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Publisher: Routledge

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## Journal of Mental Health Research in Intellectual Disabilities

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/umid20>

### Psychiatric Services for Individuals with Intellectual and Developmental Disabilities: Medication Management

Andrew T. Russell<sup>a b</sup>, Joan Earle Hahn<sup>c</sup> & Katharine Hayward<sup>b</sup>

<sup>a</sup> Division of Child and Adolescent Psychiatry, David Geffen School of Medicine at University of California Los Angeles

<sup>b</sup> Tarjan Center, Department of Psychiatry and Biobehavioral Sciences Semel Institute for Neuroscience & Human Behavior, University of California Los Angeles

<sup>c</sup> Department of Nursing, College of Health and Human Services, University of New Hampshire

Available online: 10 Oct 2011

To cite this article: Andrew T. Russell, Joan Earle Hahn & Katharine Hayward (2011): Psychiatric Services for Individuals with Intellectual and Developmental Disabilities: Medication Management, *Journal of Mental Health Research in Intellectual Disabilities*, 4:4, 265-289

To link to this article: <http://dx.doi.org/10.1080/19315864.2011.603107>

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## **Psychiatric Services for Individuals with Intellectual and Developmental Disabilities: Medication Management**

ANDREW T. RUSSELL

*Division of Child and Adolescent Psychiatry*

*David Geffen School of Medicine at University of California Los Angeles*

*Tarjan Center, Department of Psychiatry and Biobehavioral Sciences*

*Semel Institute for Neuroscience & Human Behavior, University of California Los Angeles*

JOAN EARLE HAHN

*Department of Nursing, College of Health and Human Services*

*University of New Hampshire*

KATHARINE HAYWARD

*Tarjan Center, Department of Psychiatry and Biobehavioral Sciences Semel Institute for*

*Neuroscience & Human Behavior, University of California Los Angeles*

*The purpose of this study was to describe the medication management and treatment provided in a specialty outpatient psychiatry clinic for 198 community-residing children and adults with intellectual disability and other developmental disabilities (IDD) referred to the clinic and discharged between 1999 and 2008. Using a descriptive design, data from a retrospective chart audit were examined to explain medication management from referral to discharge. The audit tool collected data on demographic variables, reasons for referral, admission date, clinic appointments, discharge date, diagnoses, and medications. Data on diagnoses and medications were grouped according to categories of the 2000 American Psychiatric Association's DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, 4th*

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Address correspondence to Andrew T. Russell, University of California Los Angeles, Semel Institute for Neuroscience & Human Behavior, Department of Psychiatry and Biobehavioral Sciences, 760 Westwood Plaza, Room 48-240 B, Los Angeles, CA 90095–1759. E-mail: ARussell@mednet.ucla.edu

*Edition, Text Revision diagnoses and medication classes, respectively. Data were analyzed using descriptive statistics, paired sample t tests, and Wilcoxon signed-rank tests. Interrater reliability was examined with Kappa values and correlation statistics. The study found that psychiatric care in the clinic led to a simplification of medication regimens. For individuals taking prescribed psychiatric medications at referral, psychiatric medication polypharmacy and same-class psychiatric medication polypharmacy were reduced by discharge. Modifications in the profile of medications prescribed generally reflected expert consensus guidelines. The overall findings suggest that this model of provision of specialized psychiatric outpatient services for individuals with IDD may be one approach to improve the quality of mental health care for this underserved population.*

**KEYWORDS** *developmental disabilities, intellectual disabilities, mental health, medication management, psychiatric diagnoses*

Persons with intellectual disability and other developmental disabilities (IDD) are at 3 to 5 times greater risk for psychiatric and behavioral disorders than the general population (Harris, 2006). This increased vulnerability to mental health problems has been found in children (Einfeld et al., 2006; Emerson & Hatton, 2007), adolescents (Einfeld et al., 2006), and adult populations (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). Despite the recognized vulnerability of persons with IDD to psychiatric and behavioral disorders, access to and quality of health and mental health care for these individuals are inadequate at the national (Krahn, Hammond, & Turner, 2006; Krauss, Gulley, Sciegaj, & Wells, 2003; U.S. Department of Health and Human Services, 2002) and local levels where this study took place (Lewis, Lewis, Leake, King, & Lindemann, 2002). Despite the need, few community-based intervention models have been developed and disseminated to serve individuals with IDD and mental health needs (Balogh, Ouellette-Kuntz, Bourne, Lunskey, & Colantonio, 2008; Hackerman, Schmidt, Dyson, Hovermale, & Gallucci, 2006; McCabe, McGillivray, & Newton, 2006; Singh et al., 2002). We located only two reports describing specialty outpatient psychiatric clinic programs in the United States published in the last 10 years (Hackerman et al., 2006; P. Holden & Neff, 2000). As new models of service delivery are being developed to provide psychiatric services for persons with IDD, a clear need exists for evidence to support different models of psychiatric care (Chaplin, 2004). This article reports on a community-university partnership model aimed to improve the psychiatric care of children and adults with IDD.

## PSYCHIATRIC MEDICATIONS

A key issue in examining the quality of mental health care for persons with IDD is the appropriateness and effectiveness of the use of psychiatric (psychotropic) medications. Although the use of psychiatric medications in the population with IDD is widespread across ages and settings—institutional, community, and home (B. Holden & Gitlesen, 2004; Matson & Neal, 2009; Olfson, Crystal, Huang, & Gerhard, 2010; Spreat, Conroy, & Fullerton, 2004)—relatively limited efficacy data is available (Deb, Sohanpal, Soni, Lenotre, & Unwin, 2007; Sohanpal, Deb, Thomas, Soni, Lenotre, & Unwin, 2007; Ulzen & Powers, 2008). Concerns about the quality of medication practices in persons with IDD have been raised, including prescription without a corresponding psychiatric diagnosis or assessment (B. Holden & Gitlesen, 2004; Lewis et al., 2002), polypharmacy (B. Holden & Gitlesen, 2004), the overuse of antipsychotic medication for aggressive and disruptive behavior (Matson & Wilkins, 2008), and the lack of sufficient monitoring of side effects and drug-drug interactions (Correll, 2008b; Handen & Gilchrist, 2006).

These issues drove the development of expert consensus guidelines for the use of psychiatric medications in persons with IDD (Aman, Crismon, Frances, King, & Rojahn, 2004; Rush & Frances, 2000; Szymanski & King, 1999; Unwin & Deb, 2008). The guidelines share numerous recommendations, including, but not limited to

1. The careful assessment of symptoms and behavior leading to, if possible, a formal psychiatric diagnosis using established criteria (e.g., *DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition, Text Revision [American Psychiatric Association, 2000]);
2. The use of evidence-based practices for medication management for that diagnosis once a psychiatric diagnosis is established;
3. Keeping medication regimens as simple as possible in situations where medication is indicated;
4. Avoiding polypharmacy; and
5. Preferential use of newer antipsychotic and antidepressant medications.

DESCRIPTION OF THE SPECIALTY OUTPATIENT  
PSYCHIATRY CLINIC

In California, supports and services for people with IDD are organized through a system of local regional centers. After a health needs study identified the need to improve access to quality psychiatric services (Lewis et al., 2002), one regional center established a contractual partnership with a division of child and adolescent psychiatry and a University Center

for Excellence in Developmental Disabilities located in a large academic medical center. The contract provided for the establishment of an outpatient specialty psychiatric clinic to serve clients referred by the regional center who had complex mental/emotional needs or behavioral issues that were not being addressed appropriately in the community. All clients of the regional center were eligible for referral. By California statutory definition this includes individuals with a developmental disability occurring before the age of 18 in one or more of five categories: "mental retardation, cerebral palsy, epilepsy, and autism." This also includes "disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation" (California Welfare and Institutions Code, section 4512(a), 2011).

The regional center was the source of all referrals to the clinic. Typically, frontline service coordinators (case managers) collected information about a patient that was forwarded to a senior psychiatric nurse at the regional center, who further screened the information and determined whether the patient was appropriate for the clinic. The regional center referred patients who were demonstrating a pattern of escalating behavior, patients in crisis, patients whose medication appeared ineffective (after 3 months), or patients to whom multiple psychiatric medications were prescribed. Patients were also referred for a second opinion or when no suitable psychiatric services were available in the community.

Child and adolescent psychiatric faculty with experience and expertise concerning both children and adults with IDD, as well as psychopharmacology, staffed the clinic. Over the time period of the study, five child psychiatrists served as attending psychiatrists in the clinic. The tenure of the attending psychiatrists varied, typically lasting at least 1 year. The junior faculty who joined the clinic were previously trained and supervised by the more senior faculty and thus shared a common point of view concerning the treatment of individuals with intellectual disabilities. A regional center registered nurse with psychiatric training and experience coordinated the clinic and served as a liaison between the regional center and the team of clinic psychiatrists. The clinic psychiatrists and nurse-liaison coordinated patient care with other health professionals (e.g., behavior therapists, neurologists, primary care physicians) while patients were in clinic. The clinic aimed to provide comprehensive psychiatric assessment, diagnosis, and short-term treatment to both children and adults with referral back to community resources for ongoing care.

## STUDY PURPOSE

The purpose of this article is to examine the impact of clinic assessment and treatment on the use of psychiatric medication regimens between initial

referral and discharge. Reflecting the consensus guidelines cited earlier, we address the following research questions:

1. Did specialized psychiatric assessment and management lead to simplification of medication regimens from initial referral to discharge as manifested by
  - a. Reduction in total number of psychiatric medications prescribed;
  - b. Reduction in total psychiatric medication polypharmacy (two or more psychiatric medications); or
  - c. Reduction in same-class psychiatric polypharmacy (two or medications of the same class)?
2. Did care in the clinic lead to changes in medication use by medication class from referral to discharge?
3. Did changes in psychiatric medication use by medication class reflect the current consensus guidelines for the use of such medications in people with IDD? Specifically,
  - a. Was the use of first-generation antipsychotic medications reduced and second-generation antipsychotic medications prescribed more frequently;
  - b. Were Selective Serotonin Reuptake Inhibitor (SSRI) medications more frequently utilized compared with tricyclic antidepressants; and
  - c. Was the long-term use of benzodiazepines reduced?

## METHOD

### Procedure

This study employed a retrospective descriptive design using a chart audit tool to examine medical records of children and adults with IDD who attended a specialty psychiatric clinic. We received approval from respective university institutional review boards prior to conducting chart abstractions and analyses.

Two trained research assistants collected the data. Both research assistants had experience conducting research and working with persons with IDD. The medical records were generally of good quality. If a point of information was illegible to one abstractor, it was reviewed with an investigator. If both found it to be illegible, it was classified as missing data. Charts with significant limitations (e.g., a missing discharge summary) were excluded from the analysis. We conducted interrater reliability analysis using the Pearson correlation and the Kappa statistic to determine consistency among abstractors for demographic variables and medications by medication class. We determined 100% agreement between abstractors on all demographic variables (i.e., age, gender, adult status, ethnicity, residence, diagnosis of

intellectual disability [ID]). Kappa values for identification of medication (by class) were in the substantial (0.60 to 0.79) to almost perfect range (0.80 to 1.00) of agreement (Landis & Koch, 1977) with one exception. This Kappa statistic (0.44) for second-generation antipsychotic medications at time of referral showed moderate agreement (Landis & Koch, 1977). Despite the moderate Kappa rating, the raters achieved 87% agreement on this item. The low occurrence of this variable at time of referral in the reliability sample affected the Kappa statistic.

## Measures

The authors created a chart abstraction tool to collect nonidentifiable demographic data, reasons for referral, admission date, clinic appointments, discharge date, and diagnoses and medications at three points in time (i.e., at referral, at initial evaluation, and at discharge). This article focuses on two time periods, initial referral and discharge, to assess changes in medication management over time.

## Sample

Medical records were identified from a master list of patients who had been referred to the clinic by the regional center. Inclusion criteria were all patients referred to and enrolled in the clinic with an identified need for specialized psychiatric services from 1999 through January 2008 who had standard medical center records with documentation of evaluation and treatment while in the clinic. Exclusion criteria were absence or unavailability of the medical record and treatment that began prior to 1999.

Two hundred fifty-five individuals were admitted to the clinic between March 1999, when the clinic opened, and January 2008, when the study began. When the study was initiated, 198 had been discharged and 57 individuals remained in active treatment. The primary focus of this article is on the 198 patients who had been admitted to the outpatient specialty psychiatric clinic and who had been subsequently discharged. Of the 198 who had been discharged, 32 patients were admitted a second time and 4 admitted a third time to the clinic. Only data between the first admission and discharge were included in the analysis.

As can be seen from Table 1, the majority of patients were male (68.7%). Patients ranged in age from 2 to 66 years old ( $M = 20$ , median = 17), with slightly more adults (51.8%). The sample was ethnically diverse with patients most frequently Caucasian (44.7%) or Hispanic (31.5%). Over half of the patients (60.2%) entered the clinic with documentation of some level of ID ranging from mild to profound. Patients were classified as having mild ID (26.8%), moderate ID (15.7%), severe ID (11.6%), and profound ID (6.1%). The majority (66.7%) lived at home.

**TABLE 1** Demographic and Clinical Characteristics of Sample ( $n = 198$ )

Demographic and clinical characteristics	Total ( $n = 198$ ) $n$ (%)	Child ( $n = 102$ ) <sup>a</sup> $n$ (%)	Adult ( $n = 95$ ) <sup>a</sup> $n$ (%)
Sex			
Male	136 (69.7)	76 (74.5)	60 (63.2)
Female	62 (31.3)	26 (25.5) <sup>a</sup>	35 (36.8) <sup>a</sup>
Ethnicity			
Caucasian	88 (44.7)	33 (32.4)	55 (57.9)
Hispanic	62 (31.5)	42 (41.2)	20 (21.2)
Asian/Pacific Islander	23 (11.7)	13 (12.7)	10 (10.5)
African American	13 (6.6)	8 (7.8)	5 (5.3)
Other	11 (5.6)	6 (5.9)	5 (5.3)
Cognitive functioning			
Average	3 (1.5)	2 (2.0)	1 (1.1)
Borderline	21 (10.6)	10 (9.8)	11 (11.6)
Mild ID	53 (26.8)	30 (29.4)	23 (24.2)
Moderate ID	31 (15.7)	9 (8.8)	22 (23.2)
Severe ID	23 (11.6)	4 (3.9)	19 (20.0)
Profound ID	12 (6.1)	0 (0.0)	12 (12.6)
ID unspecified	10 (5.1)	5 (4.9) <sup>a</sup>	4 (4.2) <sup>a</sup>
No ID documented	41 (20.7)	38 (37.3)	3 (3.2)
Deferred	4 (2.6)	4 (3.9)	0 (0.0)
Residence type			
Living at home	132 (66.7)	94 (92.2) <sup>a</sup>	37 (38.9) <sup>a</sup>
Community care facility	57 (28.8)	7 (6.9)	50 (52.6)
Living independently	7 (3.5)	0 (0.0)	7 (7.4)
Other	2 (1.0)	1 (1.0)	1 (1.1)
DSM-IV-TR Axis I category			
ADHD	25 (12.6)	16 (15.7)	9 (9.5)
Adjustment disorder	3 (1.5)	1 (1.0)	2 (2.1)
Anxiety	13 (6.6)	4 (3.9)	9 (9.5)
Autism spectrum disorder	100 (50.5)	69 (67.6)	31 (32.6)
Cognitive disorder	1 (0.5)	0 (0.0)	1 (1.1)
Conduct disorder	7 (3.5)	1 (1.0)	6 (6.3)
Elimination disorder	1 (0.5)	1 (1.0)	0 (0.0)
Impulse disorder	12 (6.1)	7 (6.9)	5 (5.3)
Learning disorder	21 (10.6)	11 (10.8)	10 (10.5)
Mood disorder	27 (13.6)	4 (3.9)	23 (24.3)
Movement disorder	4 (2.0)	1 (1.0)	3 (3.2)
Psychotic disorder	24 (12.1)	5 (4.9)	19 (20.0)
Sleep disorder	2 (1.0)	2 (2.0)	0 (0.0)
Somatoform disorder	1 (0.5)	0 (0.0)	1 (1.1)
Psychiatric medications			
ADHD medication	3 (1.5)	3 (2.9)	0 (0.0)
Anticonvulsant	9 (4.5)	2 (2.0)	7 (7.4)
Antidepressant	34 (17.7)	7 (6.9)	27 (29.5)
Antipsychotic: first generation	35 (17.7)	5 (4.9)	30 (31.6)
Antipsychotic: second generation	62 (31.3)	16 (15.7)	46 (48.5)
Anxiolytic	32 (16.1)	1 (1.0)	31 (32.7)
Hypnotic	18 (9.1)	6 (5.9)	12 (12.6)
Lithium	8 (4.0)	3 (2.9)	5 (5.3)
Mood stabilizer	52 (26.2)	10 (9.8)	42 (44.2)
Other medications	38 (19.2)	9 (8.9)	29 (30.6)

Note. ID = intellectual disability; ADHD = attention-deficit/hyperactivity disorder; DSM-IV-TR = Diagnostic and statistical manual of mental disorders, 4th ed., text revision.

<sup>a</sup>One case was missing child/adult status.

The most common reasons for referral to the clinic (more than one reason could be selected) were disruptive behavior (68.5%) and aggressive behavior (62.1%). Over half of the patients were referred for medication (58.1%) and/or diagnostic evaluation (53.5%). A third (36.5%) was referred for self-injury, 11.2% for inappropriate sexual behavior, and 10.7% for lack of community resources. The mean number of clinic visits was 5.6 (median = 3). For patients followed in the clinic (i.e., more than two visits), the mean number of clinic visits was seven (median = 5). Individuals with IDD were treated between less than 1 month and 83 months ( $M = 13.7$ , median = 9). Patients were most frequently (42.3%) seen in the clinic for 6 months or less. An additional 15.3% of patients were seen between 7 and 12 months. Nearly a quarter (23%) of patients was seen in the clinic between 13 and 24 months. Another 11.2% of patients were seen at the clinic between 25 and 36 months followed by 8.2% who were seen for more than 36 months.

Table 1 also reports data for children and adults for the sample of 198 patients who were referred and discharged. Children (74.5%) were more frequently male compared with adults (63.2%). Adults were more frequently Caucasian (57.9%) compared with children (32.4%), whereas children were more frequently Hispanic (41.2%) contrasted to adults (21.2%). At time of initial referral, adults came to the clinic with varying levels of cognitive functioning; 24.2% of adults came in with mild ID, 23.2% with moderate ID, 20.0% with severe ID, and 12.6% with profound ID. Over a third of children (37.3%) had no ID documented at time of initial referral, contrasted to only 3.2% of adults. An additional 29.4% of children came to the clinic with mild ID. Children were more frequently referred for disruptive (75.2%) and aggressive (70.6%) behavior compared with adults, 62.1% and 53.7%, respectively. Nearly all (92.2%) children lived at home with family. Half of adults (52.6%) were living in a community care facility at time of referral and 7.4% were living independently.

Children were more frequently diagnosed along the autism spectrum compared with adults at the time of initial referral, 67.6% and 32.6%, respectively. Adults appeared to have a higher occurrence of mood (24.3%) and psychotic (20.0%) disorders compared with children. At time of referral, adults were more frequently prescribed psychiatric medication compared with children (i.e., antipsychotics: second generation, mood stabilizers, anxiolytics, antipsychotics: first generation, and antidepressants).

Patients who remained in the clinic ( $n = 57$ ) were similar to those discharged ( $n = 198$ ) in the following areas: they tended to be male (68.4%); were primarily Caucasian (42.1%) or Hispanic (26.3%); and most frequently were referred for disruptive behavior (77.2%), medication evaluation (66.7%), and aggressive behavior (64.9%). They significantly differed from the discharged sample in that they were more likely to be adults (68.4%;  $\chi^2(1, n = 254) = 7.24, p = .007$ ). Patients in active treatment at the clinic had higher levels of profound ID (12.3%) and more frequently resided in

a community care facility (43.9%). At the time of the medical chart review, patients had already been in treatment between 2 and 110 months ( $M = 52.2$ , median = 55), much longer than those who had been discharged.

The most common diagnoses among those still in treatment were similar to those who were discharged: autism (49.1%), mood disorder (15.8%), psychotic disorder (14.0%), and learning disorder (10.6%). The frequency of psychiatric medications prescribed at initial referral demonstrated a pattern similar to those who were discharged but occurred at higher percentages: antipsychotic second-generation medications (40.4%), mood stabilizers (35.1%), antidepressants (28.1%), and other psychiatric medications (28.1%). The total number of psychiatric medications prescribed at initial referral ranged from zero to eight ( $M = 2.25$ ,  $SD = 1.94$ ). At time of referral, a quarter (24.6%) of the patients was not prescribed any psychiatric medications, 17.5% were prescribed one psychiatric medication, and 57.9% were prescribed two or more psychiatric medications. As the main time points reported in this study were time of referral and time of discharge, these 57 patients were not included in subsequent analyses.

## Data Analysis

The IBM SPSS Statistics 18 (SPSS, Inc., 2010) software program was utilized to conduct data analysis. In addition to descriptive analysis, paired sample  $t$  tests and Wilcoxon signed-rank tests were used to test hypotheses related to reduction of psychiatric medication use. Multiple regression was performed to describe potential predictors of the total number of psychiatric medications prescribed at discharge. Interrater reliability was examined with Kappa values and correlation statistics. Grouping specific *DSM-IV-TR* diagnoses and medications into categories (see Appendix) allowed us to simplify analysis and presentation of the results.

## RESULTS

### Diagnoses

Of the 198 patients who had been admitted to the outpatient specialty psychiatric clinic and who had been subsequently discharged, a large majority (84.8%) entered the clinic with a prior psychiatric diagnosis. At discharge, 97% of the sample had a *DSM-IV-TR* Axis I diagnosis. The 3% without a recorded diagnosis at discharge consisted of 6 individuals. All of these individuals had received a psychiatric diagnosis when first evaluated in the clinic but had missing diagnostic data at discharge.

See Table 2 for diagnoses at referral and at discharge. Half (50.5%) of the patients at initial referral had a diagnosis of autism spectrum disorder (ASD). Other common diagnostic categories at referral included mood

**TABLE 2** Number of Individuals With Diagnoses in *DSM-IV-TR* Axis I Categories at Initial Referral and at Discharge ( $n = 198$ )

<i>DSM-IV-TR</i> Axis I category	At referral	At discharge	Status at discharge ( $n = 198$ )	
	( $n = 198$ ) Total $n$	( $n = 198$ ) Total $n$	Gained <sup>a</sup> $n$	Lost <sup>b</sup> $n$
Autism spectrum disorder	100 (50.5)	93 (47.0)	4	11
Mood disorder	27 (13.6)	29 (14.6)	15 <sup>d</sup>	13 <sup>d</sup>
Bipolar disorder	4 (2.0) <sup>c</sup>	9 (4.5)	8	3
Other mood disorders	24 (12.1) <sup>c</sup>	21 (10.6)	10	13
Attention-deficity/hyperactivity disorder	25 (12.6)	26 (13.1)	14	13
Psychotic disorder	24 (12.1)	22 (11.1)	11	13
Learning disorder**	21 (10.6)	5 (2.5)	2	18
Anxiety disorder	13 (6.6)	23 (11.6)	17	7
Obsessive compulsive disorder	4 (2.0)	4 (2.0)	3	3
Other anxiety disorders	9 (4.5)	19 (9.6)	14	4
Impulse disorder***	12 (6.1)	50 (25.3)	45	7
Conduct disorder	7 (3.5)	3 (1.5)	3	7
Movement disorder	4 (2.0)	3 (1.5)	1	2
Adjustment disorder	3 (1.5)	0 (0.0)	0	3
Sleep disorder	2 (1.0)	2 (1.0)	1	1
Somatoform disorder	1 (0.5)	1 (0.5)	1	1
Cognitive disorder	1 (0.5)	0 (0.0)	0	1
Elimination disorder	1 (0.5)	3 (1.5)	3	1

<sup>a</sup>Number of individuals who gained status of having a diagnosis in category from referral to discharge.

<sup>b</sup>Number of individuals who lost status of having a diagnosis in this diagnostic category from referral to discharge. <sup>c</sup>One subject had both bipolar disorder and other mood disorder. <sup>d</sup>Three individuals had both a gain and/or loss in the bipolar disorder and/or other mood disorder diagnostic categories, therefore the totals of gains and losses for mood disorders category is smaller than the gains and losses for the subcategories.

\*\* $p < .01$ . \*\*\* $p < .001$ .

disorder (13.6%), attention-deficit/hyperactivity disorder (ADHD) (12.6%), psychotic disorder (12.1%), and learning disorder (10.6%).

*Patients with autism.* Given the large percentage of patients with a diagnosis of ASD, additional analysis was performed to describe factors related to ASD. There was a statistically significant relationship between adult status and a diagnosis of ASD at initial referral, ( $\chi^2(1, n = 197) = 24.13, p = .000$ ), and at discharge, ( $\chi^2(1, n = 197) = 20.49, p = .000$ ). Among patients with a diagnosis in the autism spectrum at time of initial referral ( $n = 100$ ), 69.0% were children. Among those who had a diagnosis of ASD at discharge ( $n = 93$ ), 68.8% were children. Gender was also significantly related to a diagnosis of autism upon initial referral ( $\chi^2(1, n = 197) = 22.03, p = .000$ ) and at discharge ( $\chi^2(1, n = 97) = 18.80, p = .000$ ). At referral, 84% of patients with ASD were male and at discharge, 83.9%. Although not statistically significant, over half (59.1%) of the patients with a diagnosis of ASD at discharge were male children.

*Change in diagnoses by discharge.* ASD remained the most common discharge category, and although slightly less frequent at discharge, did not

show a statistically significant change. In contrast, the number diagnosed with an impulse disorder significantly increased between initial referral and discharge, and learning disorder diagnoses decreased. Paired sample *t* tests support a statistically significant increase in the diagnosis of impulse disorder ( $t(197) = 5.32, p < .001$ ) and indicated a statistically significant decrease in number of learning disorder diagnoses by discharge ( $t(197) = 2.91, p < .01$ ). The number of anxiety disorder diagnoses almost doubled between referral and discharge, but this did not reach statistical significance. Table 2 also shows a large number of individuals had their referral diagnoses altered (either gained or lost) after diagnostic assessment in the clinic.

### Medication Simplification

*Reduction in total psychiatric medications.* One hundred fifteen patients (58.0%) were on at least one psychiatric medication when referred to the clinic. Of those taking psychiatric medications at referral, 42.6% had a decrease in number of psychiatric medications, 40.0% remained unchanged, and 17.4% had an increase in the number of psychiatric medications at discharge. We observed a statistically significant ( $t(114) = 4.26, p < .001$ ) decrease in the total number of psychiatric medications prescribed at initial referral ( $M = 2.96, SD = 1.95$ ) to discharge ( $M = 2.26, SD = 1.62$ ). By discharge, 10 (8.7%) of these patients were no longer taking any psychiatric medications.

As expected, for those referred to the clinic on no psychiatric medications ( $n = 83$ ), there was a statistically significant ( $t(82) = 10.23, p < .001$ ) increase in psychiatric medications prescribed at discharge ( $M = 0.77, SD = 0.69$ ). Forty-eight (57.8%) of these patients were prescribed one medication at discharge, 6 (7.2%) patients were prescribed two psychiatric medications, and 1 (1.2%) patient was prescribed four psychiatric medications. One third ( $n = 28$ ) remained on no psychiatric medications at discharge.

For the total sample ( $n = 198$ ), 19.2% ( $n = 38$ ) were taking no medications at discharge. Of these, nearly three quarters ( $n = 28$ ) were on no medication at time of referral. The remaining 10 patients had been withdrawn from all psychiatric medications while being treated in the clinic; at time of referral these patients had been taking between one and seven psychiatric medications.

*Factors associated with total medications by discharge.* Additional analysis was performed to understand factors affecting the total number of psychiatric medications at discharge. Age at initial referral is positively correlated with total number of psychiatric medications prescribed at discharge ( $r = .38, p = .000$ ). Multiple regression analysis was conducted to examine the relationship between total number of psychiatric medications

**TABLE 3** Unstandardized Regression Coefficients (Standard Errors) and Standardized Regression Coefficients for Model of Total Number of Psychiatric Medicines at Discharge ( $n = 196$ )

Predictor variable	Full model b (SE)	$\beta$
Male	.49 (.22)*	.15
Age at initial referral	.04 (.01)***	.30
Mild ID	.52 (.34)	.15
Moderate ID	.78 (.38)*	.19
Severe/Profound ID	.69 (.38)	.18
Unknown ID	-.09 (.34)	-.03
Constant	.24 (.36)	

Note. ID = intellectual disability. The categories of no ID documented, ID unspecified, and deferred were collapsed into the category of "unknown ID."

$R^2 = .21$ . \* $p < .05$ . \*\*\* $p < .001$ .

prescribed at discharge and potential predictors: sex, age, and level of cognitive functioning. Using the enter method, a significant model emerged ( $F(6, 190) = 8.217, p < .001$ ), describing 20.6% of the variance (18.1% adjusted). Statistical significant variables were sex, age at initial referral, and moderate ID; severe/profound ID approached significance ( $p = .07$ ; see Table 3). Males have 0.49 higher total number of psychiatric medications at discharge compared with females. For every year increase in age at initial referral, the total number of psychiatric medications at discharge increases by .04 medications. Individuals with moderate ID tended to have higher total number of psychiatric medications at discharge by 0.78, compared to those with borderline/average cognitive functioning.

*Reduction in total polypharmacy.* Total polypharmacy is defined as "concurrent use of multiple medications in a single patient" (National Association of State Mental Health Program Directors [NASMHPD], 2001, p. 5) or, for this article, two or more psychiatric medications. At initial referral, 78 (39.4%) patients were prescribed between 2 and 10 psychiatric medications. At discharge, 76 (38.4%) patients were prescribed between 2 and 9 psychiatric medications. Eighteen (9.1%) patients showed polypharmacy at initial referral but not at discharge. Sixteen (8.1%) did not exhibit polypharmacy at initial referral but did at discharge. Sixty (30.3%) exhibited polypharmacy at initial referral and discharge. Among those exhibiting polypharmacy at time of initial referral, paired sample  $t$  tests indicated that the total number of prescribed psychiatric medications was significantly higher at initial referral ( $M = 3.88, SD = 1.71$ ) than at discharge ( $M = 2.74, SD = 1.70$ ),  $t(77) = 5.25, p < .001$ . There was also a statistically significant relationship between adult status and polypharmacy at discharge, ( $\chi^2(1, n = 197) = 32.13, p = .000$ ). Among the 76 who exhibited polypharmacy at discharge, 73.7% were adults compared with 26.3% who were children.

*Reduction in same class polypharmacy.* Same-class polypharmacy occurs when individuals are taking two or more medications within a particular class (NASMHPD, 2001). The total number of patients exhibiting polypharmacy declined in all drug classes by discharge with the exception of anticonvulsants and antidepressants. The number of patients exhibiting same-class polypharmacy in second-generation antipsychotic medications was reduced by half between initial referral ( $n = 14$ ) and discharge ( $n = 7$ ). Selecting for those taking two or more antipsychotic second-generation medications at referral, paired sample  $t$  tests support a statistically significant decrease for only the antipsychotic second-generation same-class polypharmacy from initial referral ( $M = 2.07$ ,  $SD = 0.27$ ) to discharge ( $M = 1.21$ ,  $SD = 0.70$ ),  $t(13) = 4.16$ ,  $p = .001$ . Table 4 also shows the number of individuals who either gained or lost same-class polypharmacy status after being treated in the clinic.

### Changes in Psychiatric Medication Use by Medication Class

In further analysis, we examined changes in the use of psychiatric medications by class between initial referral and discharge (see Table 5). Patients were most commonly on antipsychotic: second generation (31.3%) and mood stabilizers (26.2%) at initial referral. Upon discharge, patients remained most frequently on antipsychotics: second generation (55.5%) and antidepressants (25.7%). Paired sample  $t$  tests indicated statistically significant differences in all categories except hypnotics and anticonvulsants from initial referral to discharge. Statistically significant increases in psychiatric medications were observed for antidepressants ( $t(197) = 2.39$ ,  $p < 0.05$ ), antipsychotic second-generation ( $t(197) = 4.36$ ,  $p < .001$ ), and ADHD medications ( $t(197) = 3.40$ ,  $p = .001$ ). In contrast, statistically significant decreases

**TABLE 4** Individuals Treated With Same-Class Polypharmacy at Time of Initial Referral Compared With Time of Discharge by Medication Class ( $n = 198$ )

Medication category	At referral	At discharge	Status at discharge	
	Total $n$	Total $n$	Gained <sup>a</sup> $n$	Lost <sup>b</sup> $n$
Antipsychotic: second generation*	14	7	2	9
Mood stabilizer	9	8	3	4
Antidepressants	5	5	3	3
Antipsychotic: first generation	4	1	0	3
Anxiolytic	3	2	1	2
Hypnotic	2	1	1	2
Lithium	1	0	0	1
Anticonvulsant	1	1	0	0

<sup>a</sup>Number of individuals who gained the status of same class polypharmacy. <sup>b</sup>Number of individuals who lost the status of same class polypharmacy.

\* $p < .001$ .

**TABLE 5** Number of Individuals in Psychiatric Medication Categories at Time of Initial Referral and at Discharge ( $n = 198$ )

Medication category	At referral	At discharge	Status at discharge	
	Total $n$ (%)	Total $n$ (%)	Gained <sup>a</sup> $n$	Lost <sup>b</sup> $n$
Antipsychotic: second generation <sup>***</sup>	62 (31.3)	110 (55.5)	61	13
Antidepressant*	35 (17.7)	51 (25.7)	26	10
Selective Serotonin Reuptake Inhibitor <sup>c**</sup>	23 (11.6)	40 (20.2)	23	6
Tricyclic Antidepressant <sup>c</sup>	5 (2.5)	3 (1.5)	1	3
Attention-deficity/hyperactivity disorder medication <sup>**</sup>	3 (1.5)	14 (7.1)	11	0
Antipsychotic: first generation <sup>***</sup>	35 (17.7)	18 (9.1)	3	20
Anxiolytic <sup>***</sup>	32 (16.1)	17 (8.6)	1	16
Mood stabilizer*	52 (26.2)	40 (20.2)	4	16
Hypnotic	18 (9.1)	10 (5.0)	6	14
Lithium*	8 (4.0)	2 (1.0)	0	6
Anticonvulsant	9 (4.5)	7 (3.5)	1	3
Other psychiatric medications*	38 (19.2)	27 (13.6)	8	19
Benzodiazepines <sup>d*</sup>	23 (11.6)	12 (6.1)	1	12

<sup>a</sup>Number of individuals who gained medication from referral to discharge to be in medication category.

<sup>b</sup>Number of individuals who lost medication and fell out of medication category from referral to discharge. <sup>c</sup>Subcategory of antidepressants (SSRI or TCA). <sup>d</sup>Benzodiazepines also appear in either anxiolytic or hypnotic classes.

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

in psychiatric medications were noted for antipsychotics: first generation ( $t(197) = 3.91$ ,  $p < .001$ ), anxiolytic ( $t(197) = 3.69$ ,  $p < .001$ ), lithium ( $t(197) = 2.36$ ,  $p < .05$ ), mood stabilizers ( $t(197) = 2.44$ ,  $p < .05$ ), and “other” psychiatric medications ( $t(197) = 2.22$ ,  $p < .005$ ). Table 5 also shows the number of individuals who were newly prescribed or had medications discontinued in the psychiatric medication categories from the time of referral to discharge.

### Changes in Medication Use and Consensus Guidelines

Reflecting consensus guidelines, we explored whether or not newer or second-generation antipsychotic medications were prescribed more commonly than first-generation, whether antidepressant medications (SSRIs) were prescribed more often than tricyclic antidepressants, and if benzodiazepines were prescribed less frequently.

The second-generation antipsychotic medications were the most frequently prescribed medication class at both referral and discharge. Whereas the number of persons on second-generation antipsychotic medication at discharge increased, the number on first-generation antipsychotic medications decreased by discharge. Comparing two antidepressant medication classes, SSRIs were more commonly prescribed than tricyclic antidepressants

( $Z = -7.018$ ,  $p = .000$ ). Few patients in the sample were prescribed tricyclic antidepressants at referral ( $n = 5$ ), and only 2 patients remained on tricyclic antidepressants at discharge. This change was nonsignificant. In contrast, the frequency of prescribed SSRIs increased from 12% at referral to 20% at discharge ( $t(197) = -3.231$ ,  $p = .001$ ). The use of benzodiazepines significantly decreased from initial referral (11.6%) to discharge (5.5%), ( $t(197) = 2.058$ ,  $p = .041$ ).

## DISCUSSION

This descriptive, retrospective study is one of only a few studies to describe the demographic characteristics and medication management of both children and adults referred to and treated at an outpatient specialty psychiatric clinic for individuals with IDD. A community agency partnered with an academic medical center to improve access to specialty psychiatric services for individuals whose behavioral and psychiatric needs were not being adequately addressed by existing resources. Our overall findings suggest that this clinic model may be one approach to optimizing medication management and, by implication, improving the quality of mental health care for individuals with IDD.

The demographic characteristics of our sample of children and adults extend the known data on individuals with IDD seen in specialty psychiatric clinics (Hackerman et al., 2006; P. Holden & Neff, 2000). The majority of the patients with IDD in our study were male, which is consistent with although somewhat higher than other community-based and population-based studies examining individuals with IDD and mental health problems (Cooper et al., 2009; Hackerman et al., 2006; B. Holden & Gitlesen, 2004; Spreat et al., 2004). An important diagnostic finding was the high proportion of the patients in our study with an ASD diagnosis. This prevalence of ASD was higher than had been reported in other specialty clinic samples (Hackerman et al., 2006; P. Holden & Neff, 2000) and in California statewide data (DDS Information Services Division, 2008). We speculate that the higher number of males in our overall sample is due to the high proportion of adults and children with ASD and the higher proportion of males within that diagnostic subgroup than previously reported in similar studies of adults (Melville et al., 2008). Although our data cannot demonstrate trends, these figures may reflect the increased prevalence of autism (Rice, 2009) and reported corresponding increase in caseloads of agencies responsible for persons with IDD (Schechter & Grether, 2008).

Although not the focus of our study, findings concerning the 57 patients who were still in active treatment and were not discharged from the clinic may have some implications for our clinic model. Although the goal of the specialized clinic was to assess, briefly treat, and discharge our patients,

these patients had significantly longer lengths of stay (mean over 4 years) and were more likely to be adults and have greater levels of ID. Subsequent analyses also showed they had higher rates of polypharmacy at time of referral (57.9% compared with 39.4%). This suggests that these individuals may represent a subset of more complex patients who require continued specialized treatment and cannot be easily managed with existing community resources.

Results suggest that referral to a specialized psychiatry clinic designed to serve individuals with IDD and psychiatric conditions could lead to simplification and modification of psychiatric medication regimens in alignment with current consensus guidelines. We documented that the number of psychiatric medications significantly declined by time of discharge for those patients who were taking one or more psychiatric medications at time of referral to the clinic. We found reductions in psychiatric medication polypharmacy and same-class polypharmacy. These findings support evidence that expert psychiatric review can contribute to reduction in polypharmacy and overall medication use (Radouco-Thomas et al., 2004). The effectiveness of the clinic in simplifying and modifying medication regimens may in part be attributed to access to psychiatrists with specialty training and expertise in both mental health issues and intellectual and developmental disabilities (B. Holden & Gitlesen, 2004). In the future, improved access to specialized mental health care for people with IDD may require improved physician training in IDD in medical school and residency programs (Ruedrich, Dunn, Schwartz, & Nordgren, 2007) as well as more cross-domain training among health professionals in the psychiatric and developmental disability fields.

Classes of psychiatric medications prescribed for individuals treated in the clinic changed over time. In concert with consensus guidelines, SSRIs were prescribed more frequently than tricyclic antidepressants and SSRI use significantly increased between referral and discharge. This preference for newer medications was also shown with antipsychotic medication. The use of first-generation antipsychotics significantly declined and the increased use of second-generation antipsychotics by discharge was the largest for any medication category.

The frequent prescription of second-generation antipsychotics (55.5% of the clinic sample at discharge) raises several questions that are discussed here.

As only 11% of our patients received a diagnosis of psychosis, it is clear that psychiatric clinicians are using antipsychotic medications for other purposes, including aggressive or self-injurious behavior. Although second-generation medication is often preferred when used for this purpose (Aman et al., 2004), this practice is subject to considerable debate, particularly when

neuroleptics are used to treat disruptive behavior without a corresponding psychiatric diagnosis.

The debate on second-generation antipsychotic use stems from several concerns. First is the sequence of intervention. Should medication be used as part of the initial treatment plan or primarily after behavioral interventions coupled with psychosocial supports have been maximized? Are these medications overused because of the lack of availability of behavioral services in the community? Second, the evidence for the efficacy of these medications in treating disruptive, aggressive, and self-injurious behavior in both children and adults is incomplete and mixed (Deb et al., 2007; Sohanpal et al., 2007; Ulzen & Powers, 2008). Third, there is an increased awareness that second-generation antipsychotic medications are associated with a number of significant short- and long-term side effects, including weight gain, metabolic syndrome, endocrine effects, cardiac effects, and sedation (Correll, 2008b).

The frequent use of second-generation antipsychotic medication and awareness of their side effects has led to a reassessment of the risk-benefit ratio for these medications. Adding to the recent literature have been two “negative” randomized, placebo-controlled trials. The first involved a comparison of typical and atypical antipsychotic medications in the treatment of adults with ID and disruptive behavior (Tyrer et al., 2008). Although this study has helped sharpen the debate on the use of these medications, particularly in adults, its methodology has been questioned (Scahill, Aman, McCracken, McDougle, & Vitiello, 2008; Tierney & Arnold, 2008). The second study examined the use of an SSRI in children with ASD and severe repetitive behaviors (King et al., 2009). The aforementioned concerns and recent controlled trials only emphasize the need for a careful and conservative approach to the use of psychiatric medications in individuals with ID presenting with disruptive behaviors. The authors concur with the most recent consensus guidelines that absent a specific psychiatric diagnosis, in most situations behavioral and supportive interventions should be the first line of treatment, followed by or integrated with medication if initial treatment is unsuccessful. Possible exceptions to this general guideline are presented in Aman et al. (2004). Additional prospective clinical trials, comparing behavioral and medication management, will be needed to answer many of these questions.

Some of the findings differed from reports in the literature. Although same-class polypharmacy is noted as a common finding for persons with IDD (B. Holden & Gitlesen, 2004), in our sample this was relatively low at referral and by discharge most patients were on no more than one medication per psychiatric drug class. Although clinicians recognize that the avoidance of same-class polypharmacy is generally the recommended

approach, certain clinical situations with specific patients may lead to a decision to initiate or maintain a second medication of the same class. Possible rationales for this practice when using antipsychotics (for patients with schizophrenia) have been outlined by Correll (2008a).

The literature raises concerns that individuals with IDD may be prescribed psychiatric medications without an appropriate psychiatric diagnosis (B. Holden & Gitlesen, 2004; Lewis et al., 2002). In contrast, we found that most of the patients in this sample had a previous psychiatric diagnosis at referral, and by discharge, all had received a *DSM-IV-TR* diagnosis. This finding suggests that despite the limitations of the current *DSM-IV* diagnostic criteria for individuals with IDD (Fletcher et al., 2009), with careful assessment, an appropriate diagnosis can be made. This also supports the consensus recommendations to establish a *DSM-IV-TR* diagnosis whenever possible to guide the establishment of the treatment plan. Although only two diagnostic categories for the total sample showed a significant change between referral and discharge, examination of the diagnoses lost and gained data (Table 2) shows that a large number of patients referred to the clinic had their diagnoses revised after specialized assessment and treatment. This suggests that a specialized psychiatric clinic may a useful model to reassess patients with IDD and modify their treatment accordingly.

Our diagnostic findings also differed somewhat from prior research. Most studies of specialized psychiatric assessment in persons with ID have shown that depressive and anxiety disorders tend to be underdiagnosed in the community, and psychotic disorders may be overdiagnosed (Antonacci & Attiah, 2008; Davis, Saeed, & Antonacci, 2008; Hurley, Folstein, & Lam, 2003). Our results showed such a trend for anxiety disorders but fell just short of statistical significance. Only two diagnostic categories (learning disorder and impulse control disorder) showed a statistically significant change between initial referral and discharge. The significant decrease in learning disorder diagnoses is explained by the fact that using *DSM-IV* criteria, learning disorders are generally not diagnosed in the context of ID. Impulse control diagnoses are frequently used to capture “problem behavior” in individuals with intellectual retardation without another psychiatric disorder that better explains the behavior. The increase in this diagnostic category from referral to discharge suggests that this diagnostic practice was frequently used by the psychiatrists in the clinic. The appropriateness of this practice (if it then leads to medication intervention) is linked to the controversy (described earlier) surrounding the use of antipsychotic medications for aggressive behavior.

### Limitations

One limitation of this study is the lack of a control group. The ability to generalize the results is limited to the sample in this study. Another limitation of this study is its retrospective, medical record-based design. All

studies of this type are limited to some degree by the completeness and legibility of the medical record. Another limitation is the lack of data from specialized tools and measures specific to the IDD population. Our clinicians typically used the psychiatric history and assessment forms that are used in all the outpatient clinics at our hospital. Although these forms are comprehensive, they had not been specially modified for use with individuals with ID. Specialized rating scales geared to the ID population (e.g., the Aberrant Behavior Checklist; Aman, Singh, Stewart, & Field, 1985) were not used in a systematic fashion.

Additional research is needed to address the relative lack of reliable and validated tools as outcome measures for individuals with IDD and psychiatric disorders. These measures are needed to improve the quality of the design and rigor of research on the effectiveness of psychiatric services for persons with IDD (Chaplin, 2004). Outcome measures that have been suggested to measure the broad effectiveness of psychiatric services include client clinical status, quality of life (P. Holden & Neff, 2000), behavioral and psychiatric symptoms, and patient and career satisfaction (Chaplin, 2004). Process measures that examine the quality of assessments, treatment, and monitoring by the specialty team are also indicated (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008).

## CONCLUSION

People with IDD and mental health needs are truly an underserved population who need improved access to quality psychiatric care. Our results suggest that access to specialized psychiatric services can be effective in clarifying psychiatric diagnoses and simplifying medication regimens. A “concerted team effort” can help to reduce unneeded medications (Radouco-Thomas et al., 2004, p. 882). This study’s findings add further support to the recommendations that access to specialized outpatient psychiatric clinic services may be necessary to improve care to underserved persons with IDD and mental health and behavioral disorders.

## ACKNOWLEDGMENTS

This research was supported by Grant O-07-23:03 from the Frank D. Lanterman Regional Center. Support for the final data analysis for the study came from the Tarjan Center at University of California Los Angeles (UCLA) with funding from the Administration on Developmental Disabilities (Grant 90DD0614). We acknowledge the support and assistance of the staff of the Frank D. Lanterman Regional Center, the UCLA psychiatrists and staff of the clinic, and the research assistants who abstracted the medical record data.

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**APPENDIX** Categories of Psychiatric Medications

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**ADHD Medications**

atomoxetine HCL  
dexamethylphenidate  
dextroamphetamine  
dextroamphetamine sustained release  
metadate  
methylphenidate

**Anticonvulsant Medications**

mysoline  
phenobarbitol  
phenytoin

**Antidepressants**

bupropion  
citalopram  
clomipramine  
desipramine hydrochloride  
doxepin  
escitalopram oxalate  
elixir/fluoxetine  
fluoxetine weekly  
fluvoxamine  
imipramine  
mirtazapine  
nefazodone  
nortriptyline hydrochloride  
paroxetine  
sertraline hydrochloride  
trazadone  
venlafaxine hydrochloride

**Antipsychotic: First Generation**

chlorpromazine  
fluphenazine decanoate  
haloperidol  
haloperidol decanoate  
molindone hydrochloride  
thioridazine  
trifluoperazine hydrochloride

**Antipsychotic: Second Generation**

aripiprazole  
olanzapine  
quetiapine  
risperidone  
ziprasidone

**Anxiolytic**

bupirone  
clonazepam  
alprazolam  
diazepam  
lorazepam

**Hypnotic**

ramelteon  
melatonin

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*(Continued)*

**APPENDIX** (Continued)

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temazepam  
zolpedem tartrate  
chloral hydrate  
diphenhydramine  
estazolam  
flurazepam  
hydroxyzine hydrochloride

**Lithium**

lithium  
lithium controlled release

**Mood Stabilizers**

carbamazepine  
gabapentin  
lamotrigine  
levetiracetam  
oxcarbazepine  
tiagabine  
topiramate  
valproic acid

**Other Medications**

atenolol  
benztropine mesylate  
clonidine  
clonidine patch  
guanfacine  
naltrexone  
propranolol hydrochloride  
trihexphenidyl hydrochloride

**Benzodiazepines\***

alprazolam  
clonazepam  
diazepam  
estazolam  
flurazepam  
lorazepam  
temazepam  
zolpedem tartrate

**Selective Serotonin Reuptake Inhibitors\***

citalopram  
escitalopram oxalate  
fluoxetine  
fluoxetine weekly  
fluvoxamine  
paroxetine  
sertraline hydrochloride

**Tricyclic Antidepressants**

clomipramine  
desipramine hydrochloride  
doxepin  
imipramine  
nortriptyline hydrochloride

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\*Medications in this category appear in other medication classes.