

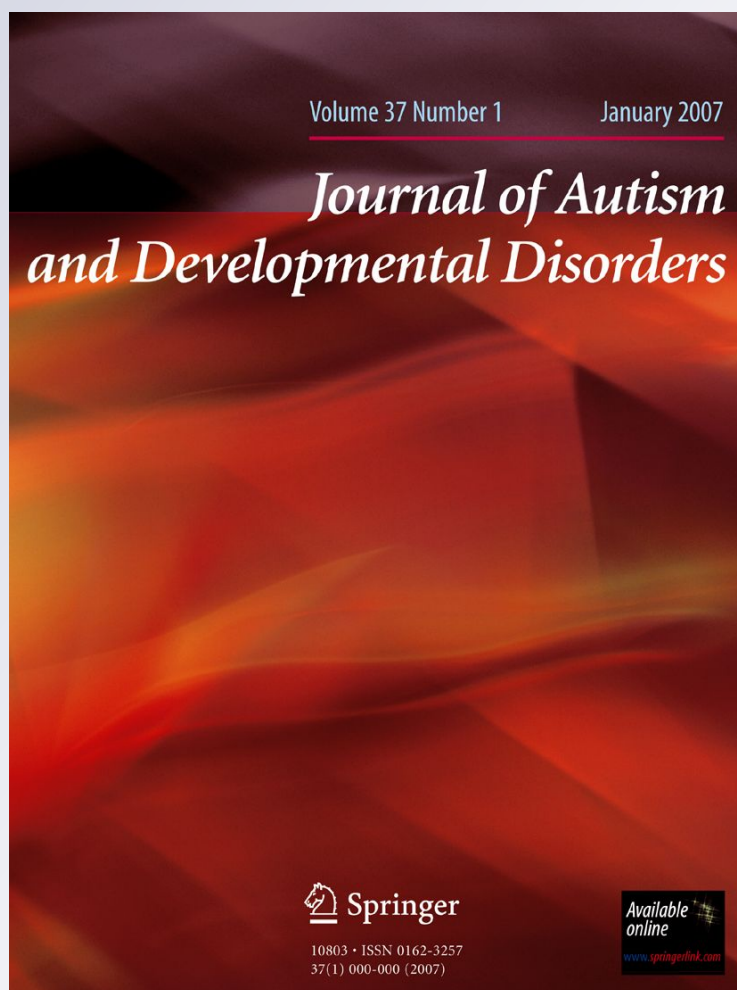
Specialized Inpatient Psychiatry Units for Children with Autism and Developmental Disorders: A United States Survey

Matthew Siegel, Kathleen Doyle, Bruce Chemelski, David Payne, Beth Ellsworth, Jamie Harmon, Douglas Robbins, Briana Milligan & Martin Lubetsky

**Journal of Autism and
Developmental Disorders**

ISSN 0162-3257

J Autism Dev Disord
DOI 10.1007/s10803-011-1426-3



Your article is protected by copyright and all rights are held exclusively by Springer Science+Business Media, LLC. This e-offprint is for personal use only and shall not be self-archived in electronic repositories. If you wish to self-archive your work, please use the accepted author's version for posting to your own website or your institution's repository. You may further deposit the accepted author's version on a funder's repository at a funder's request, provided it is not made publicly available until 12 months after publication.

Specialized Inpatient Psychiatry Units for Children with Autism and Developmental Disorders: A United States Survey

Matthew Siegel · Kathleen Doyle · Bruce Chemelski ·
David Payne · Beth Ellsworth · Jamie Harmon ·
Douglas Robbins · Briana Milligan · Martin Lubetsky

© Springer Science+Business Media, LLC 2011

Abstract A cross sectional survey was performed to obtain the characteristics of specialized inpatient psychiatry units exclusively serving children with autism and other developmental disorders in the United States. Identified units were surveyed on basic demographic characteristics, clinical challenges and therapeutic modalities. Average length of stay was 42.3 days, children with autism spectrum disorders constituted the majority of the inpatient population (62.5–87.5%), and obtaining adequate post-discharge services was identified as the greatest challenge. Health policy implications and future research directions are suggested.

Keywords Autism · Inpatient · Developmental · Admission

M. Siegel (✉) · B. Chemelski · D. Payne · B. Ellsworth ·
J. Harmon · B. Milligan
Developmental Disorders Program, Spring Harbor Hospital
& Maine Medical Center, 123 Andover Road, Westbrook,
ME 04092, USA
e-mail: siegem@springharbor.org

M. Siegel
Department of Psychiatry, Tufts University School of Medicine,
Boston, MA, USA

K. Doyle
Mount Holyoke College, South Hadley, MA, USA

D. Robbins
Division of Child Psychiatry, Maine Medical Center,
Portland, ME, USA

M. Lubetsky
Division of Child Psychiatry, Western Psychiatric Institute
and Clinic, Pittsburg, PA, USA

Introduction

The population of children with a developmental disorder, consisting of those with Intellectual Disability (ID) or an Autism Spectrum Disorder (ASD), is increasing and presents an expanding challenge for mental health care systems. Children with ID experience mental illness at a higher rate than the general youth population, with a 1 year prevalence of 38.6% for any DSM-IV Axis I disorder (Dekker and Koot 2003). Rates of co-morbid psychopathology are even greater for children with an ASD with a 3 month point prevalence as high as 70.8% for any DSM-IV Axis I disorder (Simonoff et al. 2008).

The combination of an expanding population and a high prevalence of mental illness suggests that a large number of children with developmental disorders may need psychiatric treatment, including inpatient hospitalization. In a study of over 33,000 children enrolled in the northern California Kaiser Permanente health plan, children with an ASD utilized 11.9 times as many psychiatric hospital days as children without an ASD and incurred 12.4 times the cost (Croen et al. 2006). Nationally, the average annual health care expenditure for children with an ASD has been estimated at \$6,132, compared to \$860 annually for non-ASD children (Liptak et al. 2006).

Given the public health and resource implications of these demographic patterns it is important to identify risk factors for psychiatric admission, including the types of behaviors and psychiatric disorders that predispose children with developmental disorders to be hospitalized, as well as the characteristics of efficacious treatment programs. Of particular interest is whether the country should invest in specialized inpatient psychiatry programs for this population, or continue to primarily serve these children in general child and adolescent inpatient psychiatry units.

Despite the importance of these trends, there is little information in the scientific literature examining specialized inpatient psychiatric treatment of children with developmental disorders.

Historically, there was some hesitation to provide specialized units for individuals with developmental disorders, such as ASD or ID, as the push for deinstitutionalization and normalization was realized in the 1970's. However, it has been shown that specialized units are perceived to provide a higher standard of psychiatric care for individuals with ID (Lennox and Chaplin 1995). There is also concern that on general units staff typically lack training and experience in the assessment and treatment of developmentally delayed individuals with co-morbid psychopathology (Bouras and Holt 2001) and that individuals with ID are vulnerable to exploitation by more able patients (Kwok 2001).

The United Kingdom has a number of specialized inpatient psychiatry units for children and adults with developmental disorders. A small body of literature examining the characteristics and outcomes of this specialized system has been produced, though it focuses primarily on the adult population. There is one retrospective study of 96 youth with ID admitted to a specialized psychiatric unit in England. The authors found two sub groups: two thirds of the patients had more severe disability and were admitted for neuropsychiatric management, and one third had problems more typical of mainstream psychiatry—but their intellectual disability was a barrier to obtaining effective care in mainstream services (Smith and Berney 2006).

The United States literature is limited to a book chapter published by Barrett et al. describing an inpatient unit serving children and adolescents with developmental disorders at Bradley Hospital in Rhode Island (Barrett et al. 1992). The authors performed a retrospective review of 50 serial admissions, finding an age range of 4–22 years, a 3:2 male to female ratio, 34% with an ASD, and a wide range of axis I and II disorders. The reason for admission was reported as aggression in 42% of admissions and self injurious behavior in 22% of admissions. Characteristics of irritability and oppositionality were present in 80%.

The current study is a survey of the specialized inpatient psychiatric units we were able to identify in the United States. We offer a description of the inpatient system of care available to children with developmental disorders and aim to provide the basis for further research into best practices in the psychiatric care of this needy and growing population. Our primary hypothesis was that the greatest challenge for specialized units would be obtaining appropriate follow-up services at discharge. To the best of our knowledge this is the first published report on the characteristics of specialized inpatient psychiatry units serving children with autism and developmental disorders in the United States.

Methods

Potential specialized inpatient psychiatry programs were identified by entering multiple search terms including “autism,” “inpatient,” “hospital,” “developmental,” and “psychiatry,” into the Google© internet search engine and Pub Med. In addition, the medical directors of several specialized inpatient psychiatry units known to the authors were queried regarding potential programs. The initial search produced twelve possible programs in the United States. Each program was contacted by telephone and eight units met the study inclusion criteria of being a hospital inpatient psychiatry unit that serves only children and adolescents with developmental disorders. Four programs were excluded due to either not being a hospital inpatient program or serving both children with and without developmental disorders.

Upon receiving exemption from the Institutional Review Board of Maine Medical Center, a survey was mailed and e-mailed to the medical or program directors of the eight identified units. Draft survey questions were developed by performing a focus group with clinicians and staff from an existing specialized inpatient psychiatry unit to identify gaps in knowledge. In addition, the medical directors of two specialized units reviewed the draft survey and added questions of interest on funding source and clinician training. The survey requested basic demographic information for each unit including age range served, number of beds, geographic location, percentage of admitted children with an ASD, year of unit inception, and average length of stay. We also surveyed discharge disposition, funding mechanism, clinician characteristics, staffing ratios, use of personal protective equipment, treatment modalities employed, and availability of a population-specific service continuum. Finally, we requested ratings of the most common chief complaint at admission and greatest unit challenge. Medical and program directors were also queried regarding their interest in coordinating with other similar inpatient units and whether they knew of any other units that would meet study criteria in addition to the eight initially identified.

Response rate was 100%, including identification of a ninth unit by one of the initial respondents, which was subsequently surveyed. One program responded via telephone survey. No incentive for participation was offered, though participants were given access to the de-identified data set. Survey results were double entered into Microsoft Excel and analyzed.

Results

Our survey identified nine specialized inpatient psychiatry units located in eight hospitals in the United States. We

found that there has been a rapid increase in the number of units over the last decade, with five opened in the last 9 years. Most units are part of tertiary care academic hospital systems, but the creation of units within private, non-academic institutions is a new phenomenon, with three arising since 2002. Across all units, the average length of stay was 42.3 days (mode 30 days, range 12–135 days). After removal of an outlier of 135 days, the average length of stay across the remaining units was 30.75 days. The average unit size was 15.2 beds (range 9–22 beds), and the total number of specialized beds identified in the country was 137 (Appendix 1, Table 1). The age range of children served was 4–21 years old, mean age 12.72 years, with one unit reporting acceptance of occasional individuals up to 25 years of age.

One of the most striking features of the specialized units is their geographic maldistribution, primarily clustering on the northeast coast (Fig. 1).

Most units were embedded within a continuum of specialized developmental disorder services run by the inpatient unit's host institution. This continuum potentially included day treatment, partial hospitalization, crisis, school, outpatient and/or residential settings. Of the sites surveyed, 66% provided at least one specialized continuum component associated with the specialized unit. The most common

continuum component was an outpatient service (66%), followed by day treatment or residential services (33%), a school for inpatients (22%), and a school for outpatients or in-home services (22%). One unit was associated with a specialized crisis service. There was a correlation between increasing age of the specialized unit and the number of associated specialized care components (Fig. 2).

Data was obtained regarding the types of clinicians and therapeutic modalities employed (Appendix 1, Tables 2, 3). All units employed a child psychiatrist, social worker and a psychologist or board certified behavior analyst (BCBA). 88% of units employed four or more clinical disciplines at 0.5 full time equivalence or greater, suggesting near universal use of multi-disciplinary teams. A majority of units (77%) also employed a special educator, and 33% utilized either a speech language pathologist or occupational therapist. In addition, two of the units reported employing either a physician assistant or nurse practitioner. On average, 4.6 different clinical disciplines were represented in each unit's treatment team. 100% of respondents identified utilizing both pharmacotherapy and behavioral modification therapy. Over two-thirds also utilized family therapy and sensory-oriented therapies and 44% provided individual psychotherapy, speech therapy or occupational therapy.



Fig. 1 Geographic distribution of specialized inpatient psychiatry units in the United States

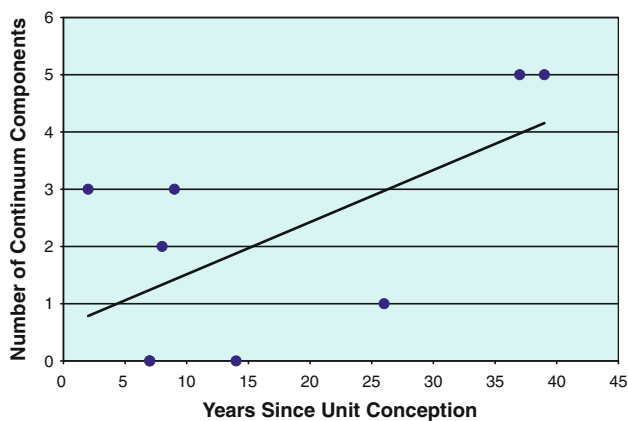


Fig. 2 Depth of service continuum as a function of unit age

All programs served as a training site for at least one clinical discipline. 77% provide training for nursing students, 66% for medical fellows, residents and students, 66% for psychology interns and BCBA's, and 33% and 22% serving occupational therapy and speech therapy trainees respectively (Appendix 1, Table 4). Units located in academically-associated institutions averaged a significantly higher number of disciplines being trained (4.33 disciplines) compared to the non-academically associated sites (1.66 disciplines).

All units reported from 62.5 to 87.5% of their patients as having an ASD. Other children admitted had a diverse set of non-ASD developmental disorders. Despite the heterogeneity of the population served, there was a large degree of commonality in the chief complaint at admission. As seen in Fig. 3, aggression and self-injurious behavior were the most common chief complaints.

Perhaps due to the externalizing nature of the most common chief complaints, the units reported a relatively

high staff to patient ratio, averaging three direct care staff (technicians + nurses) per four patients (range 1:3–1.75:1). Almost all units (88%) used personal protective equipment (PPE) on direct care staff, and 77% reported utilizing PPE on patients, though some reported that the latter was an infrequent practice. In addition, almost 60% of patients were reported to be discharged to home, suggesting that these units serve as an acute inpatient service that in the majority of instances returns children to their home environment.

The units were also asked to rate their greatest challenges from a list that included maintaining adequate staffing levels, finding clinicians trained in developmental disorders, staff injuries, obtaining adequate follow-up services for patients after discharge, funding, and intra-program communication. As displayed in Fig. 4, obtaining adequate follow-up services after discharge was rated the greatest challenge across units. This was followed by funding, maintaining adequate staffing levels, staff injuries, intra-program communication, and obtaining clinicians with expertise in this sub-specialty area.

Large disparities were seen in the type of funding mechanism utilized by each unit. Some units were 90% funded by public health insurance and one unit was 90% funded by commercial health insurance. On average, 58.9% of funding was through public insurance, 38.9% by commercial insurance, and self pay rates were universally low, averaging 7.8% (Appendix 1, Table 5). The average length of stay for the unit receiving 90% of its funding through commercial insurance was higher than the average length of stay of the units that were primarily funded by public insurance (Fig. 5).

Finally, all respondents indicated a desire to meet and collaborate to develop best practices in serving the

Fig. 3 Average rating of chief complaint at admission

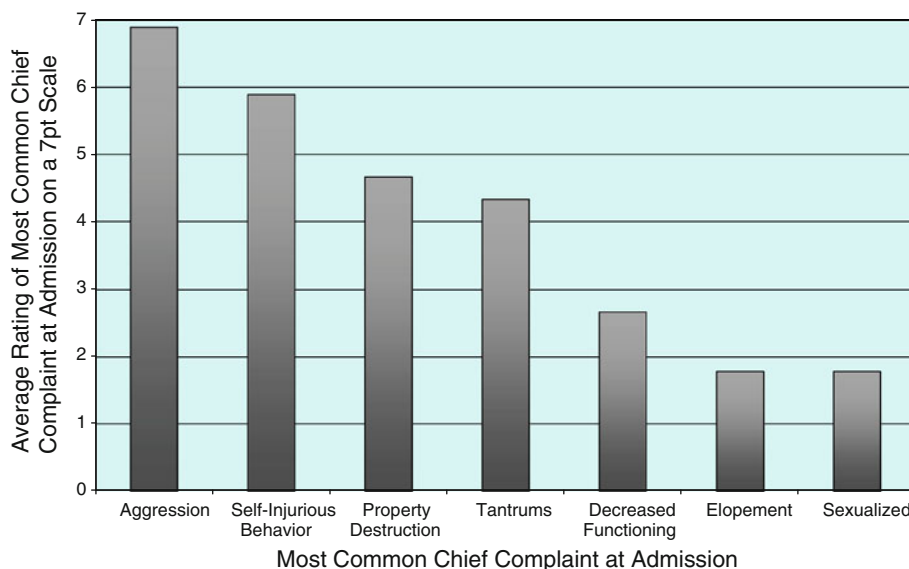


Fig. 4 Average rating of greatest unit challenge

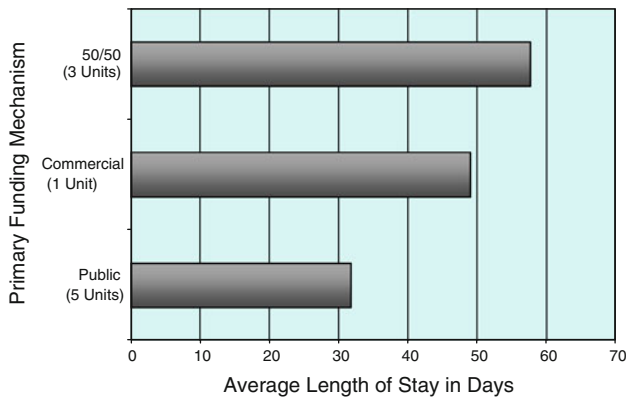
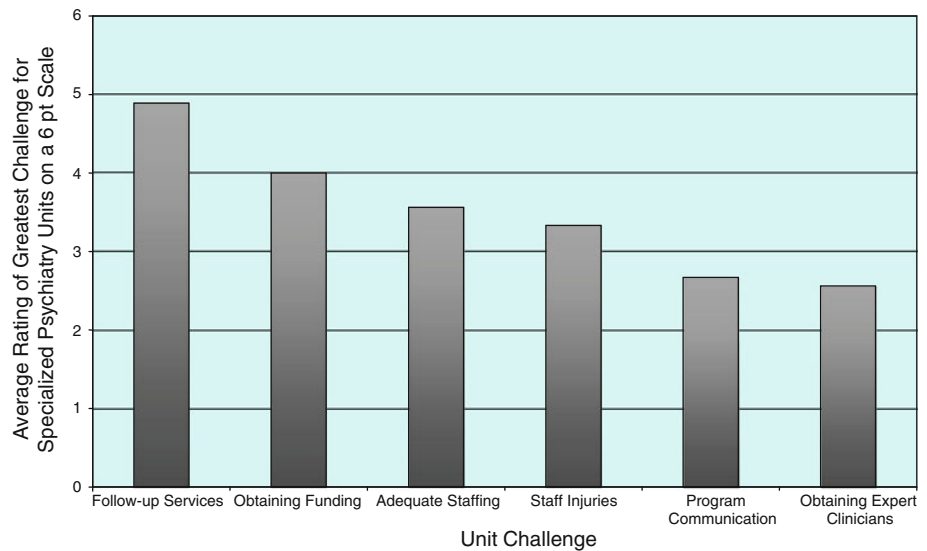


Fig. 5 Average length of stay and primary funding mechanism

inpatient developmental disorders population and identify areas for further research.

Discussion

Our study indicates there has been significant growth in specialized inpatient psychiatric care for children with developmental disorders, and that this type of service is expanding beyond academic centers to more diverse hospital settings. This growth may relate to increased identification of the ASD population, as 67.5–87.5% of admitted children were stated to have an ASD. This may represent a change in the population of these units, as one of the few statistics previously reported identified only 34% of a specialized inpatient population as having an ASD in 1992 (Barrett et al. 1992) At an average of 8.6 patients per bed per year (based upon an average length of stay of 42.3 days, 137 total beds, and assumption of 85% occupancy), these units are estimated to serve approximately

1,001 children with developmental disorders per year, 686 of whom have an ASD.

Our data indicate that these programs function as a major training ground for those who seek to work with children with developmental disorders. The recent federal focus on increasing training opportunities in this area, via the LEND (Leadership and Education in Neurodevelopmental Disabilities) system and other programs, suggests a possible increasing training role for these units. Notably, units in non-academically affiliated hospitals trained far fewer disciplines on average than those with academic affiliation, suggesting that training opportunities may not increase if continued growth in specialized units is without academic affiliation.

Our primary hypothesis, that obtaining adequate post-discharge follow-up services would be the greatest challenge for specialized units, was supported by the survey data. At a local level, our data indicate that creation of a specialized unit is associated with the development of one or more other specialized care components in the host institution's system, with the number of components increasing with the age of the inpatient unit. This may be indicative of the lack of community resources for the population at discharge or result from the aggregation of practitioners with a specialty focus. At a national level, our data highlights the non-systematic development of specialized units, producing an uneven geographic distribution. Additionally, the variability in funding mechanisms, with some units 90% funded by public health insurance and others 90% funded by private commercial health insurance, suggests differences in each payer's medical necessity definitions and approach to care.

Our study identified a number of unique characteristics of specialized units. The units reported, on average, a significantly longer length of stay and higher staff to

patient ratio than general units. Average length of stay was 42.3 days, compared to a 2008 national average of 12.6 days for children's inpatient psychiatric units and 10.0 days for adolescent units (National Association of Psychiatric Health Systems 2009). The longer length of stay for the specialized inpatient psychiatric unit population may be explained by a different course of illness, greater severity of illness, a longer time horizon for efficacy with a bio-behavioral approach, and/or higher barriers to discharge due to the lack of appropriate follow up services identified in this study. Higher staff to patient ratios may be necessitated by the population's decreased ability for self care, higher intensity of externalized behavior and communication challenges. Higher staff to patient ratios could also reflect institutional or staff discomfort or inexperience with this specialized population.

The clinical treatment team included more disciplines than are typically employed in general units, indicating the multi-disciplinary nature of developmentally focused work. The finding that all units, despite likely regional and institutional culture variations, reported employment of both a child psychiatrist and a psychologist or BCBA and the use of both psychopharmacologic and behavior modification treatments, provides strong evidence of the preference for a bio-behavioral approach to this population.

Limitations and Opportunities for Future Research

Limitations for this study include the possibility that additional specialized inpatient psychiatry units serving this population were not identified by our search methods, which could exclude important regional or national data, and that the study utilized a survey measure to collect estimated data, rather than performing direct prospective measurement. The study is also limited by the inclusion criteria of self-defined specialized units, as it is possible that these units may actually substantially vary in the acuity of the population served or other unmeasured characteristics, which could skew study results.

As the basic characteristics and trends of these specialized units are now known, future inquiries can focus on the sub-populations served. Lengths of stay and types of treatment provided may prove to differ significantly across demographic categories such as gender, age bracket,

severity of ID or sub-type of ASD. Furthermore, descriptive information regarding the qualifications and training of professionals employed by specialized inpatient units would be a useful contribution to the field.

To better inform public health decision making, it would be of value to compare clinical outcomes and utilization costs of treating children with developmental disorders in specialized versus general inpatient psychiatry units. The large number of children with an ASD admitted for a relatively long stay to these controlled environments also offers an opportunity for research on co-morbid psychopathology and pilot treatment trials, particularly for conditions that are difficult to study or treat in the community, such as self injurious behavior.

Conclusions

The growing population of children with developmental disorders, in particular ASD, presents a tremendous challenge to our current mental health care system, including inpatient hospitalization. There are an increasing number of specialized inpatient psychiatry units in the United States seeking to meet this need, though they are geographically concentrated in the Northeast and utilize highly variable funding mechanisms. These units serve a high-needs population that is primarily admitted due to externalizing behaviors, and appear to require a higher staffing ratio, longer length of stay, and more multi-disciplinary treatment than populations in general inpatient psychiatry units. The greatest challenges reported by these units were obtaining adequate follow up services and securing funding for inpatient care. There is no information yet available to evaluate the efficacy of these programs, though it is urgently needed to determine if, as the authors hypothesize, special kids do indeed need special treatment.

Acknowledgments This study was funded in part by the Pond Family Foundation and a grant from the Maine Medical Center Research Institute. The authors thank Wendy St. Pierre, Ph.D. for contributions to this study. The authors report no financial conflicts of interest.

Appendix 1

Table 1 Demographic characteristics of specialized inpatient psychiatry units in the United States

| Total # units in the U.S. | Total # beds in the U.S. | Average unit size | Average length of stay | Average patient age | Age range served |
|---------------------------|--------------------------|-------------------|------------------------|---------------------|------------------|
| 9 | 137 | 15.2 beds | 42.3 days | 12.72 years old | 4–21 years old |

Table 2 Percentage of specialized inpatient units employing specialist

| Child psychiatrist | Psychologist or board certified behavior analyst | Social worker | Special educator | Speech language pathologist or occupational therapist | Physician's assistant or nurse practitioner | Multi-disciplinary team or 4 or more clinicians |
|--------------------|--|---------------|------------------|---|---|---|
| 100% | 100% | 100% | 77% | 33% | 22% | 88% |

Table 3 Percentage of specialized inpatient psychiatry units utilizing treatment modality

| Pharmacotherapy | Behavioral modification | Family therapy | Other (e.g. speech and language) |
|-----------------|-------------------------|----------------|----------------------------------|
| 100% | 100% | 67% | 44% |

Table 4 Percentage of specialized inpatient psychiatry units serving as training site for clinical specialty

| At least one clinical specialty | Nursing students | Medical residents, fellows, students | Psychology interns and BCBAs | Occupational therapists in training | Speech therapists in training |
|---------------------------------|------------------|--------------------------------------|------------------------------|-------------------------------------|-------------------------------|
| 100% | 77% | 66% | 66% | 33% | 22% |

Table 5 Percentage funding of specialized inpatient psychiatry units

| Public insurance | Commercial insurance | Self-pay |
|------------------|----------------------|----------|
| 58.9% | 38.9% | 7.8% |

References

Barrett, R. P., Walters, A. S., Mercurio, A. F., Klitzke, M., & Feinstein, C. (1992). Mental Retardation and Psychiatric Disorders. In V. B. VanHasselt & D. J. Kolko (Eds.), *Inpatient behavior therapy for children and adolescents* (113–149). New York: Plenum Press.

Bouras, N., & Holt, G. (2001). Community mental health services for adults with learning disabilities. In G. Thornicroft & G. Szmukler (Eds.), *Textbook of community psychiatry* (397–407). London: Oxford University Press.

Croen, L. A., Najjar, D. V., & Ray, G. T. (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), 1203–1211.

Dekker, M. C., & Koot, H. M. (2003). *DSM-IV Disorders in children with borderline to moderate intellectual disability I: prevalence*

and impact. *Journal of the American Academy of Child and Adolescent Psychiatry*, *42*(8), 915–922.

Kwok, H. W. M. (2001). Development of a specialized psychiatric service for people with learning disabilities and mental health problems: report of a project from Kwai Chung Hospital, Hong Kong. *British Journal of Learning Disabilities*, *29*, 22–25.

Lennox, N., & Chaplin, R. (1995). The psychiatric care of people with intellectual disabilities: perceptions of trainee psychiatrists and psychiatric medical officers. *Australian and New Zealand Journal of Psychiatry*, *29*, 632–637.

Liptak, G. S., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders*, *36*, 871–879.

National Association of Psychiatric Health Systems. (2009). *Annual Survey*. Washington, DC.

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 Academy of Child and Adolescent Psychiatry*, *47*(8), 921–929.

Smith, P., & Berney, T. P. (2006). Psychiatric inpatient units for children and adolescents with intellectual disability. *Journal of Intellectual Disability Research*, *8*(50), 608–614.