

# AAA

## Adolescents & Adults with Autism A Study of Family Caregiving

---

**Report #12:  
Changes in Medication Use over Time in  
Adolescents and Adults with Autism Spectrum Disorders**

---

**- Principal Investigators -**

**Marsha Mailick Seltzer, Ph.D.  
Jan S. Greenberg, Ph.D.  
Waisman Center  
University of Wisconsin – Madison**

**Gael Orsmond, Ph.D.  
Sargent College of Health and Rehabilitation Sciences  
Boston University**

**- January 2009 -**

## **Acknowledgements**

This project is supported by grants from the National Institute on Aging (R01 AG08768) and the National Institute on Child Health and Human Development (P30 HD03352). We gratefully acknowledge the support from the Graduate School and the Waisman Center at the University of Wisconsin-Madison, and Sargent College of Health and Rehabilitation Sciences at Boston University. We also acknowledge Dr. Michael Aman for informing the analysis of the data we present here. We are extremely grateful to the mothers, fathers, adolescents and adults with an autism spectrum disorder, and siblings who have given so generously of their time and shared their lives with us.

Visit our websites: <http://www.waisman.wisc.edu/family>  
<http://people.bu.edu/gorsmond/research.html>

## Table of Contents

	<u>Page</u>
<b><u>Section I: Introduction</u></b>	<b>1</b>
<b><u>Section II: Medications</u></b>	<b>2</b>
<b>Types of Medications</b>	<b>5</b>
<b>Proportion of Sample Members Taking Medications</b>	<b>7</b>
<b>Number of Medications Taken</b>	<b>9</b>
<b>Likelihood of Starting or Stopping Medication</b>	<b>10</b>
<b>Factors Leading to an Increase in Medication Use</b>	<b>11</b>
<b><u>Section III: Summary and Conclusions</u></b>	<b>12</b>

## **Section I: Introduction**

Over the years, participants in our study have provided us with a great deal of information about the clinical diagnoses of their family members with autism spectrum disorders (ASD), and the medications that they take. This information has been very valuable in improving our understanding of medication prevalence among adolescents and adults with ASD, the factors that influence who takes medication, and how much medication is taken. Medications are not prescribed *for* autism, but rather to treat behaviors and symptoms *associated with* autism. Therefore, this report may inform treatment and intervention programs.

This report describes the prevalence of medication use among a cohort of adolescents and adults with ASD from two rounds of data collection in our study; the first round in 1998-2000 and the fourth round in 2004-2005. Data for this report came from families of 286 adolescents and adults with ASD from our study who provided complete medication information at the first and fourth round of data collection. We refer to these rounds of data collection as Time 1 and Time 4. The adolescents and adults with ASD described in this report were between the ages of 10 and 48 at the first round of data collection, with an average age of 21 years.

We are very grateful to the families who have provided us with this detailed medication information. From the ongoing participation of families, we continue to gain unique insights about ASD. We look forward to the opportunity to use this information to enhance future intervention efforts and public education programs for individuals with ASD and their families.

## **Section II: Medications**

During each of our rounds of data collection, details about the prescription medications taken by the adolescents and adults with ASD were collected from the mothers (or other primary caregivers), in addition to the dosage and reason for taking each medication. These medications were then classified into their respective drug categories and subcategories based on standard drug classifications in the Physicians Desk Reference (PDR) Drug Guide for Mental Health Professionals with the aid of a pharmacist at the University of Wisconsin – Madison.

The accurate classification of medications is complex, in part because some medications that are typically given for a physical condition are also given for psychotropic purposes. By “psychotropic,” we mean medications that alter brain function, resulting in temporary changes in perception, mood, consciousness and behavior. For example, anticonvulsant medications can be prescribed to treat the physical condition of seizures or epilepsy, and also to treat the psychotropic condition of certain behavior problems. Similarly, hypotensives can be given to control high blood pressure as well as to treat mood disorders. Also, some medications have multiple uses. For example, some antidepressants treat depression, anxiety, and stereotyped behavior. Therefore, we classified medications to appropriately reflect the reason that the medication was prescribed for each individual, as reported by the family.

For the purposes of this report, we focus on the use of the prescribed medications listed below. We do not analyze the use of over-the-counter medications.

Medications have both generic names and trade names. The generic names are listed below, with their trade names capitalized within parentheses.

### **Psychotropic medications:**

#### ***Antipsychotic:***

aripiprazole (Abilify), chlorpromazine (Thorazine), clozapine (Clozaril), fluphenazine (Prolixin), haloperidol (Haldol), loxapine (Loxitane), mesoridazine (Serentil), molindone (Moban), olanzapine (Zyprexa), perphenazine (Trilafon), quetiapine (Seroquel), risperidone (Risperdal), thioridazine (Mellaril), ziprasidone (Geodon)

***Antidepressant:***

amitriptyline (Elavil, Endep), bupropion (Wellbutrin, Zyban), citalopram (Celexa), clomipramine (Anafranil), escitalopram (Lexapro), fluoxetine (Prozac), fluvoxamine (Luvox), mirtazapine (Remeron), nefazodone (Serzone), paroxetine (Paxil), sertraline (Zoloft), trazodone (Desyrel), venlafaxine (Effexor)

***Anxiolytic*** (typically used for treating symptoms associated with anxiety):

alprazolam (Xanax), buspirone (Buspar), chlordiazepoxide (Librium), clorazepate (Tranxene), diazepam (Valium), lorazepam (Ativan)

***Sedative/Hypnotics*** (typically used as a sleep aid or for calming purposes):

chloral hydrate, phenobarbital, temazepam (Restoril), zaleplon (Sonata), zolpidem (Ambien)

***Antimanic*** (typically used to treat manic or hyperactive symptoms):

lithium carbonate (Eskalith, Lithobid)

***Psychotropic anticonvulsants*** (used for purposes other than for seizures):

carbamazepine (Epital, Tegretol), clonazepam (Klonopin), divalproex sodium (Depakote), gabapentin (Neurontin), lamotrigine (Lamictal), levetiracetam (Keppra), methylphenobarbital (Mebaral), oxcarbazepine (Trileptal), phenytoin (Dilantin), primidone (Mysoline), tiagabine (Gabitril), topiramate (Topamax), valproic acid (Depakene), zonisamide (Zonegran)

***Psychotropic hypotensives*** (used for purposes other than for hypertension):

amlodipine/benazepril (Lotrel), atenolol (Tenormin), clonidine (Catapres), guanfacine (Tenex), hydrochlorothiazide (Hydrodiuril), lisinopril (Prinivil), nadolol (Corgard), pindolol (Visken), propranolol (Inderal), spironolactone (Aldactone), triamterene (Dyrenium), verelan (Isoptin)

***Central Nervous System (CNS) stimulants*** (typically used to treat hyperactivity and impulsivity):

amphetamine/dextroamphetamine (Adderall), atomoxetine (Strattera), dextroamphetamine (Dexedrine, Dextrostat), fenfluramine (Pondimin), methylphenidate (Metadate, Ritalin), modafinil (Provigil), pemoline (Cylert)

**Non-psychotropic medications:**

***Antiepileptic medication:***

carbamazepine (Epital, Tegretol), clonazepam (Klonopin), divalproex sodium (Depakote), gabapentin (Neurontin), lamotrigine (Lamictal), levetiracetam (Keppra), methylphenobarbital (Mebaral), oxcarbazepine (Trileptal), phenytoin (Dilantin), primidone (Mysoline), tiagabine (Gabitril), topiramate (Topamax), valproic acid (Depakene), zonisamide (Zonegran)

***Antiparkinsons:***

benztropine (Cogentin), procyclidine (Kemadrin), trihexyphenidyl (Artane)

***All other non-psychotropic medications:***

Including antilipemics, antibiotics, anti-emetics, and medications for hypertension, thyroid, diabetes, respiration, hormones, ocular, gastrointestinal, and other miscellaneous purposes.

Throughout this report, we will refer to the categories of “psychotropic” and “non-psychotropic” medications. We defined psychotropic medications on page 2. Non-psychotropic medications refer to all other prescription medications. Sometimes we will refer to “any medication,” which refers to both psychotropic and non-psychotropic medication. And occasionally we will refer to the sub-categories of medications.

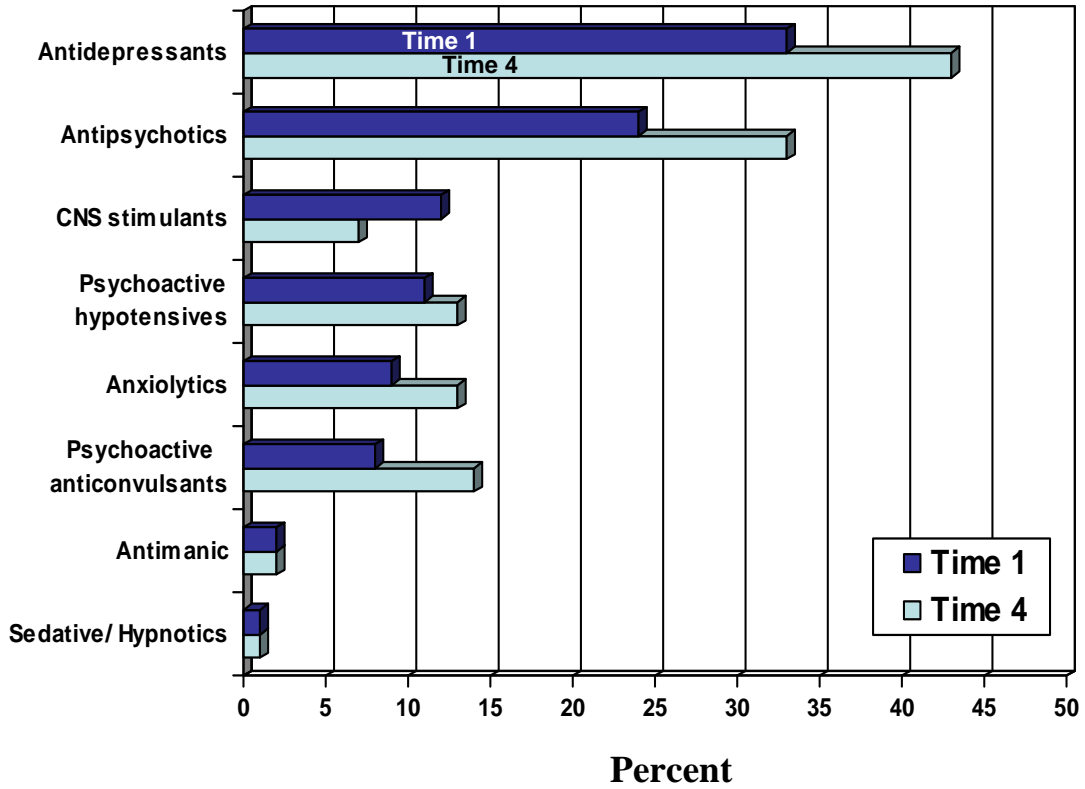
## **Types of Medications**

As shown in Figure 1 (page 6), our more recent analysis showed that antidepressant and antipsychotic medications were the most commonly prescribed medications for our sample members, and their use increased during the study period from Time 1 to Time 4. The increased use of these medications is consistent with recent medical reports that they are effective for individuals with ASD. For example, some antipsychotic medications (such as risperidone) have been shown to reduce irritability, behavior problems, and repetitive behaviors in individuals with ASD and developmental disabilities, and some antidepressant medications (such as fluoxetine) have been found to be helpful in managing perseverative behaviors. CNS stimulants declined in use during the study period, consistent with medical findings that stimulants are not as effective among individuals with ASD as compared to among individuals in the general population.

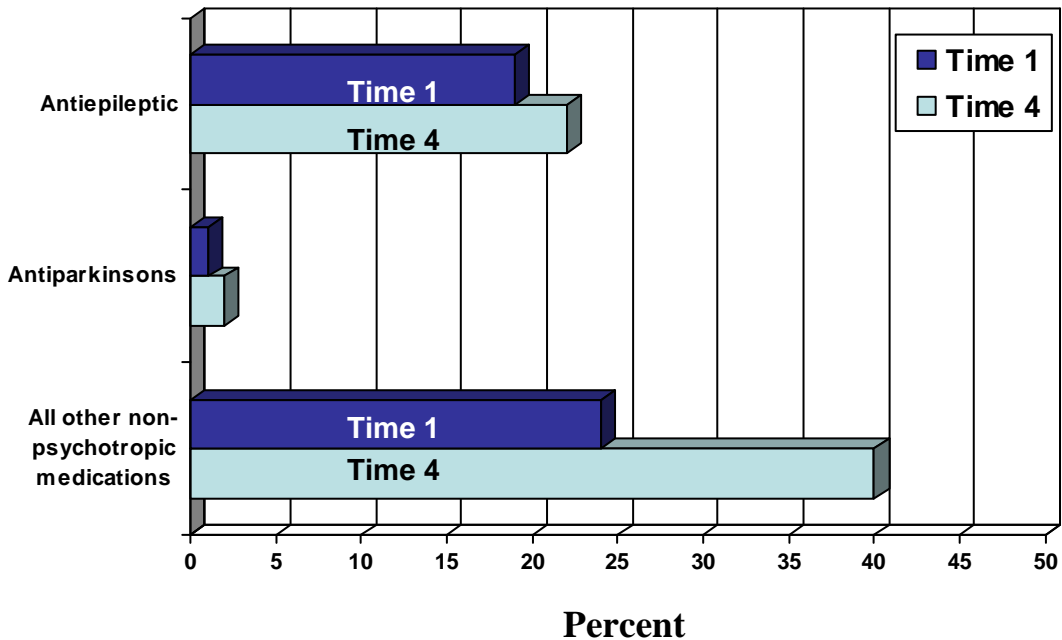
There also was an increase in the use of non-psychotropic medications over the study period, as shown in Figure 2. Many of the individuals with ASD were taking antiepileptic medication. This is because over a quarter of the individuals with ASD (27%) had a diagnosis of epilepsy by Time 4, and of these, 81% were taking a medication to control their seizures. Very few individuals with ASD were taking antiparkinson medications. Among those who were, none was prescribed these medications to control the symptoms of Parkinson's disease. Rather, these medications were taken to control the side effects (e.g., muscle tremors) of other medications, specifically some antipsychotic medications.

The increased use of non-psychotropic medication may be related to an age-associated increase in physical health problems. But the increase in their use could also reflect increased prescriptions to counteract side effects of psychotropic medication.

**Figure 1. Percentage of Sample Members Taking Psychotropic Medications, at Time 1 and Time 4.**



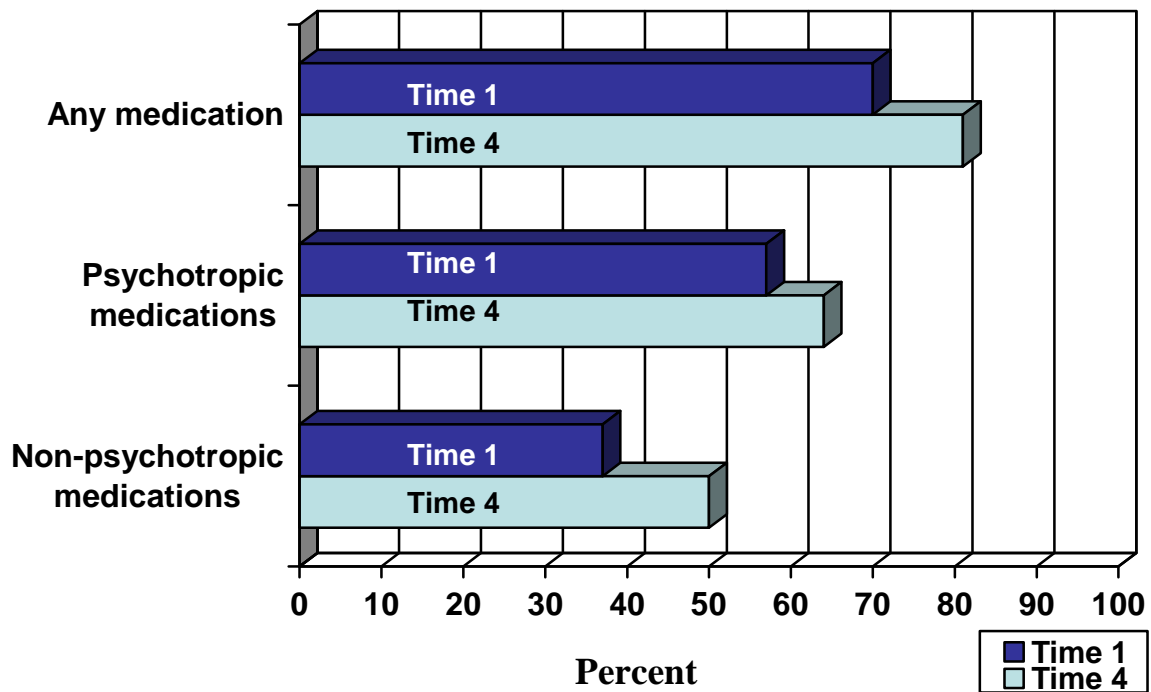
**Figure 2. Percentage of Sample Members Taking Non-Psychotropic Medications, at Time 1 and Time 4.**



## Proportion of Sample Members Taking Medications

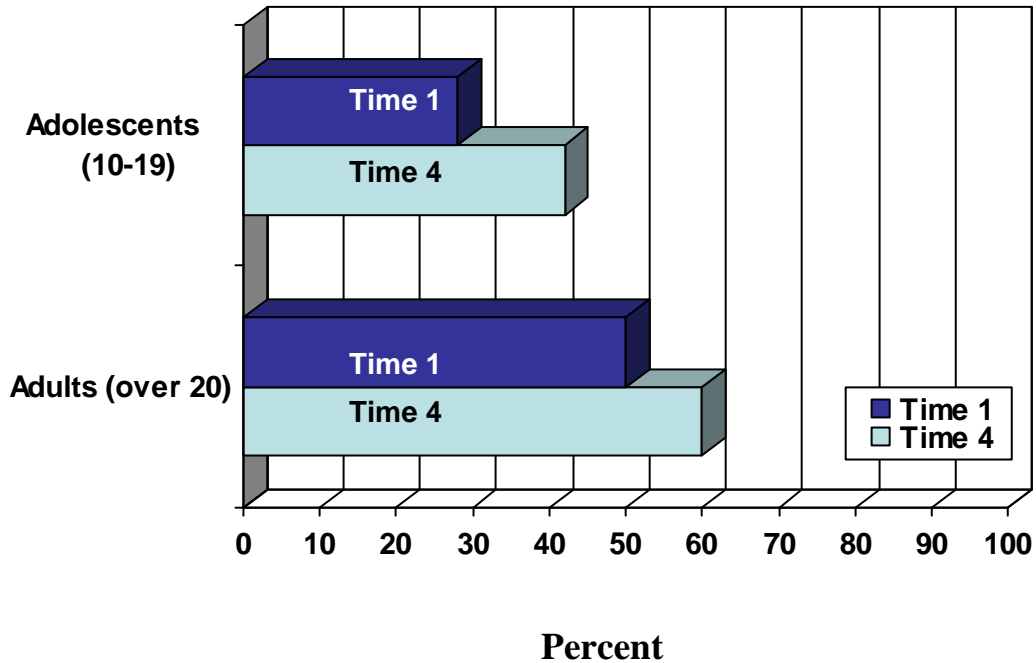
We found that a large majority of adolescents and adults with ASD were taking medications. At Time 1, 70% of individuals with ASD in our study were taking at least one medication, either psychotropic or non-psychotropic, which we refer to as “any medication.” This percentage significantly increased to 81% by Time 4. As presented in Figure 3, the proportion of individuals in our sample taking psychotropic or non-psychotropic medications also significantly increased from Time 1 to Time 4.

**Figure 3. Percentage of Sample Members Taking Medications, at Time 1 and Time 4.**

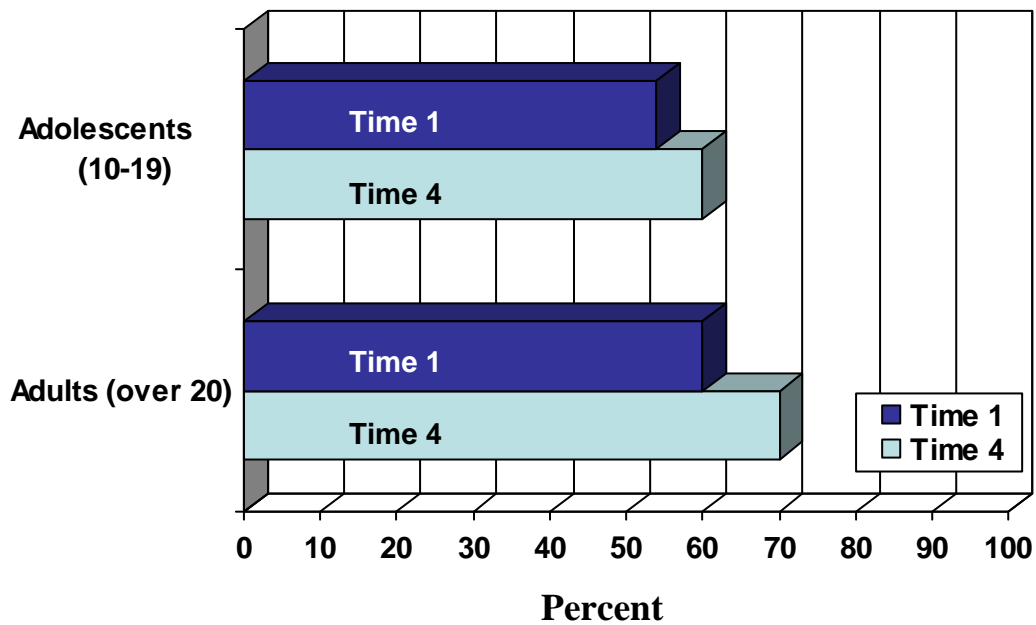


We also found that a significantly greater proportion of *adults* were taking non-psychotropic medication than were *adolescents* (see Figure 4), reflecting age-related health problems. However, the proportion of adolescents taking psychotropic medications did not differ significantly from the proportion of adults taking psychotropic medications in either year (see Figure 5).

**Figure 4. Percentage of Adolescents and Adults Taking *Non-Psychotropic Medications*.**



**Figure 5. Percentage of Adolescents and Adults Taking *Psychotropic Medications*.**



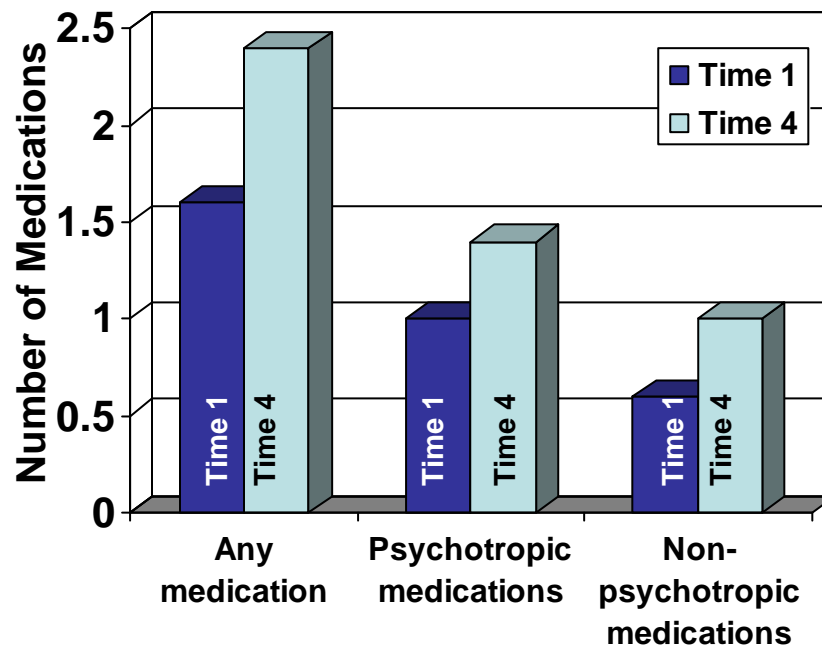
## Number of Medications Taken

The previous four pages reported on the *proportion* of sample members who took prescription medications. Now we report on the *number* of medications taken by our sample members with ASD.

We found that adolescents and adults with ASD were taking between 0 and 11 medications at Time 4. The average number of medications (both psychotropic and non-psychotropic) taken by an individual with ASD at Time 1 was between 1 and 2 medications. This significantly increased by Time 4 to taking an average of between 2 and 3 medications.

As shown in Figure 6, significant increases over the study period were observed in the number of psychotropic medications taken per person, and also in the number of non-psychotropic medications taken per person.

**Figure 6. Average Number of Medications Taken at Time 1 and Time 4.**



## **Likelihood of Starting or Stopping Medication**

Although we observed that medication use increased from Time 1 to Time 4, there was also considerable stability in psychotropic and non-psychotropic prescription patterns over this time period. Once adolescents and adults with ASD were prescribed medications, they were very likely to stay medicated.

This pattern of staying medicated was observed for both psychotropic and non-psychotropic medications, although the pattern was more pronounced for psychotropic medications. Individuals taking *psychotropic* medications at Time 1 (57% of the sample) were 10 times more likely to also be taking psychotropic medications at Time 4 rather than to have stopped taking these medications. And the 37% of individuals taking *non-psychotropic* medications at Time 1 were almost 5 times as likely to still be taking non-psychotropic medications at Time 4 as opposed to having stopped taking these medications.

On the other hand, adolescents and adults with ASD who were not previously medicated were unlikely to start taking medications over the study period. Specifically, if an individual was taking no *psychotropic* medication at Time 1, he or she was twice as likely to remain non-medicated by Time 4 as to start medication. Similarly, if an individual was taking no *non-psychotropic* medication at Time 1, he or she was twice as likely to remain non-medicated by Time 4 as to start medication. This finding suggests that if an individual with ASD is not on medication by the time he or she reaches adolescence and adulthood, he or she is over twice as likely to stay non-medicated as to begin medication.

## **Factors Leading to an Increase in Medication Use**

Finally, we sought to identify characteristics of the adolescents and adults with ASD that were predictive of medication use. Although there are numerous individual reasons why a person is prescribed a medication, we sought to identify the most typical reasons for medication use. We found that gender and severity of autism symptoms were NOT related to medication use. In other words, males and females are equally likely to be medicated, as are those with more or less severe autism symptoms.

Rather, individuals who were prescribed more *psychotropic* medications at Time 1 tended to have more severe behavior problems, and to have additional mental health diagnoses, such as depression, anxiety, ADHD, or obsessive-compulsive disorder. In contrast, individuals who were prescribed more *non-psychotropic* medications at Time 1 tended to be older, in worse health, have fewer functional skills, and have seizures.

Taking a greater number of medications at Time 1 was the strongest predictor of being prescribed *even more* medications by Time 4. In addition, we found that the individuals who were prescribed more *psychotropic* medication in Time 4 than Time 1 were also more likely to be diagnosed with intellectual disability, and to have additional mental health diagnoses. The individuals who were prescribed more *non-psychotropic* medication in Time 4 than Time 1 were older, more likely to be living at home, had more behavior problems, and were in worse health.

Although the factors that contribute to being prescribed medications and to an increase in medication use will not necessarily apply to every individual with ASD, our results provide insight into the general trends that contribute to medication use in this population.

### **Section III: Summary and Conclusions**

This report has described the types of medications taken by adolescents and adults with ASD, how many individuals take medications and how many different medications they take, changes in medications between Time 1 and Time 4, and the factors that may account for these changes in medications. We found that, at Time 1, many adolescents and adults with ASD are medicated, with 56% taking at least one *psychotropic* medication and 37% taking at least one *non-psychotropic* medication at the beginning of the study. About a quarter of sample members were taking both psychotropic and non-psychotropic medications. Our report also described increases in medication use over a period of 4.5 years.

There were four central themes prominent in our findings. First, medication use is becoming more prevalent over time, in that more people are taking medications, and more medications are taken, on average. Second, taking psychotropic medications and increases in psychotropic medications over time are strongly related to having additional mental health conditions. Third, similar increases in non-psychotropic medications are strongly related to older age. And fourth, use or lack of use of medication tends to be highly stable over time.

These preliminary results provide families, researchers, and practitioners with an important new understanding of patterns of, and the factors that contribute to, the prescription of medication, in adolescents and adults with ASD. Indeed, our results demonstrate that medication decisions have implications for future medication patterns. These findings may help families to formulate expectations for medication use by their adolescent or adult with ASD and inform researchers studying the potential impact of medications on the health, behavior problems and symptom expression among adolescents and adults with ASD.

We hope that our continued examination of these data, along with future data collection from our study participants, will yield further evidence to help us inform programs and interventions. Ultimately it is our goal that this research will improve the quality of health care and quality of life for individuals with ASD.