits will receive treatment oriented toward cognitive flexibility and emotion regulation, whereas a more functionally challenged child with ASD with a high frequency of self-injurious behavior may receive high-density reinforcement of incompatible behaviors and in-depth occupational therapy support. The program runs its own 6-hour school day, and the school is often used as the laboratory to trial new interventions or behavioral plans.

The program seeks to address both the acute symptoms as well as the key underlying factors that contribute to the presentation of unsafe behavior. For example, identifying that an aggressive nonverbal child has no functional communication system might prompt treatment of the aggression with medication *and* training the child and family on the use of a visual picture communication system. The response to intervention is monitored by daily team analysis of behavioral data.

The benefits of family engagement in educational and behavioral interventions for children with ASD are well described.<sup>52–54</sup> Parental involvement has been deemed a critical component for reinforcing clinical treatments and promoting the generalization of learned skills to nonclinical environments. To this end, the primary caregivers of patients admitted to the program are offered the opportunity to participate in a 3-step behavior management training program where they are taught the child's individualized behavioral plan, shadow the staff running the plan, and ultimately run the plan themselves with staff supervision and coaching. Key community providers, such as local school staff and in-home therapeutic staff, are offered the same training. The goal of the program is to provide sustained improvement in behavioral functioning after discharge, and the readmission rate within 1 year is less than 10%.

## Model 2: Specialized Inpatient Treatment with Integrated Step-down Model

The Neuropsychiatric Special Care (NSC) program at the Children's Hospital Colorado (previously, The Children's Hospital) is associated with the University of Colorado Anschutz Medical Center and is part of the Department of Psychiatry and Behavioral Sciences. In April 2004, this program was initiated to provide a specialized psychiatric continuum of care that includes both an inpatient unit and partial hospitalization program for patients aged 4 to 17 years diagnosed with ASD and/or ID who are in a state of crisis.<sup>48</sup> The partial hospitalization program component was developed to decrease lengthy inpatient stays and repeat admissions by allowing patients to leave the inpatient unit as soon their condition stabilizes, yet continue their involvement in the NSC program.

The objectives for designing this program were to develop a structured hospital environment with specialty-trained staff to address the following areas:

- 1. Decrease behavior problems related to patients' anxiety and limited socialcommunication skills so that the issues underlying presenting crisis behaviors could be better detected and addressed.
- 2. Decrease the need for high staffing ratios.
- Increase the patients' involvement in a variety of milieu activities that simulate the community environment in order to assess the effects of interventions and promote generalization of skills into the community setting.
- 4. Increase caregiver sense of competence in understanding and managing patient behavior in order to decrease hospital recidivism rates.

Patients admitted to the NSC are assigned a core treatment team consisting of 3 professionals: a master-level clinician (family therapist/community coordinator), a psychologist (individual therapist/evaluator and behavior management coordinator), and a child psychiatrist (medical evaluation/management). Other staff include nursing and mental health counseling staff, creative arts therapists, occupational and speech therapists, and consulting medical specialty services as needed. At admission, the multidisciplinary staff conduct an evaluation process with the individual patient and their caregivers to identify intervention goals and plans. This process typically includes a milieu observational functional behavior assessment, an interactional assessment with patients and their caregivers, and a tip-of-the-iceberg assessment interview conducted by the psychologist with the patients' caregivers.

The structured setting and positive behavior intervention approach of the NSC program is based on cognitive behavioral and behavior learning theories. Specifically, NSC staff are trained on the TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) model developed by the University of North Carolina, Chapel Hill, which capitalizes on the visual strengths of the ASD population to create highly structured and visually clear environments and routines. Intervention strategies are focused on taking a positive and proactive approach to managing challenging behaviors and teaching alternative functional behaviors.<sup>34</sup>

Caregiver education and involvement is a key component of the NSC program. Caregivers and community providers observe and interact with the patients in the therapeutic milieu with staff coaching and attend several different topic-specific weekly multifamily education-training groups. Direct-care staff maintain their competency with intervention methods by rotating participation in the multifamily groups, coleading weekly patient social groups with program therapists and psychologists, and daily consultation with psychologists about patients' behavior management plans.

#### IMPROVING CARE FOR ALL PSYCHIATRICALLY HOSPITALIZED INDIVIDUALS WITH ASD

Although most general psychiatry units do not have the resources to provide an extensive multidisciplinary team or a behavioral data collection and analysis system, the literature on specialized units suggests several avenues for improving the care of all individuals with ASD and ID admitted to psychiatric hospital units.

Clinical practice pathways have been shown to improve hospital care and outcomes for acute exacerbations of multiple chronic medical conditions, including congestive heart failure and ischemic heart disease.<sup>50–56</sup> The common components of these pathways include standardized evaluation components (draw a hemoglobin A1c and assess for foot health in all patients with diabetes), checklists to ensure the provision of proven treatment components (compression stockings and angiotensin-converting enzyme inhibitor for all admitted with congestive heart failure), and measurement of institutional benchmarks to track performance (readmission within 30 days and so forth). Psychiatric hospitals have been slower to adopt clinical practice pathways than medical hospitals, although acute psychiatric admission is commonly conceptualized as an exacerbation of a chronic illness.

Based on the extant literature and the authors' experience, the authors offer the following elements to consider as potential components of a clinical practice pathway for children or adults with ASD admitted to any psychiatric hospital unit (Fig. 2).

Other options for improving care include obtaining consultation from clinicians who specialize in the population or inserting a potentially critical treatment



Fig. 2. Clinical practice pathway for psychiatrically hospitalized patients with ASD.

component, such as a functional behavioral analysis or a communication assessment, into the standard unit evaluation process when an individual with ASD or ID is admitted.

#### SUMMARY AND FUTURE DIRECTIONS

Children with ASD are psychiatrically hospitalized at disproportionately high rates, typically as a result of an acute decline in behavioral functioning. The core characteristics and presenting problems of the inpatient ASD population vary significantly from hospitalized neurotypical children because aggression and self-injurious behavior are the most common chief complaints. There is preliminary evidence that specialized inpatient treatment programs deliver positive behavioral outcomes for this population that endure 2 months after discharge. There are also multiple opportunities to improve ASD inpatient care.

As the number of children identified with ASD increases, the demand for inpatient psychiatric services is likely to continue to increase. This point elevates the importance of comparing the effectiveness of different treatment models and exploring the means of raising the standard of care for individuals with ASD in all hospital psychiatry settings.

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