
Report #7: Health-Related Needs for Adolescents and Adults with Autism and Their Parents

Table of Contents

<u>Section I: Context for the Study</u>	1
<u>Section II: Health of Adolescents and Adults with Autism</u>	
Physical Health	2
Symptoms and Conditions	3
Health Care	7
Medications	8
<u>Section III: Parental Health</u>	
Physical Health of Mothers	10
Mothers' Conditions and Symptoms	11
Mothers' Medications	13
Physical Health of Fathers	15
Fathers' Conditions	16
<u>Section IV: Summary</u>	17
<u>Section V: Selected Resources</u>	18

Section I: Context for the Study

In 1998, we began this study to investigate the changes and challenges faced by adolescents and adults with autism and their families. We followed the families of over 400 adolescents and adults with autism spectrum disorders (ASD) over a five-year period, with data collected every 18 months from mothers, and occasionally from fathers and siblings. When the study began, the individuals with autism ranged in age from 10 to 53, averaging 22 years of age. Most were male (about 75%) and two-thirds lived at home with their parents.

One goal of our study is to better understand the physical health of individuals with autism and their parents. This report contains information provided by 286 families who completed the questionnaire portion of the fourth round of visits. It focuses on the health of adolescents and adults with autism, as well as the health of their parents. Very little is known about the special health care needs and problems of individuals with autism spectrum disorders across the life course. Anecdotal reports document a substantial risk of secondary health problems. Our study is unique in being able to provide systematic data about health problems for this population and their families, and we are very appreciative of your participation in this research.

After the completion of the fourth round of interviews, we hope to be awarded continued funding to visit you again in the future. Some findings from this study have been published in scientific journals and several more papers will be published soon. These studies are breaking new ground in understanding the lives of adolescents and adults with autism and their families.

We are deeply grateful to the families who have participated in this study. You have welcomed us into your homes, spent hours of your limited time with our interviewers, and provided information and insights that only the family can offer. We have learned so much in this process and are committed to using this knowledge to improve the quality of lives of individuals with autism spectrum disorders and their families.

Sincerely,

Marsha Mailick Seltzer, Ph.D.
Vaughan Bascom Professor
Director, Waisman Center
University of Wisconsin-Madison
Co-Principal Investigator

Marty Wyngaarden Krauss, Ph.D.
John Stein Professor of Disability Research
Provost
Brandeis University
Co-Principal Investigator

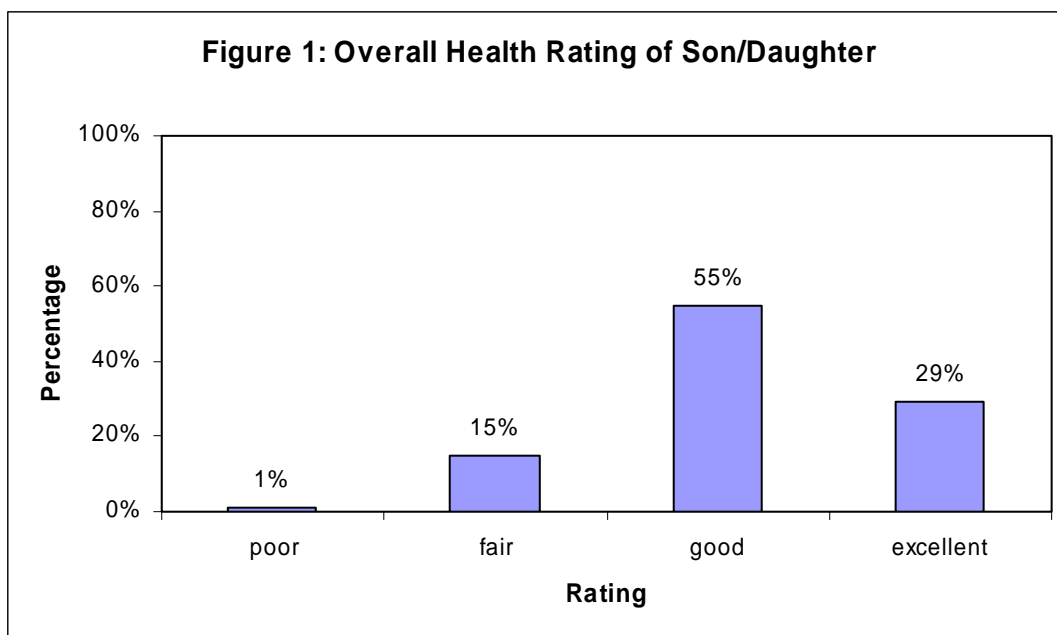
Section II: Health of Adolescents and Adults with Autism

This section of the report provides a description of the health of adolescents and adults with autism. The questions in the study focused on general physical health, specific health conditions, the use of health care services, and the use of medications. Our goal was to identify what health problems are common in autism, as well as what types of health care services and medications are most frequently used.

Physical Health

Because we are interested in the overall health of the individuals in our study, we asked parents the following two questions: *How would you rate your son or daughter's physical health status at the present time (poor, fair, good, or excellent)? Is your son or daughter's physical health worse, about the same, or better than it was on our last visit with you?*

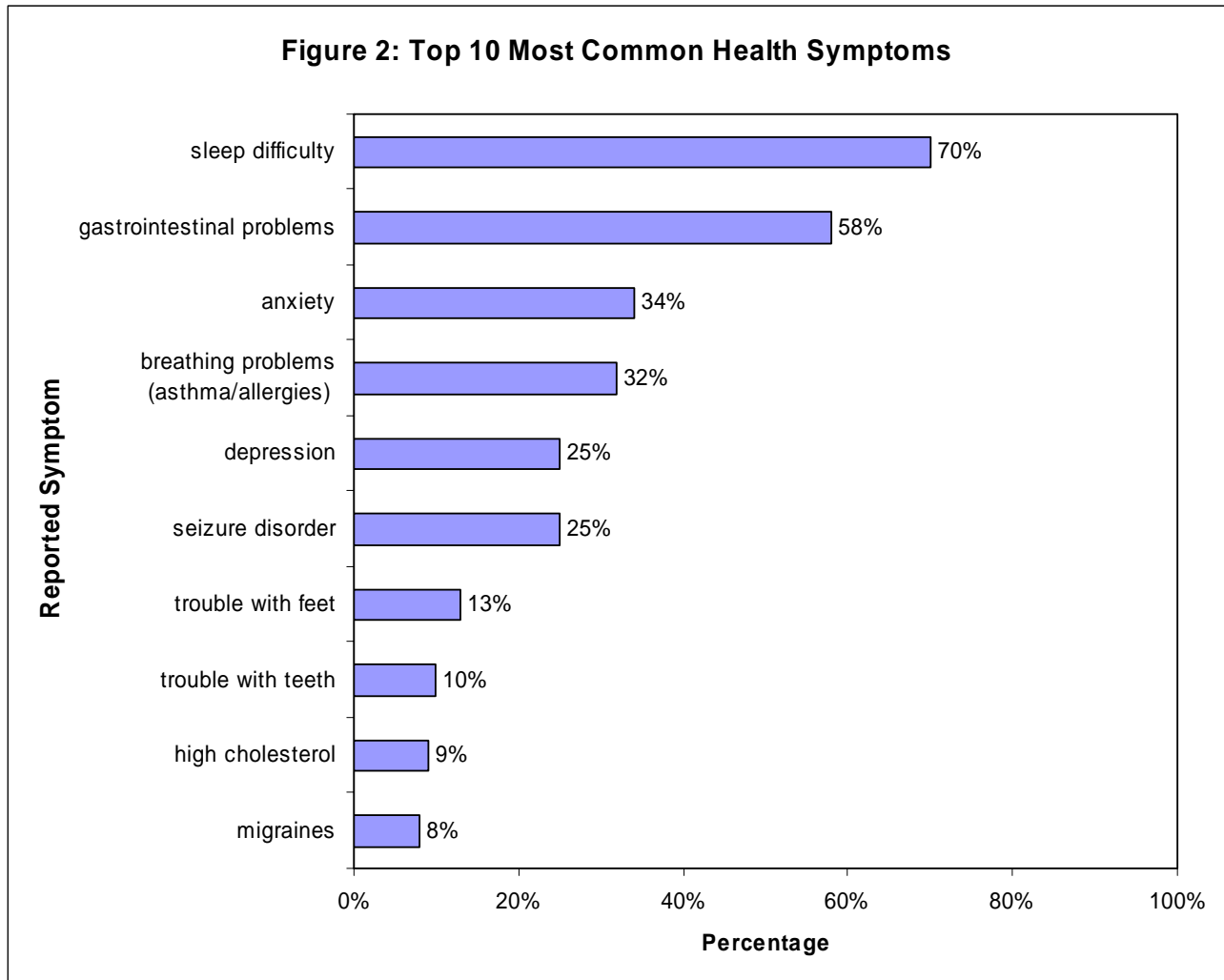
Figure 1 below shows how parents rate the health of their sons and daughters.



- A majority (over 80%) of parents rated their son or daughter's health as good or excellent, while only 1% rated their child as having poor health.
- When compared with health ratings during the last visit, 74% of parents reported that the health of their son or daughter had not changed.
- Of the 26% of parents who reported a change in their son or daughter's health, 15% reported worse health, while 11% reported better health.

Symptoms and Conditions

To determine the specific health problems of sons and daughters with autism, we asked parents to report on common symptoms or conditions. Listed below are the conditions reported by more than 5% of families in our study.



- Sleep difficulty and gastrointestinal problems were by far the most commonly reported health symptoms. Although these symptoms were reported by a majority of parents, the frequency of their occurrence varied greatly (see Figures 3 and 4).
- Approximately one-quarter of parents reported that their son or daughter had seizures, which also occurred with varying frequencies (see Figure 5).
- Parents additionally reported on the types of seizures that their sons or daughters have (see Figure 6).

Figure 3 below shows the frequency of sleep difficulty.

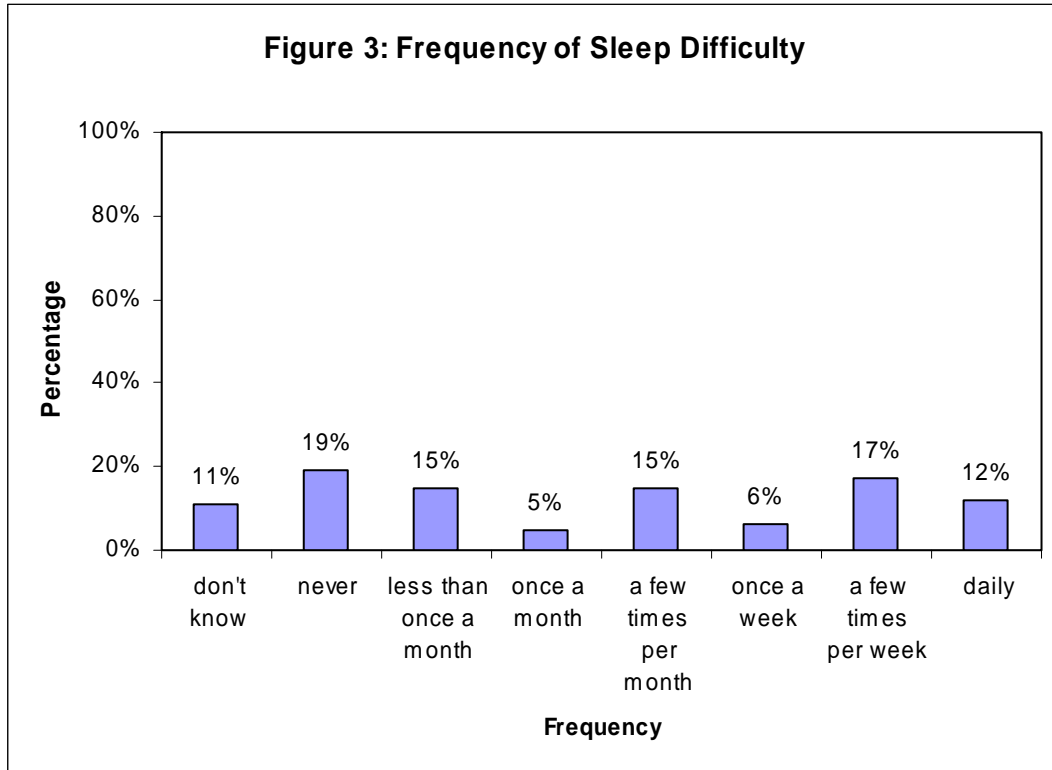
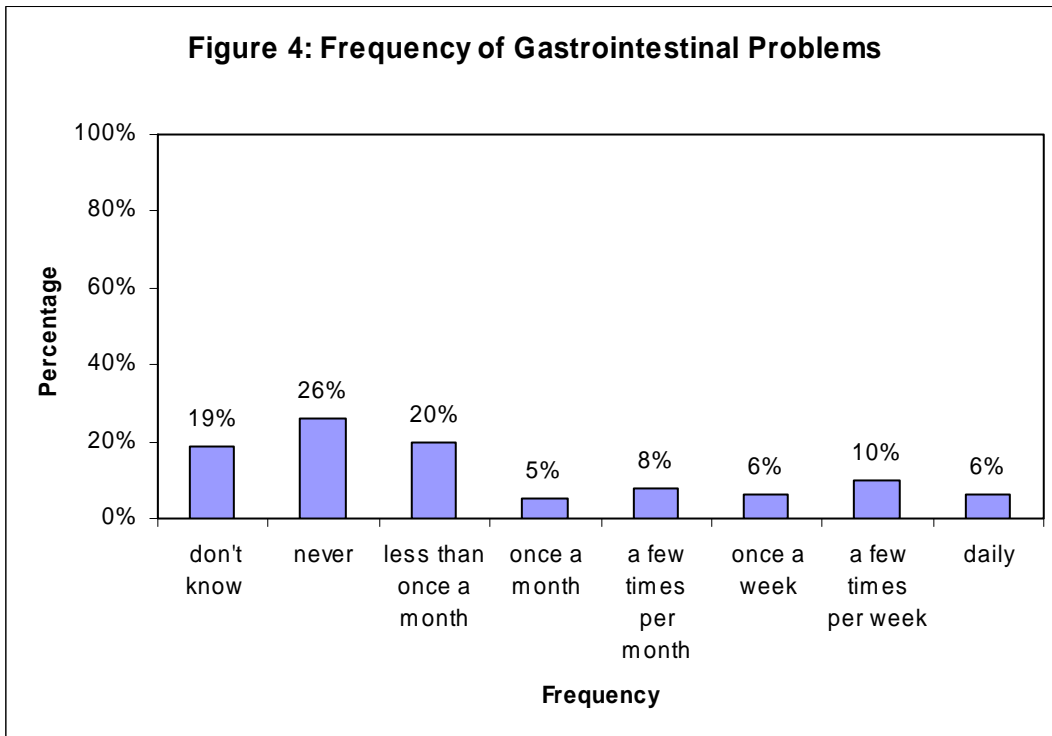
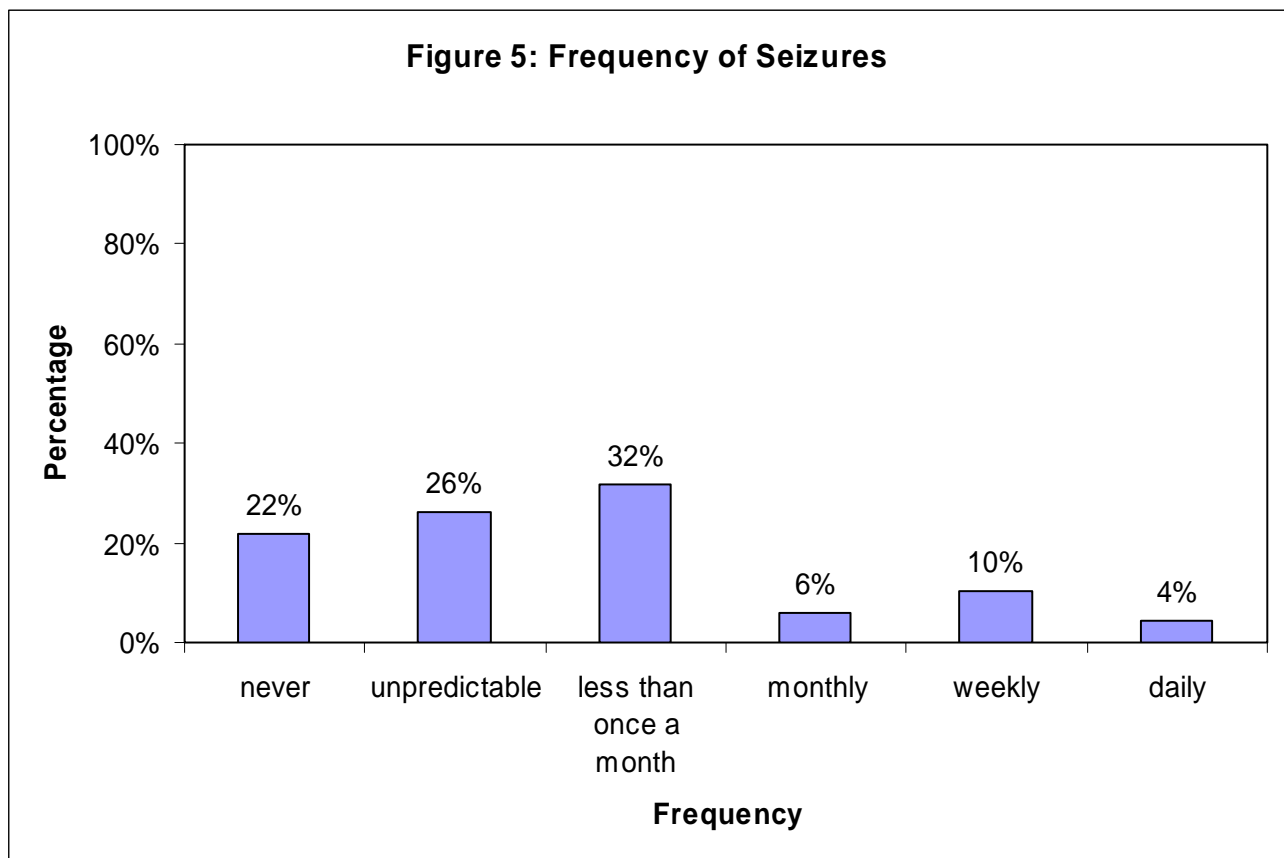


Figure 4 below shows the frequency of gastrointestinal problems, such as indigestion or constipation.



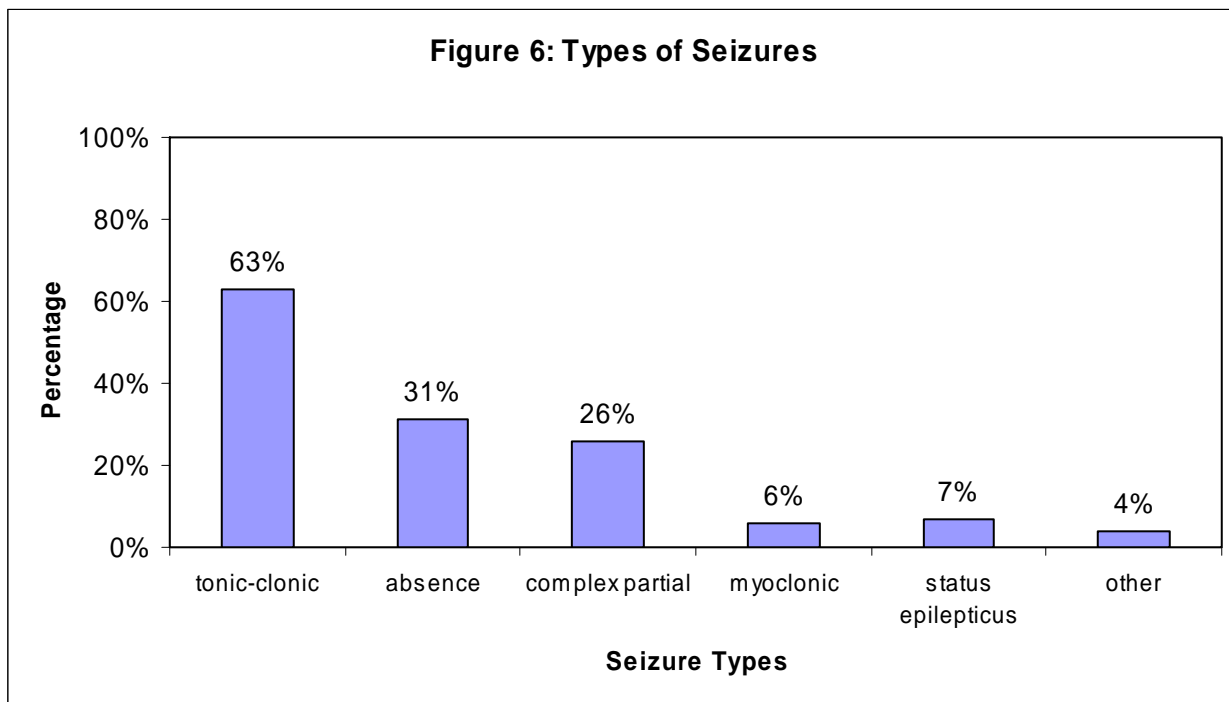
For adolescents and adults with autism who have seizure disorders, the frequencies with which the seizures occur can vary greatly. Figure 5 below shows the frequency of seizures reported by parents.

Note that this graph is based only on the 25% of parents who reported that their son or daughter had a seizure disorder.



- Some parents whose son or daughter has a seizure disorder reported that their son or daughter never has seizures, as the seizures are currently fully controlled by some form of treatment.
- Of the adolescents and adults who have a seizure disorder, 90% take medication to help control the seizures.
- For the individuals taking medications for seizures, 73% of parents report that the seizures are well-controlled by medications, while 17% of parents report that the seizures are not well-controlled.

In addition to varying frequencies of seizures, sons and daughters also experience different types of seizures. Figure 6 below describes different types of seizures reported by parents. Note that sons and daughters may have multiple types of seizures.

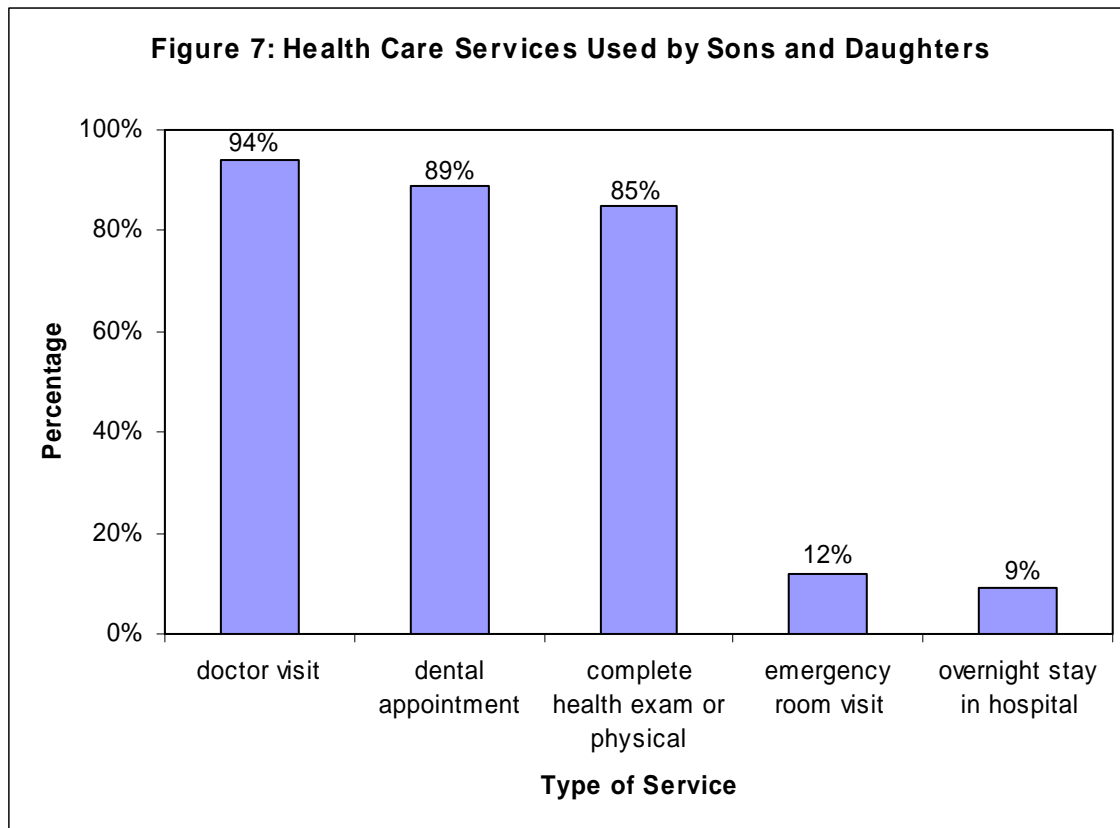


- **Tonic-clonic seizures:** Characterized by convulsions, during which the individual loses consciousness. These are also known as "grand mal" seizures and are most commonly associated with epilepsy.
- **Absence seizures:** Characterized by brief episodes of staring, during which awareness and the ability to respond are temporarily impaired. These are also known as "petit mal" seizures.
- **Complex partial seizures:** Characterized by an alteration or loss of consciousness, which results in a loss or distortion of memory, but during which the person may seem to be functioning normally. Sometimes these include 'automatisms,' which are repetitive or purposeless actions.
- **Myoclonic seizures:** Characterized by rapid and brief repeated contractions of bodily muscles that cause them to jerk.
- **Status epilepticus:** Characterized by one prolonged seizure lasting at least 30 minutes or a series of seizures between which the individual does not recover. These episodes require emergency medical attention.

Health Care

In addition to health status and symptoms, we are also interested in how sons and daughters utilize health care services.

Figure 7 below summarizes the different types of services sons and daughters have used in the past year.

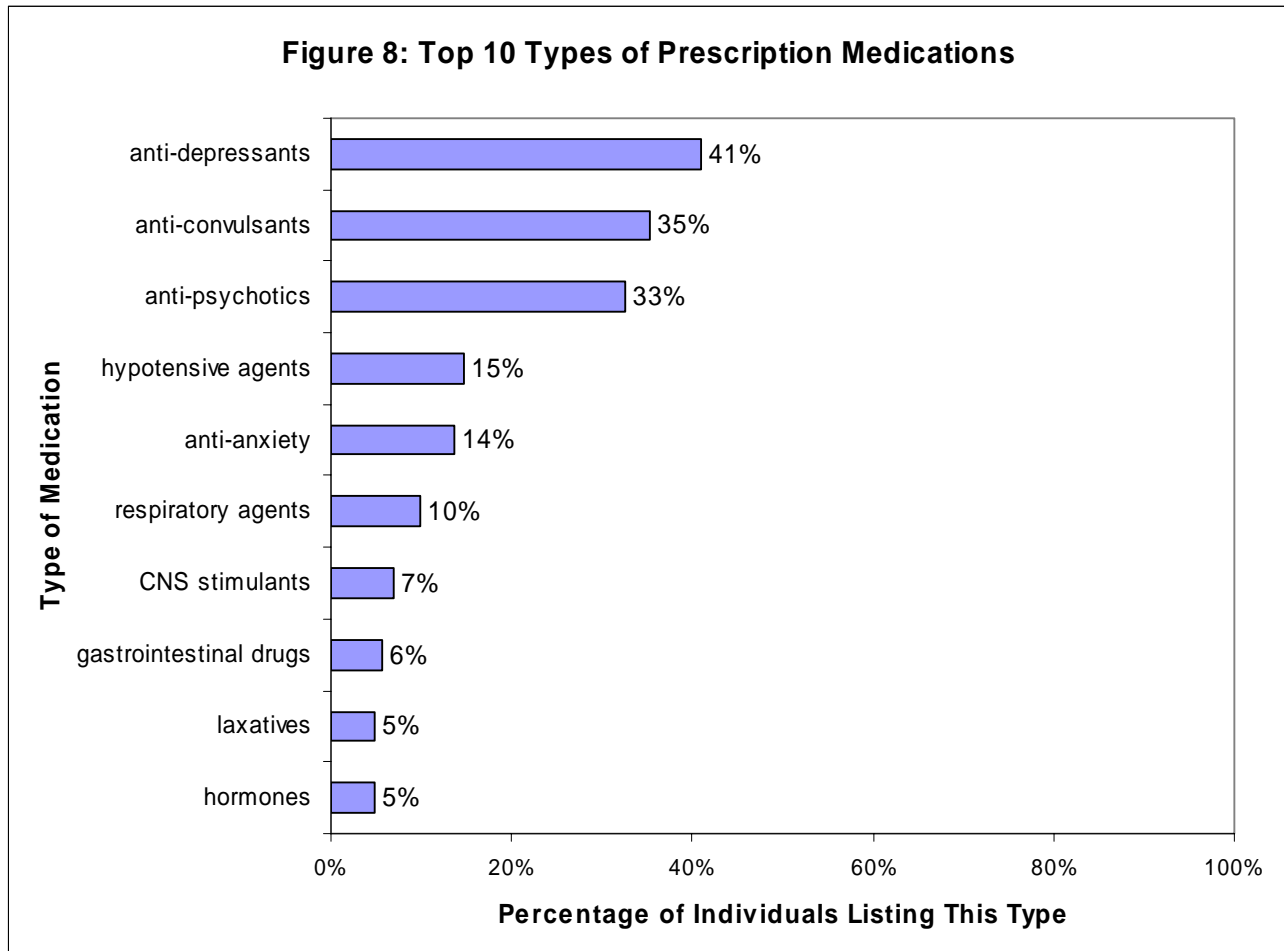


- Nearly all parents reported that their son or daughter had a doctor visit, a dental appointment and a complete health exam or physical in the past year.
- The number of doctor visits varied greatly. While some parents reported no doctor visits, there was a small percentage of parents who reported well over 50 doctor visits. Parents most commonly reported that their son or daughter had 2 visits to the doctor during the past year.
- Similarly, the number of visits to the emergency room ranged from 0 to well over 50.
- When a son or daughter had overnight hospital stays, the number of nights in the hospital ranged from 1 to well over 50, with parents most commonly reporting 1 night spent in the hospital in the past year.

Medications

Over 80% of the individuals with autism in our study take prescription medications. We asked parents to provide information about those medications, including the primary reasons why their son or daughter takes medications. In response, the parents in our study provided information on nearly 700 prescription medications that their sons and daughters were currently taking.

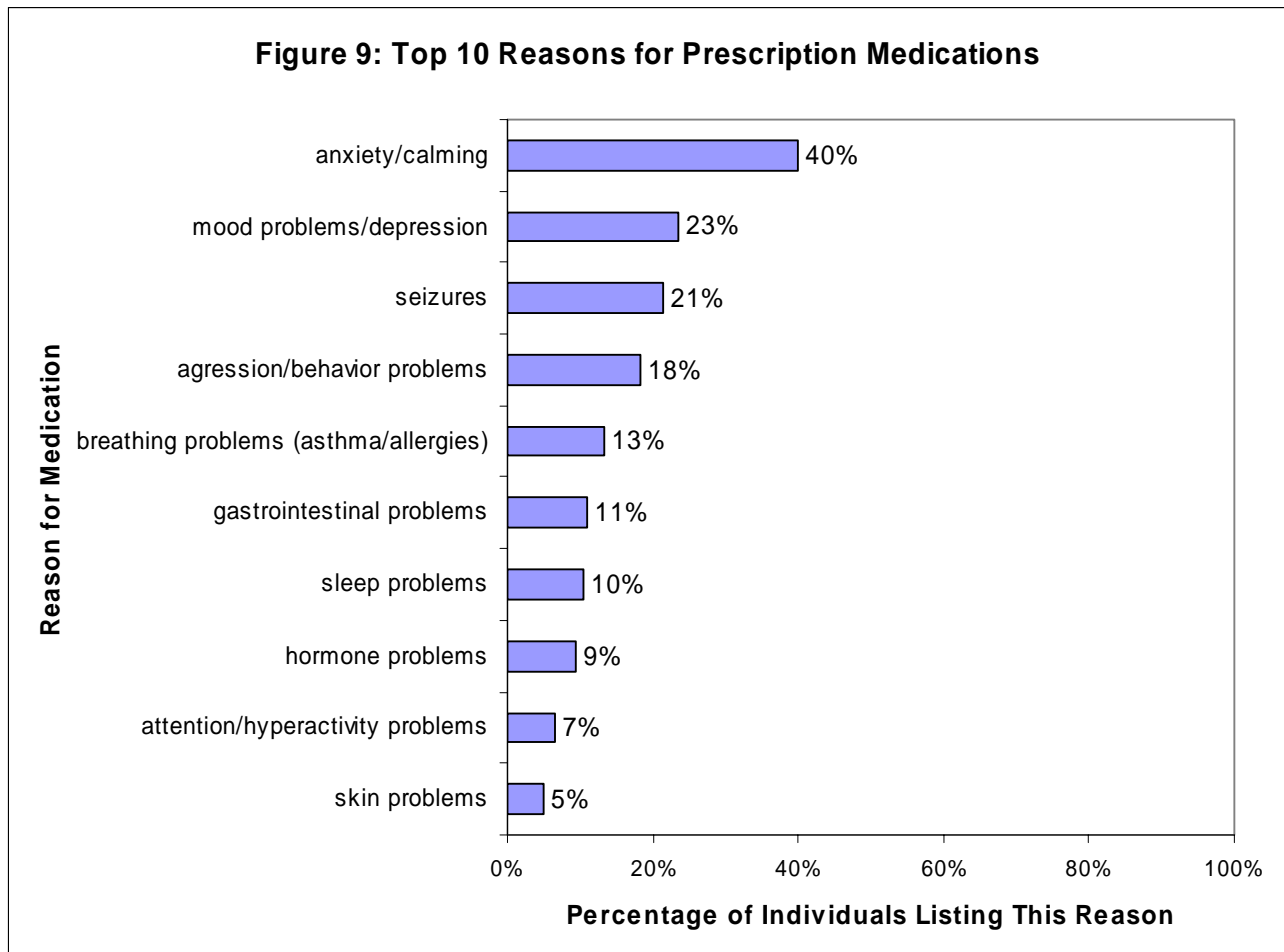
Figure 8 below displays the 10 most common types of medications taken by the adolescents and adults with autism in our sample.



- Of those sons and daughters taking a prescription medication, the number of medications ranged from 1 to 12. On average, parents reported that their sons and daughters were taking 3 prescription medications.
- The most frequently prescribed types of medications were anti-depressants.
- In addition to the type of medication, parents also provided the reason(s) their son or daughter takes a specific medication (see Figure 9 below).

It is important to note that although a medication may belong to a category of medications (i.e. anti-depressants, anti-convulsants, etc.), the reason for taking the prescribed medication may diverge from the general medication type.

Figure 9 below presents the 10 most common reasons parents listed for their sons and daughters' medications.



- To alleviate anxiety or induce calming was by far the most common reason listed for medication use.
- However, in contrast to Figure 8, which showed that 14% of medications were anti-anxiety medications, around 40% take medications for anxiety/calming.
- Conversely, over 41% of individuals take anti-depressants (see Figure 8), while only 23% report that medications are used for mood problems or depression (see Figure 9).

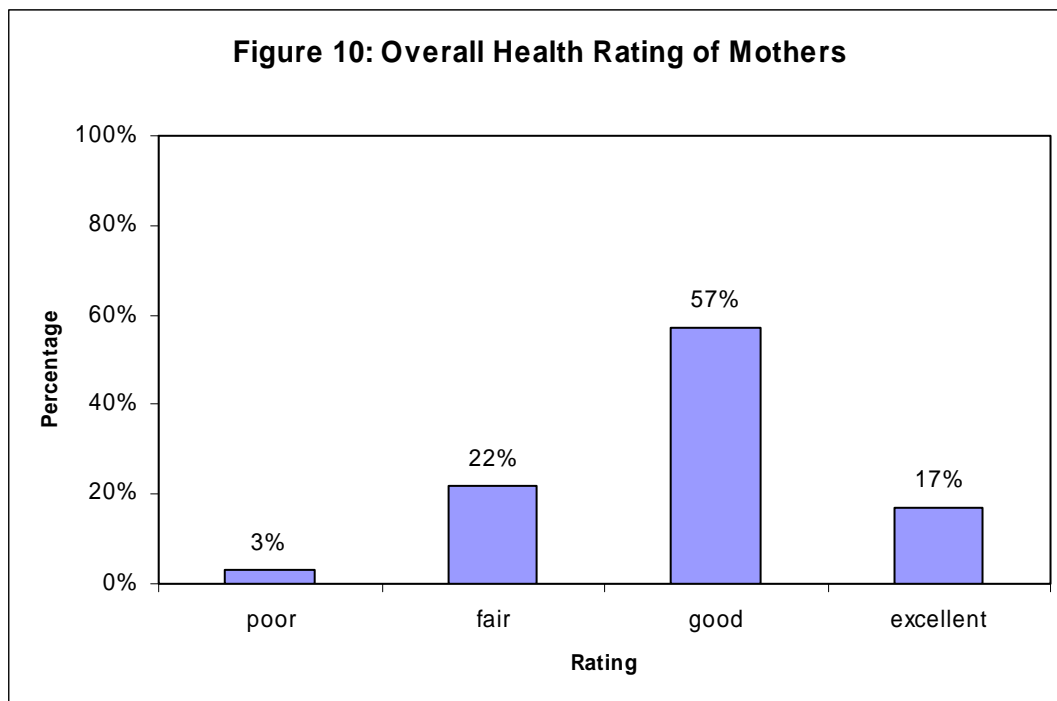
Section III: Parental Health

This section of the report provides an overview of the health of the parents of individuals with autism. The questions in the study focused on general physical health of mothers, their specific health conditions, their use of medications, and the health of their spouses. Our goal was to identify the physical health problems common among parents of individuals with autism. We received information on the health of 284 mothers and 208 fathers.

Physical Health of Mothers

Because we are interested in the impact of caregiving on overall health, we asked mothers the following two questions (in a few cases, fathers reported on the health of their wives): *How would you rate your overall health at the present time? Is your physical health worse, about the same, or better than it was on our last visit with you?*

Figure 10 below shows how mothers rate their own health at the present time.

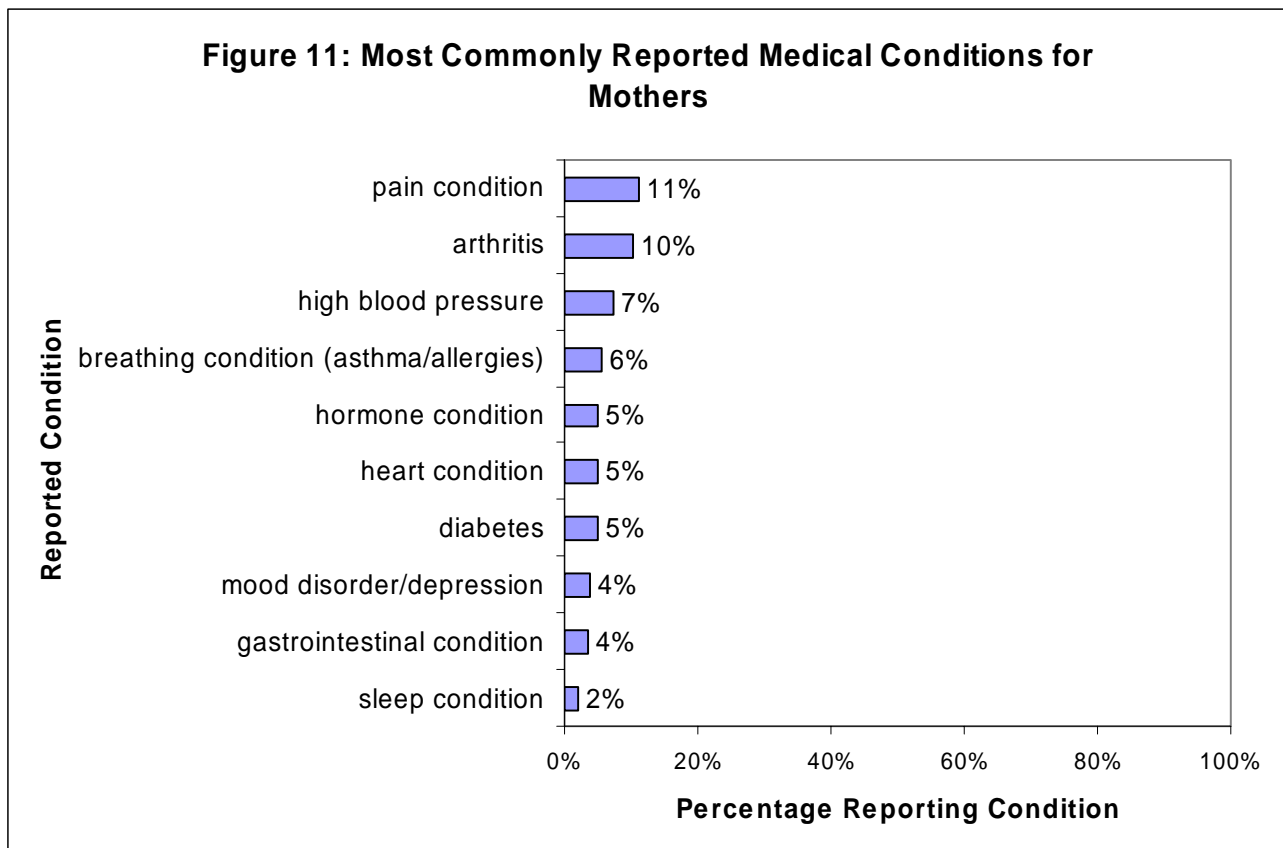


- A majority (nearly 75%) of mothers rate their own health as good or excellent, while only 3% rate themselves as having poor health.
- When compared with health ratings during the last visit, 69% of mothers reported that their own health had not changed.
- Of the 31% of mothers who reported a change in their own health, 22% reported worse health, while 9% reported better health.

Mothers' Conditions and Symptoms

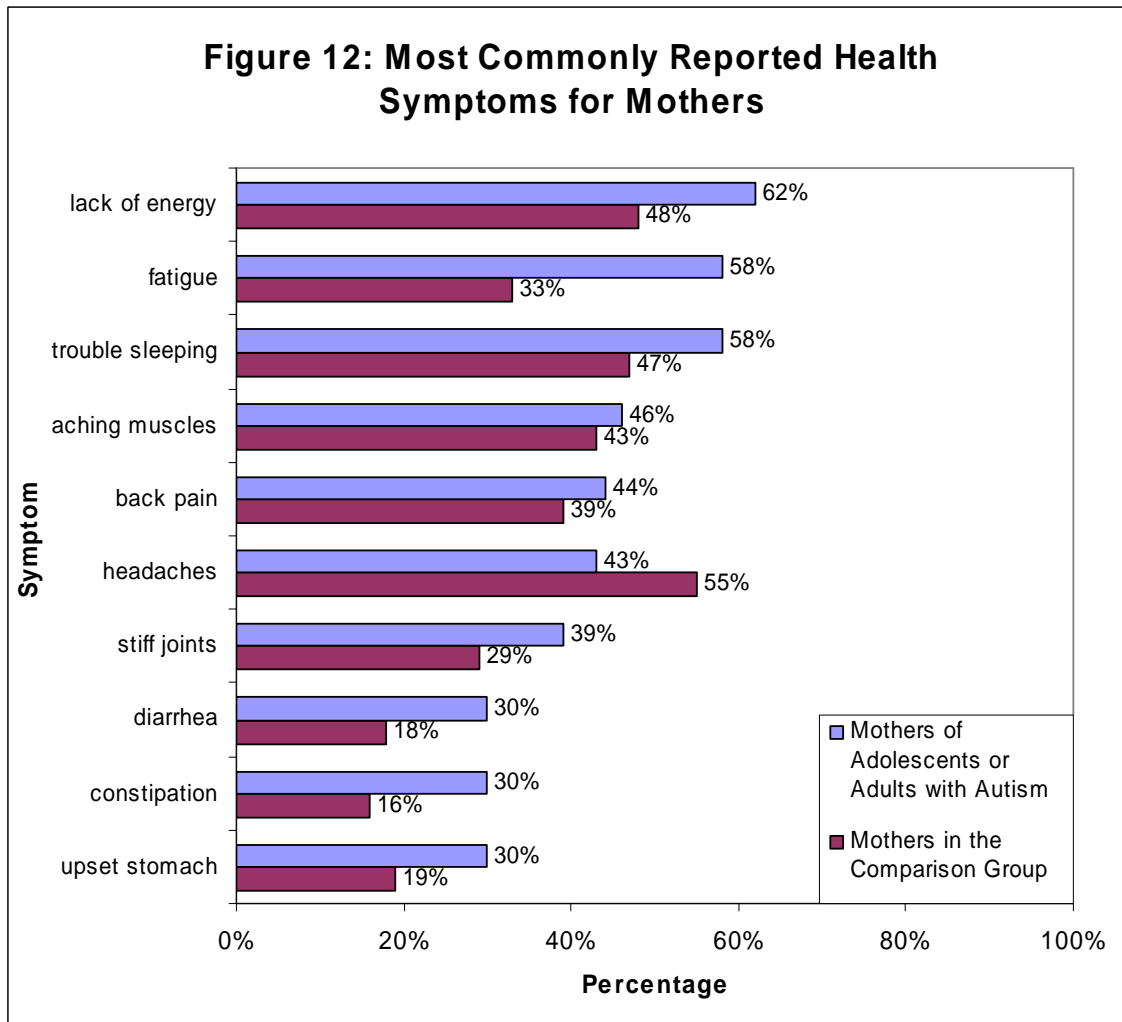
To determine more specific health concerns of mothers, we asked them about any chronic medical conditions and to report on several common physical and health problems. Approximately 50% of mothers indicated that they had a chronic medical condition or disability.

Figure 11 below lists the most commonly reported chronic medical conditions or disabilities for mothers. Note that some mothers reported more than one condition or disability.



- Pain conditions were the most commonly reported medical conditions. These included conditions such as fibromyalgia, chronic back pain, and pain resulting from accident or injury.
- Other medical conditions were also reported by multiple mothers, including anemia, anxiety, cancer, neurological disorders and osteoporosis.

In addition to listing medical conditions, mothers also completed a checklist of common health symptoms they had experienced in the past 6 months. For this list of health symptoms, we had information from a comparison group of similarly-aged mothers who do not have a child with a disability. Figure 12 below summarizes symptoms reported by at least 30% of mothers of adolescents and adults with autism, as well as the comparison rates of mothers in the general population.

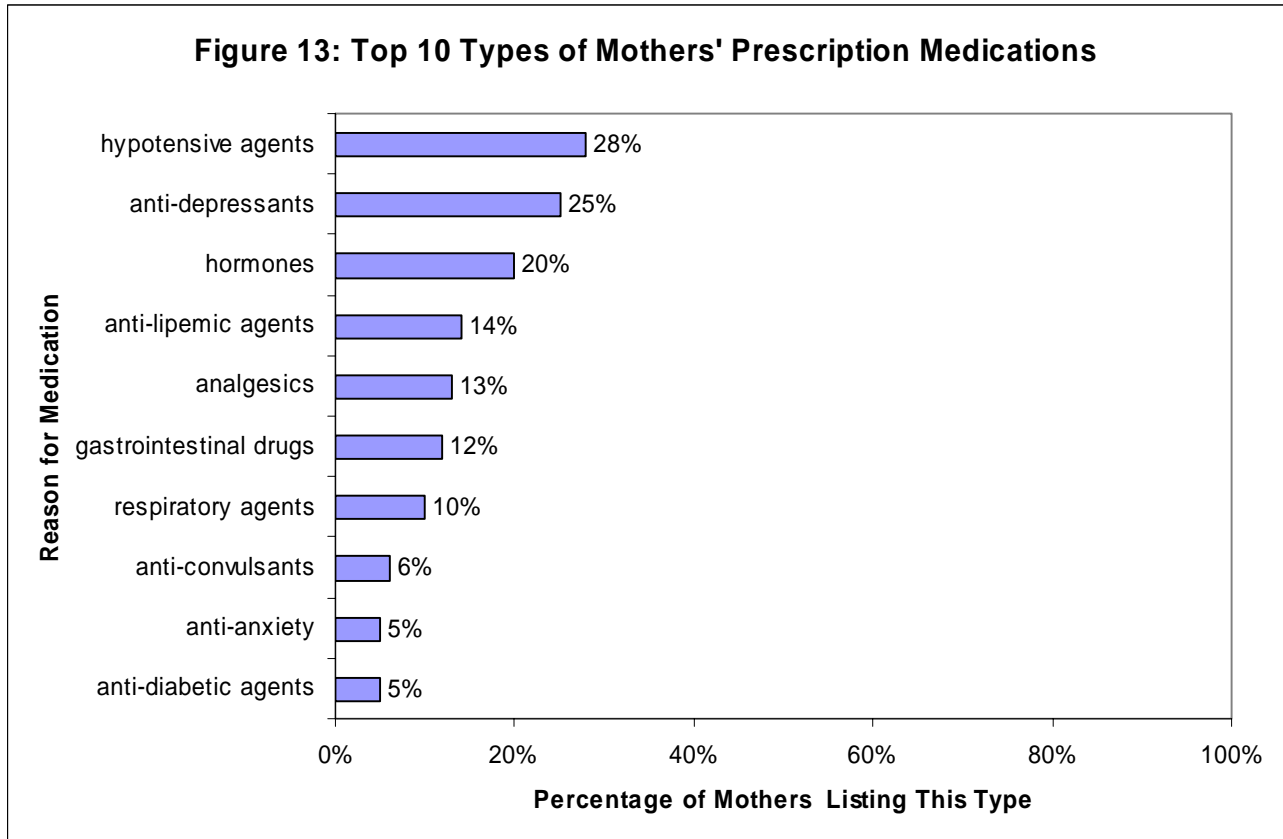


- When compared to mothers in the general population, mothers of adolescents and adults with autism report higher rates of many physical health symptoms. Headaches are the only symptoms that these mothers report less often.
- Over half of mothers of adolescents and adults with autism reported lack of energy, fatigue and trouble sleeping.
- In addition to those listed above, over 10% of these mothers also reported the following health symptoms: high blood pressure, nausea, numbness, shortness of breath, excessive sweating, visual problems, dizziness, ringing in the ears, respiratory problems, skin problems, urination problems, chest pain and vomiting.

Mothers' Medications

Over 70% of mothers in our study reported that they take prescription medications. We asked mothers to provide information about those medications, including the primary reasons why they take medications. For this, mothers collectively provided information on over 600 prescriptions that they were taking.

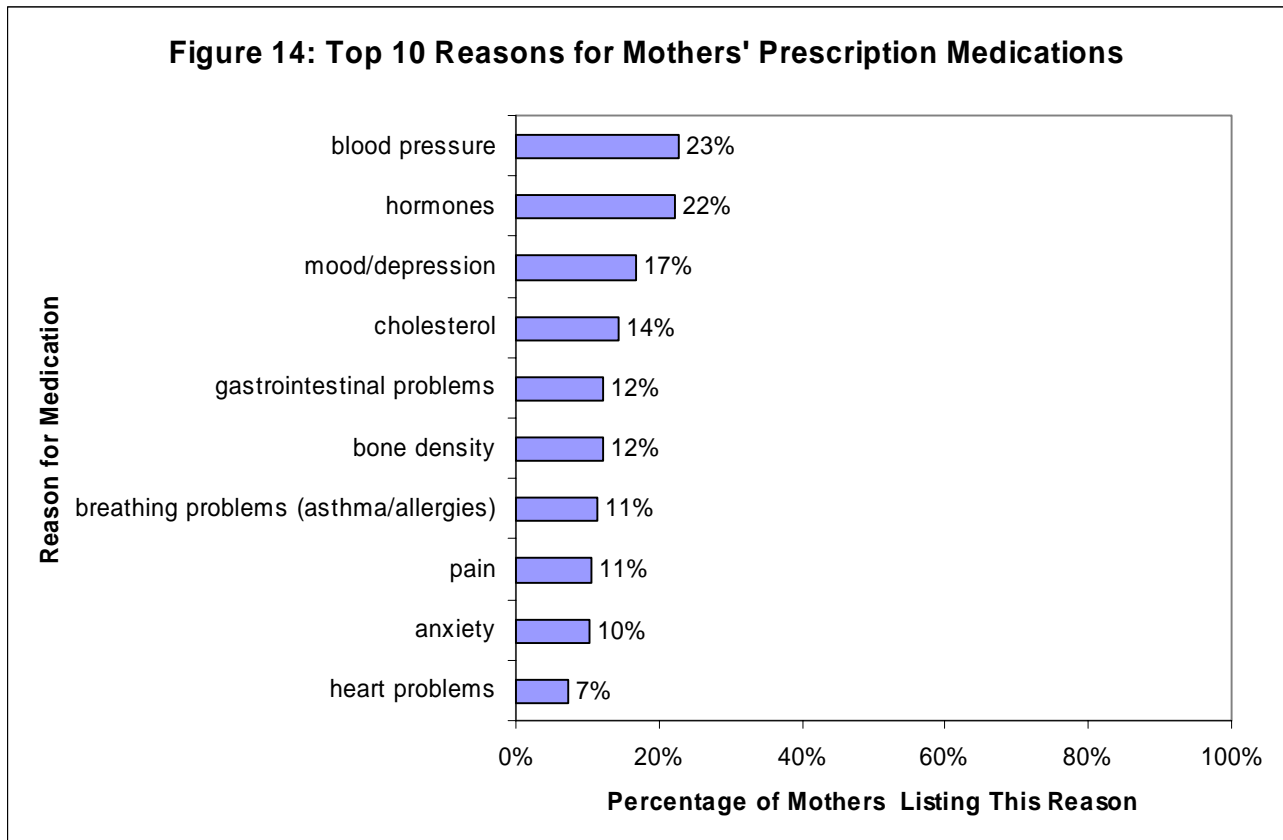
Figure 13 below displays the 10 most common types of medications taken by mothers.



- Of those mothers taking a prescription medication, the number of medications ranged from 1 to 16. On average, mothers reported that they were taking 3 prescription medications.
- Over one-third of mothers who take prescription medications take at least one hypotensive agent (intended to lower blood pressure), and over one third take at least one anti-depressant medication.
- In addition to the type of medication, mothers also provided the reason(s) that they take a specific medication (see Figure 14).

Much like sons and daughters who have autism, mothers' reported reasons for taking the prescribed medication sometimes diverged from the general medication categories listed in Figure 13.

Figure 14 below outlines the 10 most common reasons mothers listed for their own medications.



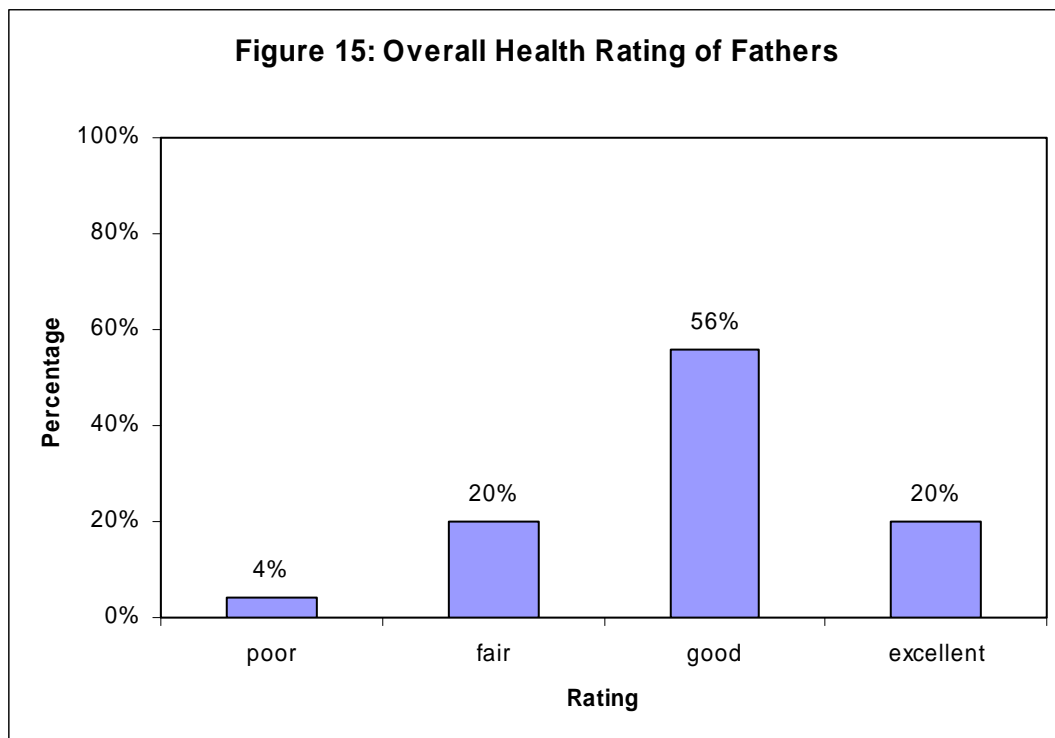
- The most common reasons listed for mothers' medication use were to control blood pressure and hormones.
- In addition to the reasons shown in Figure 14, other common reasons for taking medications included arthritis and diabetes, which were each listed by more than 5% of mothers.
- For mothers, the medication type often closely matched the reported reason for taking the medication. For instance, 20% of mothers listed they were taking hormone medications, and 22% listed hormones as their primary reason for taking a medication. This was a different pattern than was evident for the sons and daughters, where the type of medication was often different than the reasons they were used (see Figures 8 and 9).

Physical Health of Fathers

Because we are interested in the overall health of both parents, we also asked some questions about the health of fathers. In most instances, we asked mothers to answer questions about the health of their spouses, but in a few cases, we asked fathers directly about their own health. We did not collect information about fathers' prescription medications.

We received information on fathers for 73% of the families in our study. Of the 27% not reported, 18% of the mothers were separated or divorced, 8% of the mothers were widowed, and less than 1% of the mothers were never married or did not respond to spouse health questions.

Figure 15 below shows how the health of fathers was rated overall.

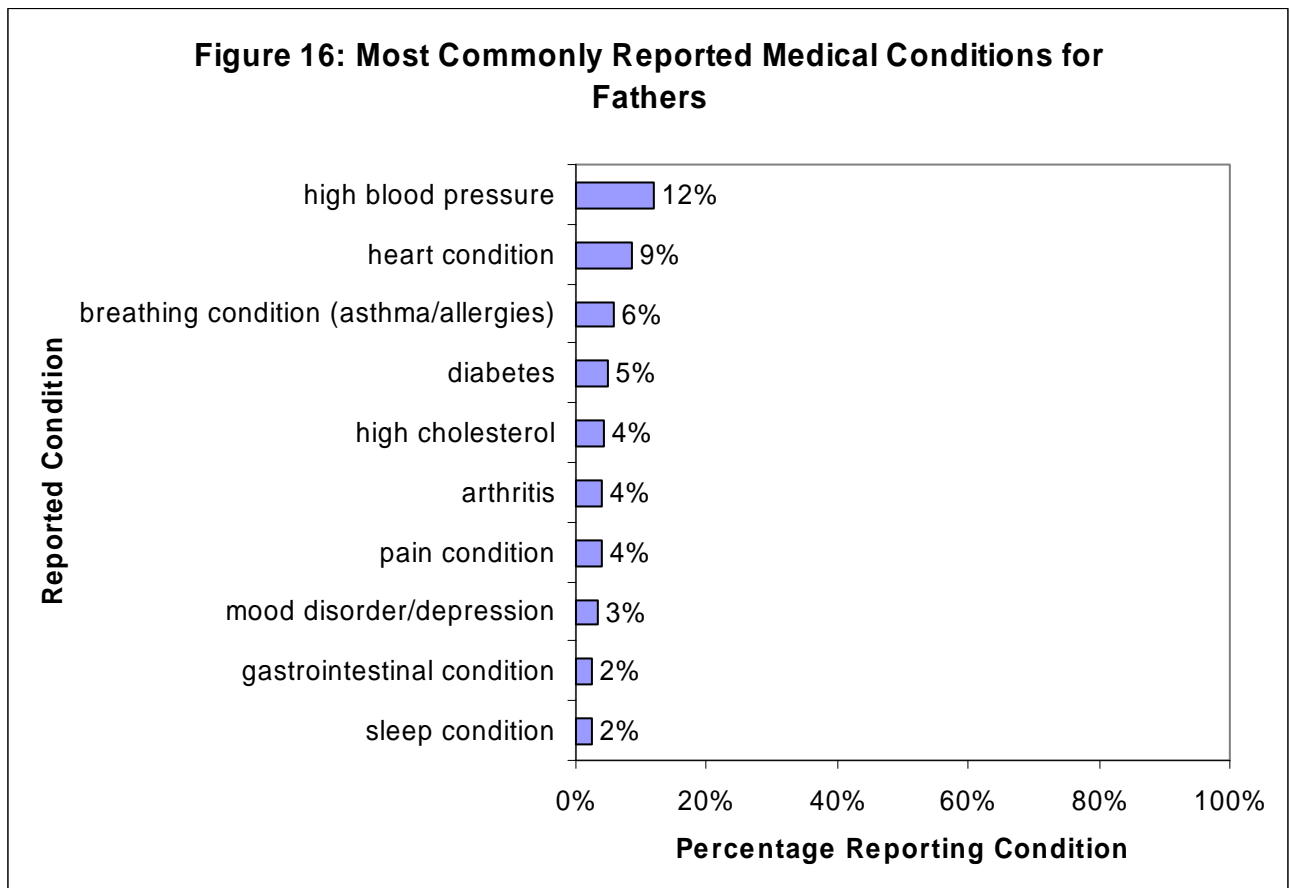


- Consistent with the reports of mother health, a majority (over 75%) of fathers have health that is rated as good or excellent, while only 4% are rated as having poor health.
- When compared with health ratings during the last visit, 77% reported that fathers' health had not changed.
- Of the 23% of parents who reported a change in father health, 18% reported worse health, while 5% reported better health.

Fathers' Conditions

We asked parents about fathers' ongoing conditions or disabilities. Approximately 47% reported an ongoing condition or disability.

Figure 16 below lists the most commonly reported chronic medical conditions or disabilities for fathers. Note that several fathers had more than one condition or disability.



- High blood pressure was the most commonly reported chronic medical condition for fathers.
- The most common conditions for fathers were somewhat different than those for mothers, who listed pain conditions and arthritis as the two most common conditions. This difference may reflect gender differences in health problems.

Section IV: Summary

This report focused specifically on health and health-related problems of adolescents and adults with autism spectrum disorders and their parents. Because we interview families at multiple time points, we are able to study how health changes over time.

Parents have provided such rich and detailed information about their own health and the health of their son or daughter, and therefore we can draw several important conclusions in this report.

- Overall, a majority of adolescents and adults with ASD are in good health, and, in general, their health has remained stable over time. On the other hand, they experience a variety of health-related symptoms and conditions, some of which (i.e., sleep difficulty and gastrointestinal problems) are experienced by a majority of the individuals in our study.
- Most families utilize common health care resources for their sons and daughters, including doctor visits, regular health exams and dental visits. Further, many adolescents and adults with autism take prescription medications to help control both physical and mental health symptoms.
- A majority of parents are also in good health, though about half experience some sort of chronic medical condition or disability. Although mothers and fathers are almost equally likely to have a medical condition or disability, the types of conditions most common vary by gender.
- Mothers of adolescents and adults with autism report health symptoms more frequently than similarly-aged mothers in the general population.
- Like their children, most mothers also utilize prescription medications to help control both physical and mental health symptoms. However, their most common reasons for taking medications differ substantially from their sons' and daughters' reasons for taking medications.

These preliminary findings indicate that the health problems of adolescents and adults with autism and their parents are complex. It is our hope that the findings from this study can help inform health care providers, policy makers and the general public about the health-related needs of individuals with ASD and similar needs for their families.

Section V: Selected Resources

Organization/Website:

The Family Village, located in the Waisman Center, provides multiple resources for individuals with disabilities and their families. For further information about health and health-related resources please refer to their website listed below and click on the “hospital” icon.

The Family Village
Waisman Center
University of Wisconsin-Madison
1500 Highland Avenue
Madison, WI 53705-2280



<http://www.familyvillage.wisc.edu>

Book:

Volkmar, Fred R. & Wiesner, Lisa A. *Healthcare for Children on the Autism Spectrum: A Guide to Medical, Nutritional and Behavioral Issues*. Bethesda, MD: Woodbine House.