

AAA

Adolescents & Adults with Autism A Study of Family Caregiving

**Report #11:
Daily Experiences and Biological Markers of
Stress in Mothers of 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**

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

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Section I: Introduction

Over the past 10 years, participants in our study have provided us with a great deal of information about the experiences of individuals with autism spectrum disorders (ASD) and their families. This knowledge has been very valuable in informing our understanding of how ASD both affects, and is affected by, family experiences across the lifespan.

In a recent wave of data collection, we were also able to gather information about the “day-to-day” experiences of a sub-group of the families in our study, namely those whose son or daughter with ASD lives at home. Learning about the daily experiences of mothers of adolescents and adults with ASD complements the other data we collect in this study and has provided us with new insights into what life is like for these mothers and their families. Additionally, many of our participants provided salivary samples, which allowed us to assess the biological impacts of daily experiences by measuring levels of cortisol (a stress hormone).

This report describes results from the first phase of our study on *daily experiences* as well as levels and patterns of cortisol expression among mothers whose adolescent or adult with ASD was living at home. During our next phase, we plan to collect similar information from all of the families in our study, regardless of the residential status of the son or daughter. This will give us a more complete understanding of the daily lives of families that include an adolescent or adult with ASD.

We are very grateful to the families who have participated in all phases of our study. 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: Daily Experiences

This report includes data from 96 mothers from our study, the Adolescents and Adults with Autism (AAA) study. Mothers were between the ages of 40 and 85, with an average age of 54 at the time of this data collection. As noted earlier, all of these mothers were living with their son or daughter with ASD. The sons and daughters with ASD were between the ages of 14 and 51, with an average age of 22.

Over the course of an eight day period in 2007, mothers were called each evening and asked about their experiences that day. Questions asked about how mothers spent their time during the day, the occurrence of any stressful or positive events, and the types of behavior problems and autism symptoms their son or daughter displayed.

In order to better understand how the daily lives of families with a son or daughter with ASD compare to families without a son or daughter with a disability, a sample of mothers was drawn from a nationally representative study (the MIDUS study). MIDUS stands for “Midlife in the United States”. The MIDUS study contains many of the same questions that were asked of the mothers in our study, including the daily and cortisol measures, which allowed us to compare the groups.

The comparison sample from MIDUS included 230 mothers. They were somewhat younger than mothers in the AAA sample, with an average age of 48. Although these mothers were not parenting a child with a disability, all of them had at least one child living at home. The sons and daughters in the MIDUS study, on average, were 18 years of age. This age difference between the sons and daughters in the AAA and MIDUS studies was statistically controlled in the analyses reported here.

If you are interested, you can learn more about the MIDUS by visiting the MIDUS website (<http://midus.wisc.edu>).

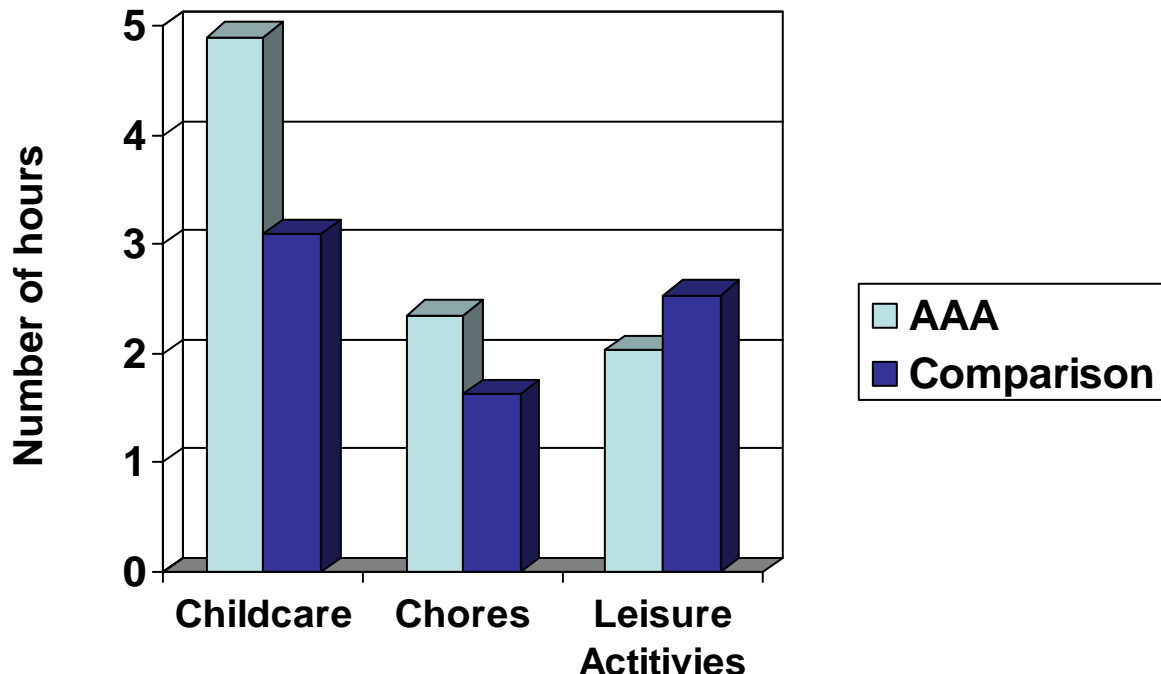
Time Use

Over an 8-day period, mothers were asked how many hours and minutes they had spent during the previous 24 hours doing the following activities:

- Sleeping
- Caring for children
- Household chores
- Business, paid work, school
- Leisure activities
- Watching TV
- Vigorous physical activity

These same questions were asked of mothers in the MIDUS comparison sample who were not parenting a child with a disability. As shown in Figure 1, mothers of a son or daughter with ASD spent significantly more time caring for their children and doing chores, and less time in leisure activities, than mothers in the comparison group. There were no significant differences between the two groups of mothers in time spent sleeping, doing business/paid work, watching TV, or physical activity. Taken as a whole, these data illustrate that mothers of an adolescent or adult with ASD have much busier days than the norm, with less time for leisure activities.

Figure 1. Average Number of Hours per Day Spent on Childcare, Chores, and Leisure Activities



Fatigue, Sleep, and Work Schedules

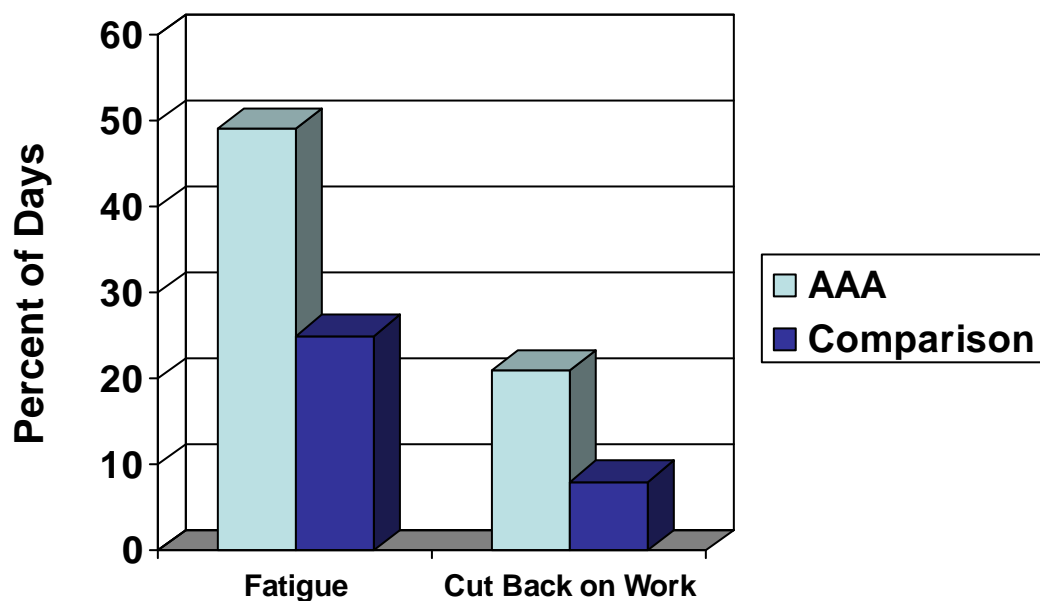
On each of the 8 days, mothers were asked to indicate whether or not they had experienced certain events related to their sleep or work schedules during the previous 24 hours. Mothers in both the AAA and comparison samples responded *yes* or *no* to the following items:

- Did you experience fatigue during the day?
- Did you cut back on normal work?

Mothers with a son or daughter with ASD reported significantly more days with fatigue and more days needing to cut back on work than mothers in the comparison group who did not have a child with a disability. As shown in Figure 2, mothers of individuals with ASD reported fatigue on 50% of the study days, which is almost twice the number of days as mothers of children without disabilities. Additionally, 19% of mothers of individuals with ASD reported fatigue on all 8 days and only 14% reported no fatigue during the 8 day period. Also noteworthy, mothers of individuals with ASD reported having to cut back on their typical amount of work on 21% of days.

Not shown in the figure, but also striking, is that fully 93% of mothers of children with ASD reported experiencing a sleep disturbance at least one night during the 8-day study period. This information was not available from the comparison group.

Figure 2. Percent of Days with Fatigue and Cutting Back at Work



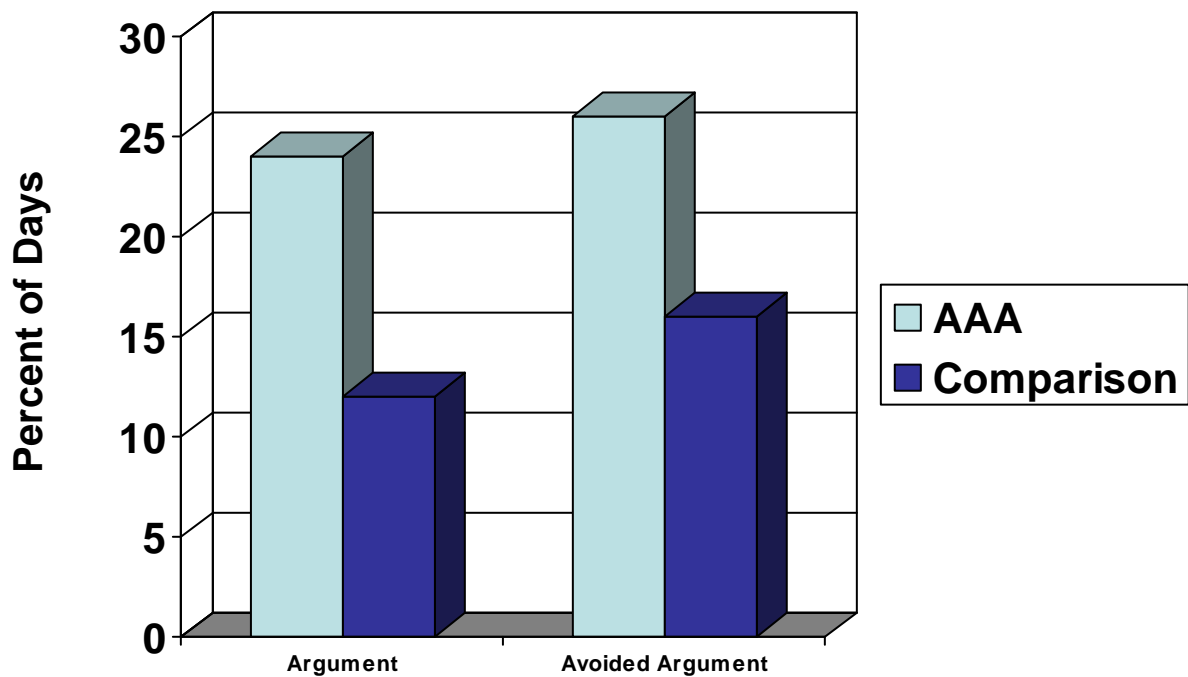
Stressful Daily Events

On each of the 8 days, mothers reported whether they had experienced various *stressful* events in the previous 24 hours. Mothers responded *yes* or *no* to the following questions:

- Did you have an argument or disagreement with anyone since this time yesterday?
- Since this time yesterday, did anything happen that you **COULD** have argued about but you decided to **LET PASS** in order to **AVOID** a disagreement?
- Since this time yesterday, did anything happen at work or school that most people would consider stressful?
- Since this time yesterday, did anything happen at home that most people would consider stressful?
- Since this time yesterday, did anything happen to a close friend or relative that turned out to be stressful for **YOU**?

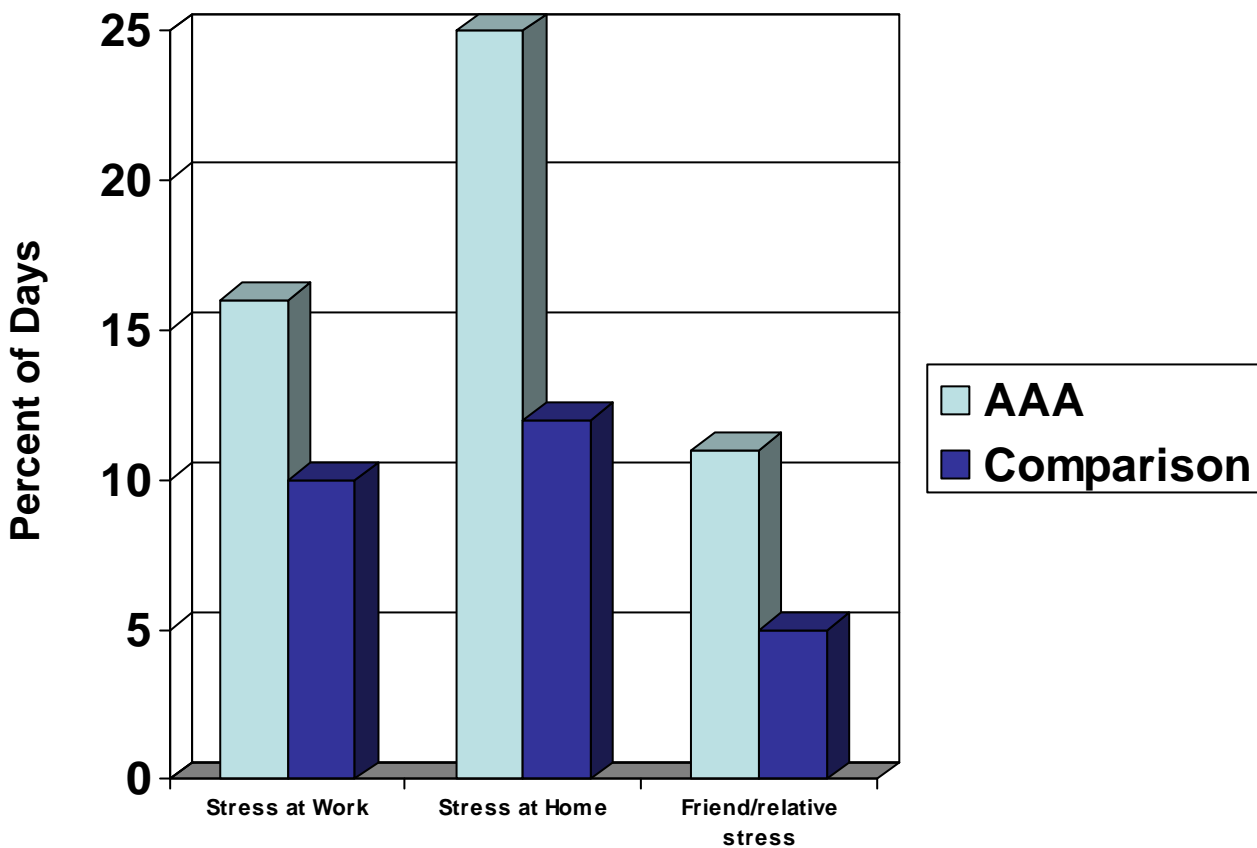
The two groups of mothers differed significantly on all five of these measures of daily stress.

Figure 3. Percent of Days with Arguments and Avoided Arguments



As shown in Figure 3 on the previous page, mothers with a son or daughter with ASD experienced arguments on twice as many days as did mothers in the comparison group. When compared to mothers of individuals without disabilities, mothers of individuals with ASD also reported more days during which there was a time they could have had an argument, but chose not to.

Figure 4. Percent of Days with Stress at Home, Stress at Work, and Stress Experienced by a Friend/Relative



As seen in Figure 4, in contrast with mothers in the comparison group, mothers in the AAA sample reported significantly more days with something stressful happening to them at work, at home, or to a friend or relative. In fact, mothers of adolescents and adults with ASD experienced twice as many days with stress at home as well as stress among friends and family, as did mothers in the comparison group.

Positive Daily Events

On each of the 8 days, mothers also responded with a *yes* or *no* to each of the following questions about positive events:

- Did you have an interaction with someone that most people would consider particularly positive since this time yesterday?
- Since this time yesterday, did you spend any time doing formal volunteer work?
- Since this time yesterday, did anything happen to a close friend or relative that turned out to be particularly positive for YOU?

Mothers of a son or daughter with ASD did not differ from mothers in the comparison group in terms of the percent of days that they had positive interactions, did volunteer work, or reported positive events for friend/relative. Mothers with a son or daughter with ASD reported (a) having positive interactions on 70% of the days that they participated in the daily study, (b) doing volunteer work on 12% of the days, and (c) experiencing positive events for friends/relatives on 18% of the days, all similar to findings from the comparison group.

Thus, having a son or daughter with ASD did not interfere with mothers' experiences of everyday positive events.

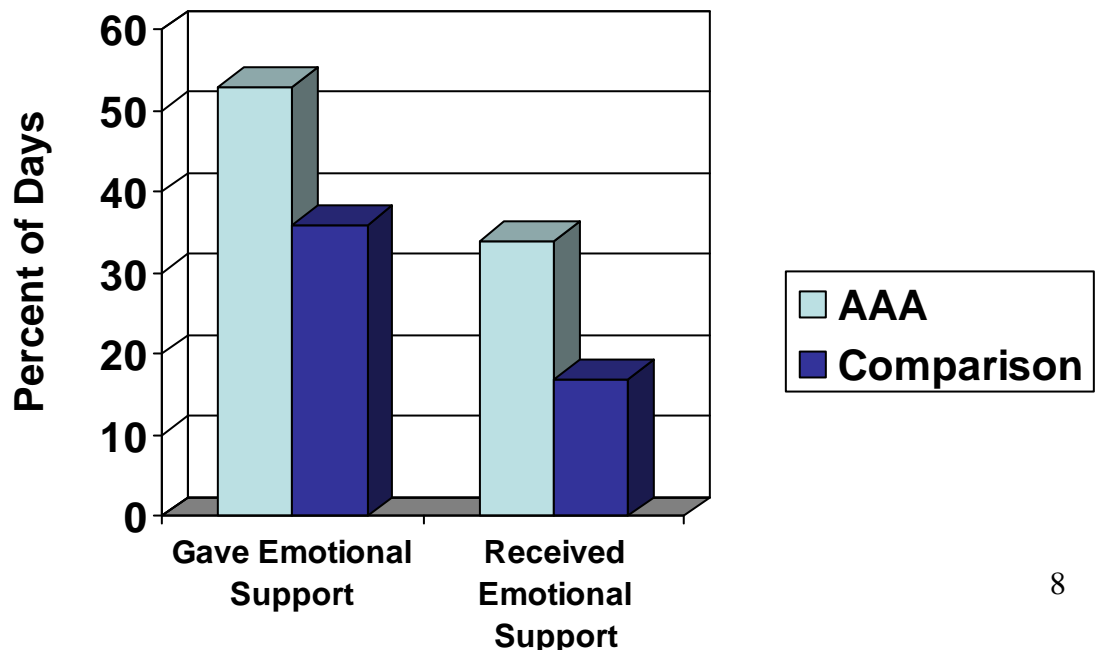
Social Support

Additionally, mothers reported on giving and receiving unpaid assistance and emotional support. Mothers responded with a *yes* or *no* when asked the following questions:

- Since this time yesterday, did you RECEIVE any emotional support from anyone or any organizations?
- Not counting work you might do as part of your job, did you spend any time GIVING emotional support to anyone?
- Since this time yesterday, did you RECEIVE any unpaid assistance from any organization or person who does not live with you?
- Since this time yesterday, did you spend any time GIVING any unpaid assistance to people who don't live with you?

There were no differences between the two groups of mothers for giving and receiving unpaid assistance. Mothers in the AAA sample reported giving unpaid assistance on 15% of days and receiving unpaid assistance on 6% of days. However, as presented in Figure 5, mothers of adolescents and adults with ASD were more likely than comparison group mothers to both give and receive emotional support. They gave emotional support to others on more than half of the days, on average, and received support on one-third of the days.

Figure 5. Percent of Days with Emotional Support Given and Emotional Support Received



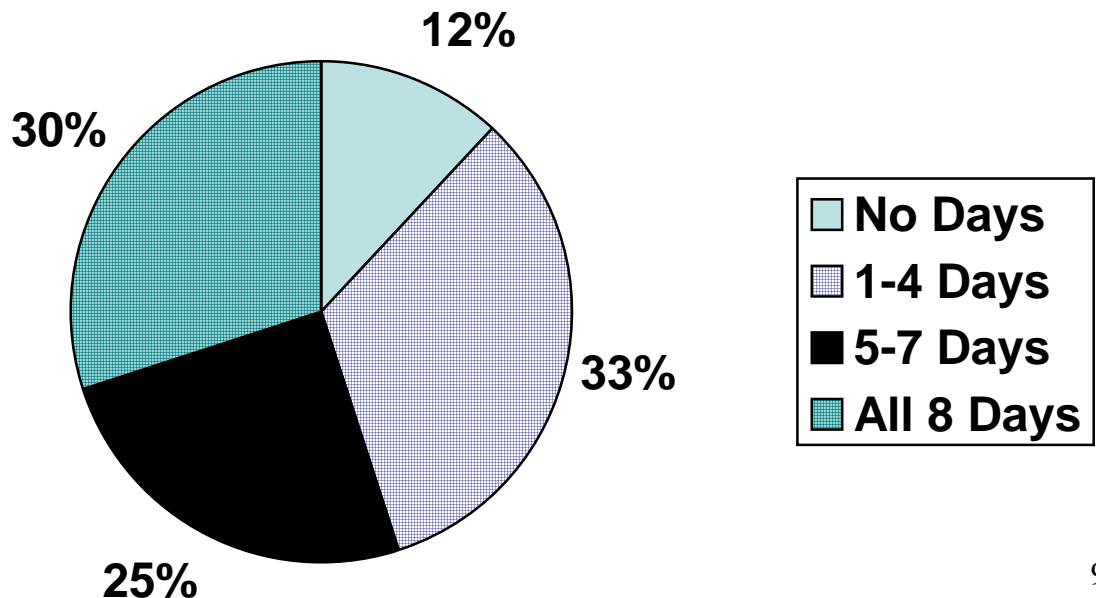
Behavior Problems

As part of the daily interview, mothers in the AAA study reported whether their son or daughter with ASD exhibited various behavior problems during the previous 24 hours. These questions were not asked of the comparison group. Mothers in the AAA study responded *yes* or *no* to the following questions:

- Did your child hurt himself or herself today?
- Was your child destructive or hurtful to others?
- Was your child destructive to property today?
- Did your child show any unusual or repetitive behavior today?
- Did your child show any socially offensive behavior today?
- Was your child withdrawn or inattentive today?
- Was your child uncooperative today?

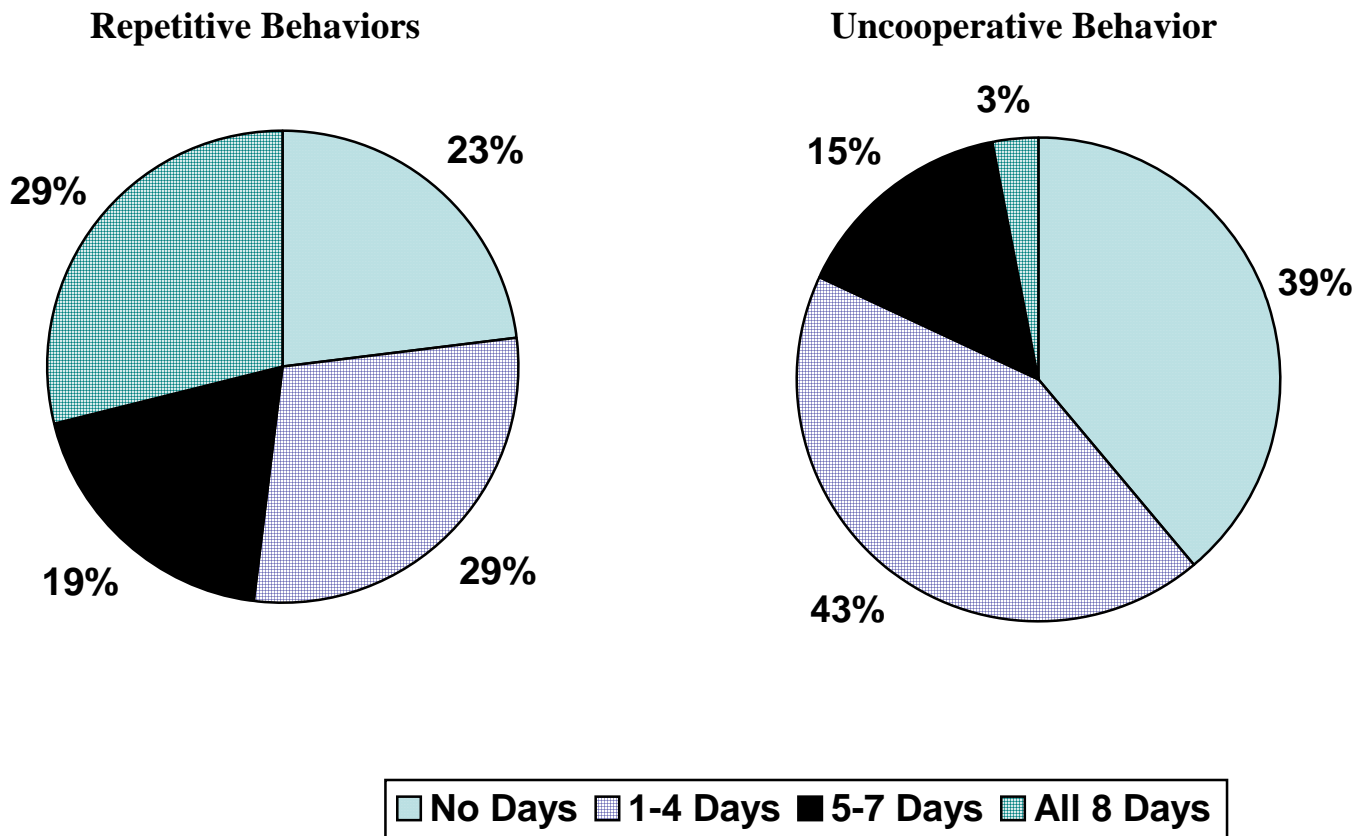
We calculated the number of days on which mothers reported that their son or daughter exhibited at least one behavior problem. On average, mothers reported that their son or daughter exhibited at least one behavior problem on 4.6 days during the 8-day study period. As shown in Figure 6, only 12% of mothers did not report any behavior problems during the study and 30% of mothers reported at least one behavior problem on all 8 days.

Figure 6. Percent of Mothers Reporting at Least One Behavior Problem

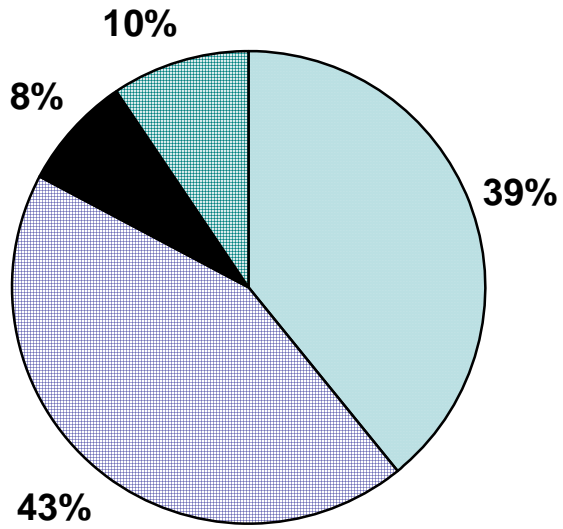


We also calculated the number of days on which mothers reported that their son or daughter experienced each type of behavior problem. As presented in Figure 7, (which continues onto the next page), 77% of mothers reported *repetitive behaviors* on at least one day of the 8-day study. Additionally, 61% of mothers reported *uncooperative behavior* as well as *withdrawn behavior* at some time during the study period. Other behavior problems were also evident in this sample; 49% of mothers reported that their son or daughter exhibited *socially offensive behavior* on at least one day. Also presented in Figure 7, 20% of mothers reported that their son or daughter displayed behavior that was *hurtful to self* on at least one day of the 8-day study period. Similarly, 17% and 13% of mothers reported at least one day in which their son or daughter exhibited behavior that was *hurtful to others* or *hurtful to property*, respectively. Thus, the most prevalent behavior problem was repetitive behaviors and the least prevalent was destruction of property.

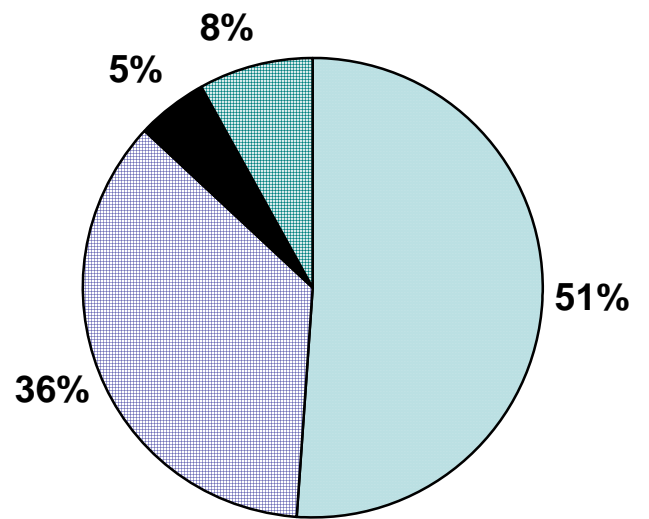
Figure 7. Percent of Mothers Reporting Specific Types of Behavior Problems



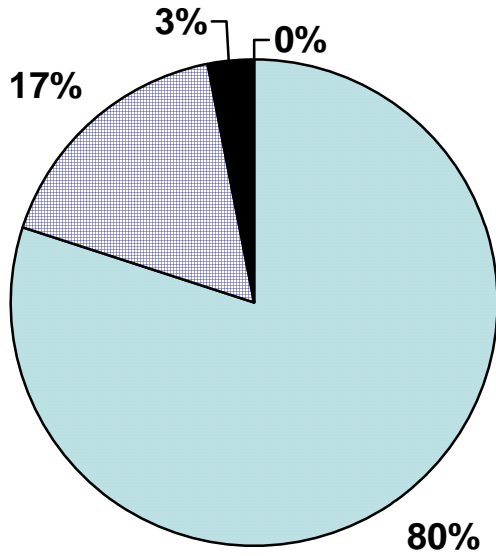
Withdrawn Behavior



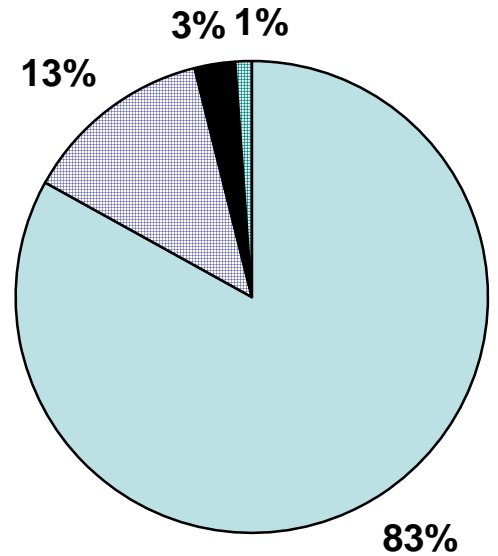
Socially Offensive Behavior



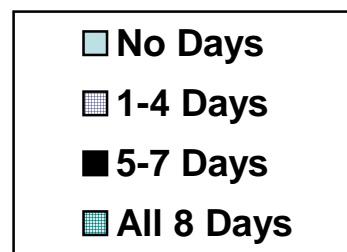
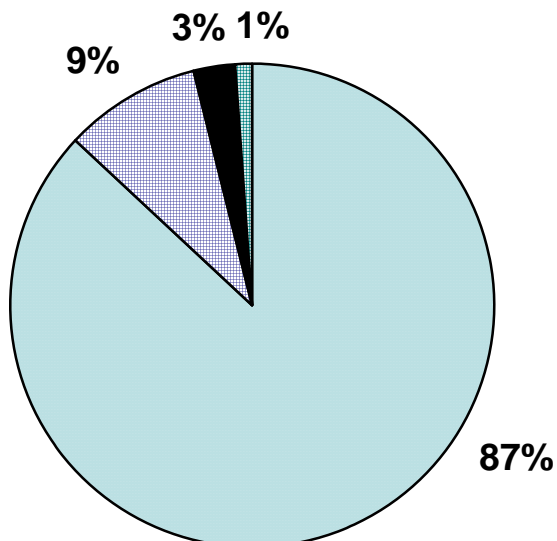
Hurtful To Self



Hurtful To Others



Hurtful To Property



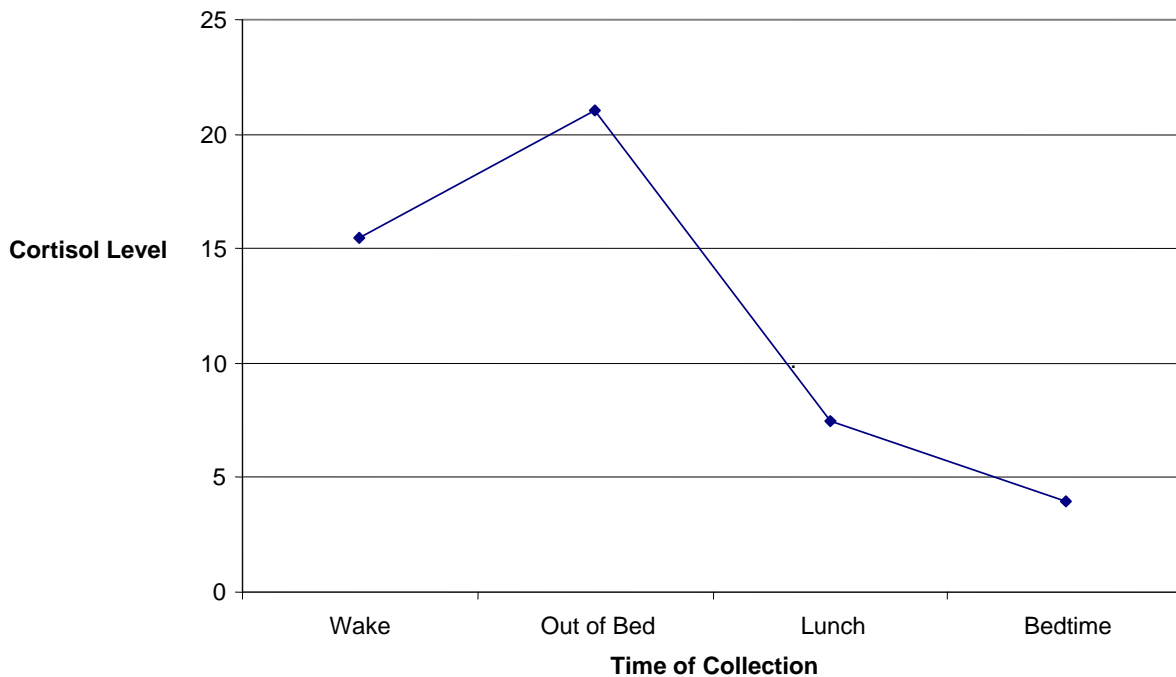
Section III: Cortisol

Cortisol is a hormone that is released by the body in response to stress. Researchers have become increasingly interested in cortisol because it serves as a biological marker for stress. Additionally, cortisol may play a role in several other physiological systems that affect health, including the body's immune response to the threat of illness.

Cortisol is contained in saliva. In our study, we measured the cortisol levels of mothers by asking them to provide saliva samples at four different points during the day (waking up, getting out of bed, lunch time, and bed time). Mothers provided saliva for these 4 different points during the day on 4 days of the 8-day study. Thus, we were able to obtain 16 different cortisol samples to measure how stress fluctuates during the week.

In most people (see Figure 8), levels of cortisol change throughout the day. The typical pattern is for cortisol to be highest shortly after a person wakes up in the morning and then to decline steadily until the end of the day. It is thought that cortisol peaks early in the day in order to help us get up and get going in the morning, and then declines as our body winds down and prepares for sleep.

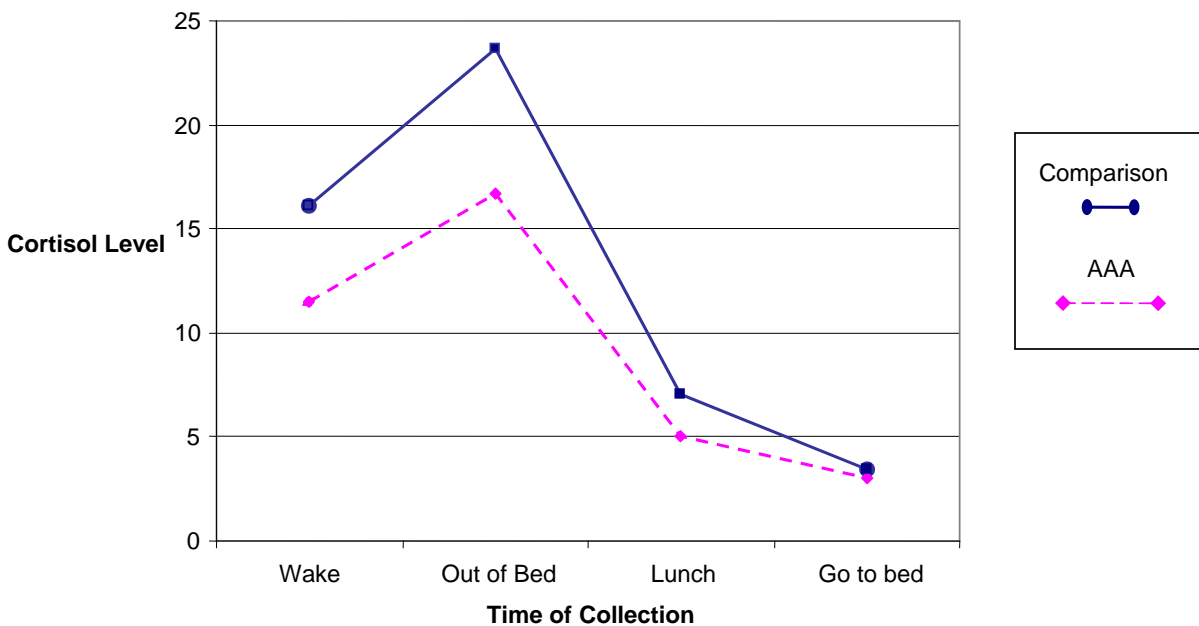
Figure 8. Normal Daily Cortisol Rhythm



Average Cortisol Levels

As shown in Figure 9, mothers of individuals with ASD generally had lower levels of cortisol than mothers in the comparison group. Although higher cortisol levels are related to higher levels of short-term stress, some individuals who experience high levels of stress over extended periods of time tend to exhibit *lower* levels of cortisol overall. It is possible that over time, mothers of children with ASD get accustomed to stress, until eventually they produce less cortisol. This may help explain why in our study mothers of individuals with ASD tended to have significantly lower cortisol levels than mothers in the comparison sample.

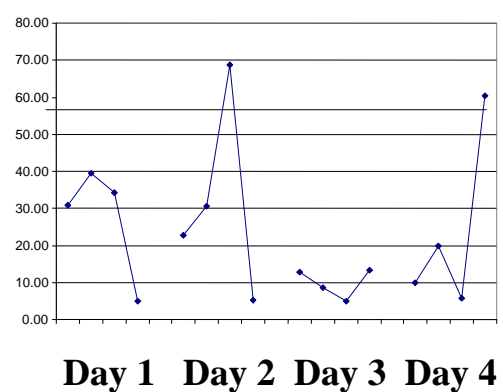
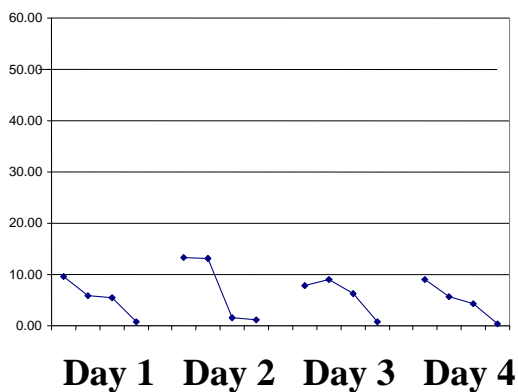
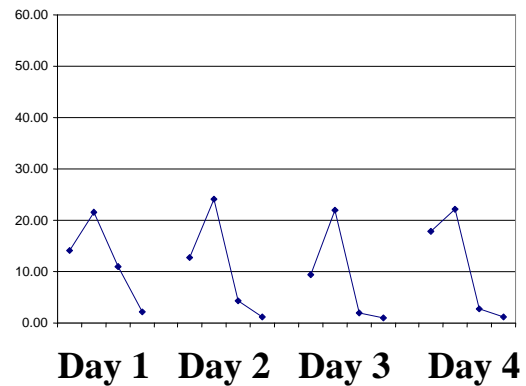
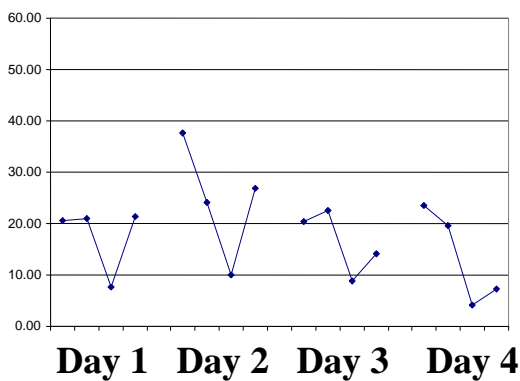
Figure 9. Average Cortisol Levels of Mothers of Individuals with ASD and Mothers of Individuals without Disabilities



It is important to note that there was a great deal of variation in the amount of cortisol expressed by mothers in both groups. Some mothers of individuals with ASD had cortisol levels that were similar to mothers in the comparison group, and others had higher or lower levels. Nevertheless, Figure 9 shows that the average cortisol levels of mothers in the ASD group were much lower than the average cortisol levels of mothers in the comparison group.

As shown in Figures 10, there was much variability in the levels of cortisol expressed by mothers of individuals with ASD throughout the day and across different days. For instance, some mothers displayed the same pattern of cortisol expression every day whereas others had very different profiles across the four days. Additionally, although some mothers exhibited the expected pattern of decreasing cortisol after an initial rise in the morning, other mothers displayed an increase at the end of the day. This is a nice opportunity for us to remember that despite the fact that mothers of individuals with ASD all share the common experience of parenting a son or daughter with a disability, each person approaches and responds to the world a little bit differently. By describing the profiles of cortisol in mothers of individuals with ASD, we can begin to understand how parenting a son or daughter with a disability may affect individual people in different ways.

Figures 10. Examples of Cortisol Profiles in Four Different Mothers of Individuals with ASD



Section III: Conclusions

This report has described the types of daily events experienced by mothers of a son or daughter with ASD compared to mothers who are not parenting an individual with a disability. Within the group of mothers who have a son or daughter with ASD, we also reported on the day to day fluctuations of behavior problems.

There were a number of differences between the groups in terms of their daily experiences. Mothers of a son or daughter with ASD tended to report more fatigue, as well as more episodes of having to cut back on typical work hours, likely the result of their special parenting responsibilities. Mothers of individuals with ASD also reported experiencing, as well as avoiding, more arguments and more stress at home, at work, and with friends.

Behavior problems in the son or daughter with ASD were frequently reported by mothers across the 8-day period of data collection. Repetitive behaviors were the most commonly reported problem, whereas destructive behaviors were less frequent.

Unlike our findings with regard to stressful daily events, we did not find group differences in the number of positive daily events. The groups did not differ in the amount of time they spent on volunteer work or providing assistance to others. This suggests that despite experiencing a greater number of stressful events and having higher demands on their time, mothers of a son or daughter with ASD still find time for positive interactions. In fact, mothers of a son or daughter with ASD reported providing and receiving *more* emotional support than mothers in the comparison group.

We have also provided a brief summary of our findings about cortisol, a hormone associated with stress. Mothers of a son or daughter with ASD generally had lower levels of cortisol compared to mothers in the comparison group; however there was a great deal of individual variability. We are currently studying how variability in cortisol affects the health and psychological well-being of mothers and look forward to sharing these findings in greater detail in the future.

These preliminary results provide researchers and practitioners with an important new understanding of how mothers' daily lives can be affected by parenting a son or daughter with ASD. Hopefully this work will motivate those in public health and policy to design new ways of supporting families, such as providing respite care programs, behavior modification interventions, and helping to develop family-friendly employee policies so that quality of life can be enhanced for individuals with ASD and their families.

We hope that our continued examination and publication of these results, along with future data collection from our study participants, will yield further evidence to help us inform programs and interventions. Ultimately, our goal is to have our research improve the quality of life and well-being of families who have a son or daughter with ASD.