



Adolescents and Adults with Autism

A Study of Family Caregiving

**Report #2:
A Profile of Adolescents and Adults
with Autism Spectrum Disorders**

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We are extremely grateful to the families of the 405 adolescents and adults who have given so generously of their time and shared their lives with us.

Visit us at our website: <http://www.waisman.wisc.edu/family/index.html>

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Section I: Context for the Study

Introduction

We want to thank you and your family for participating in our study, “Adolescents and Adults with Autism: A Study of Family Caregiving.” Without your commitment, we would not be able to conduct this important research. This report is the second in the series of reports to you about what we have learned thus far in this study. The first report was titled "A Book of Quotes: Shared Experiences of Families of Adolescents and Adults with Autism."

The report describes the history and purpose of the project, the recruitment of participants for this study, and some of our findings regarding adolescents and adults with autism spectrum disorders (ASD). We also present a range of information on the lives of the adolescents and adults with autism spectrum disorders, including their diagnoses and symptoms, social and recreational activities, challenging behaviors, services and treatments, and changes in symptoms over time.

Autism spectrum disorders form a continuum, with individuals ranging from mildly to moderately to severely affected. The findings in this report are based on 405 individuals with autism spectrum disorders. While this report may not describe your family member exactly, it does describe the differences and commonalities among the individuals who participate in our study. It is with much gratitude that we share our findings with you.

What is the history of this study?

This research began in 1998. We have conducted research on the challenges of lifelong parenting among families of individuals with developmental disabilities for nearly fifteen years. Several years ago, we recognized a gap in knowledge about the unique needs of families whose son or daughter had an autism spectrum disorder. Our goal is to chart the course of autism symptoms across the life course and to investigate the impact on families of providing a lifetime of care to a son or daughter with an autism spectrum disorder.

With initial support from the Nancy Lurie Marks Foundation and the Graduate School of the University of Wisconsin-Madison, we recruited the sample of families who are participating in this study. Ongoing grants from the National Institutes of Health and the National Institute on Disability and Rehabilitation Research have made it possible to extend this research through 2005.

This is the largest study of adolescents and adults with an autism spectrum disorder ever to be conducted, and it is the only study to investigate family well-being across the life course. Thank you for joining us in this important investigation!

What is the purpose of this study?

There is a heightened interest in and increased research funding for studying the neurological, genetic, and environmental causes of disorders on the autism spectrum. There is also social and public policy concern regarding the quality of life of persons with autism spectrum disorders and the adaptation of their families. As is true for many people with lifelong disabilities, families play a critically important role in helping their children with ASD mature, obtain the services and supports they need, and develop meaningful lives as adults. However, there is very little public understanding of the family life accommodations that must be made, the challenges faced in securing appropriate educational and adult services, and the impact of the varying needs of their child with ASD on all family members. These issues are central to our research.

Most studies of families of children with ASD have focused on the period when the children are young, usually under 8 years of age. There is a vast amount of uncharted territory in understanding how families of adolescents and adults manage their caregiving responsibilities, how changes in the child's functioning affect families over time, and how parents and siblings cope with the challenges of a family member with ASD. There is also much to be accomplished in the development of informed public policy and services for families and for adolescents and adults with ASD.

This study was designed to address these important concerns and questions. Our study spans a five-year period, in which we hope to collect information from participants four times. As we continue this study, we will provide additional reports to you about our findings.

How did we find the families who are participating in this study?

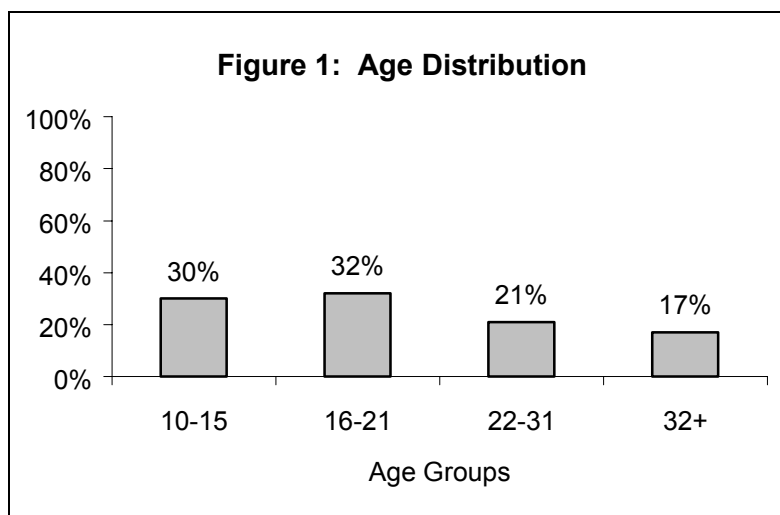
Our goal was to recruit 400 families (half from Wisconsin and half from Massachusetts) with a son or daughter who had an autism spectrum disorder and who ranged in age from 10 years old through adulthood. To accomplish this, we enlisted the help of professionals from diagnostic clinics, schools, service agencies, and advocacy groups such as the Autism Society, to distribute and post descriptions of the study and invitations for families to participate. We also promoted the study through the news media. Informational packets were distributed to families inviting them to participate.

In total, our sample consists of 201 individuals from Wisconsin and 204 individuals from Massachusetts - for a total of 405 adolescents and adults with an autism spectrum disorder. Some of these families have more than one child with ASD, so the total number of families participating in the study is 396.

Section II: Description of Adolescents and Adults with ASD

Who are the sons and daughters with an autism spectrum disorder?

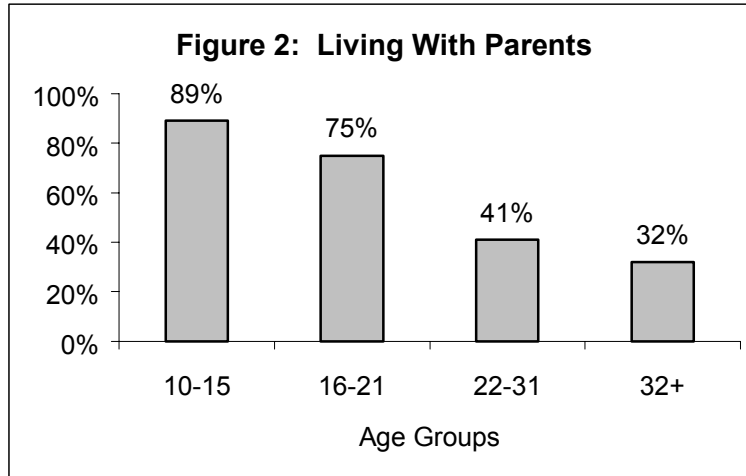
- There are 405 individuals with an autism spectrum disorder in this study. When our study began, they ranged in age from 10 to 53 years. Figure 1 below shows the percentage of individuals in the study that fall into each of four age groupings. Nearly two-thirds (62%) of our study participants are adolescents, while more than one-third (38%) are adults.



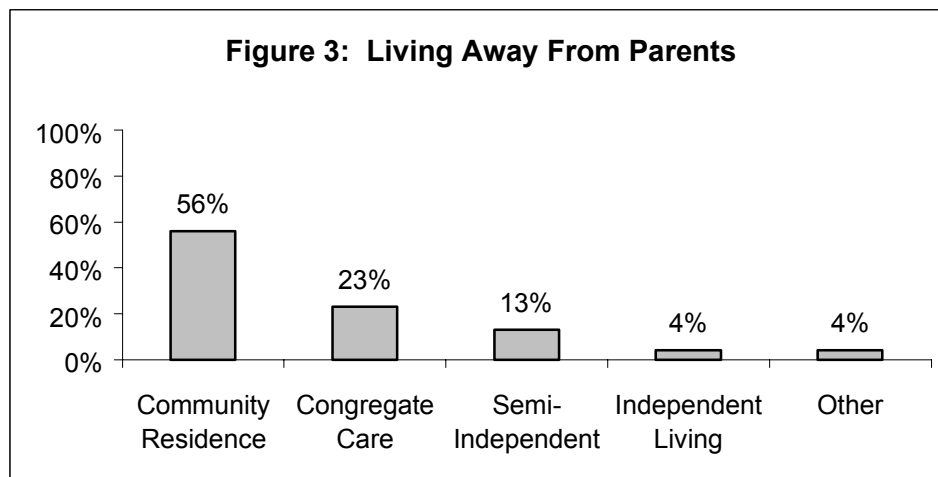
- At the first round of data collection, the average age of the individuals with an autism spectrum disorder was 21.7 years old.
- Nearly three-fourths (73%) are male, while one-fourth (27%) are female. This is consistent with what we know about autism, which occurs about 3 to 4 times more frequently among males than females.

Where do they live?

- Overall, 65% of the adolescents and adults in our study live at home with their parent(s) and 35% live away from home. As shown in Figure 2, many more of the adolescents live with their parents than the adults, who are more likely to live in community settings. Figure 2 shows the percentage of each age group who lived with their parents at the time of our first round of data collection.

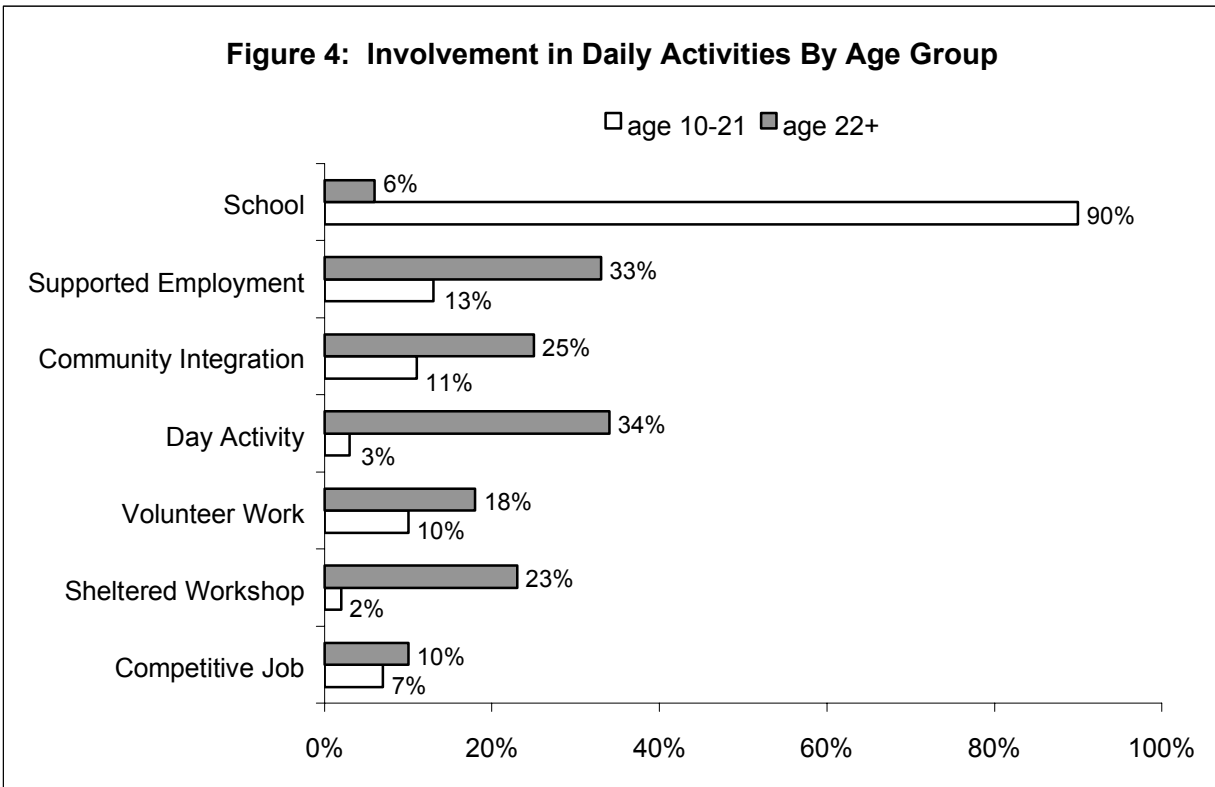


- Most of the 142 sons and daughters who live away from their parent's home are in some kind of supported or supervised living situation. Figure 3 shows the percentage of these individuals who live in different types of settings.



What do they do during the day?

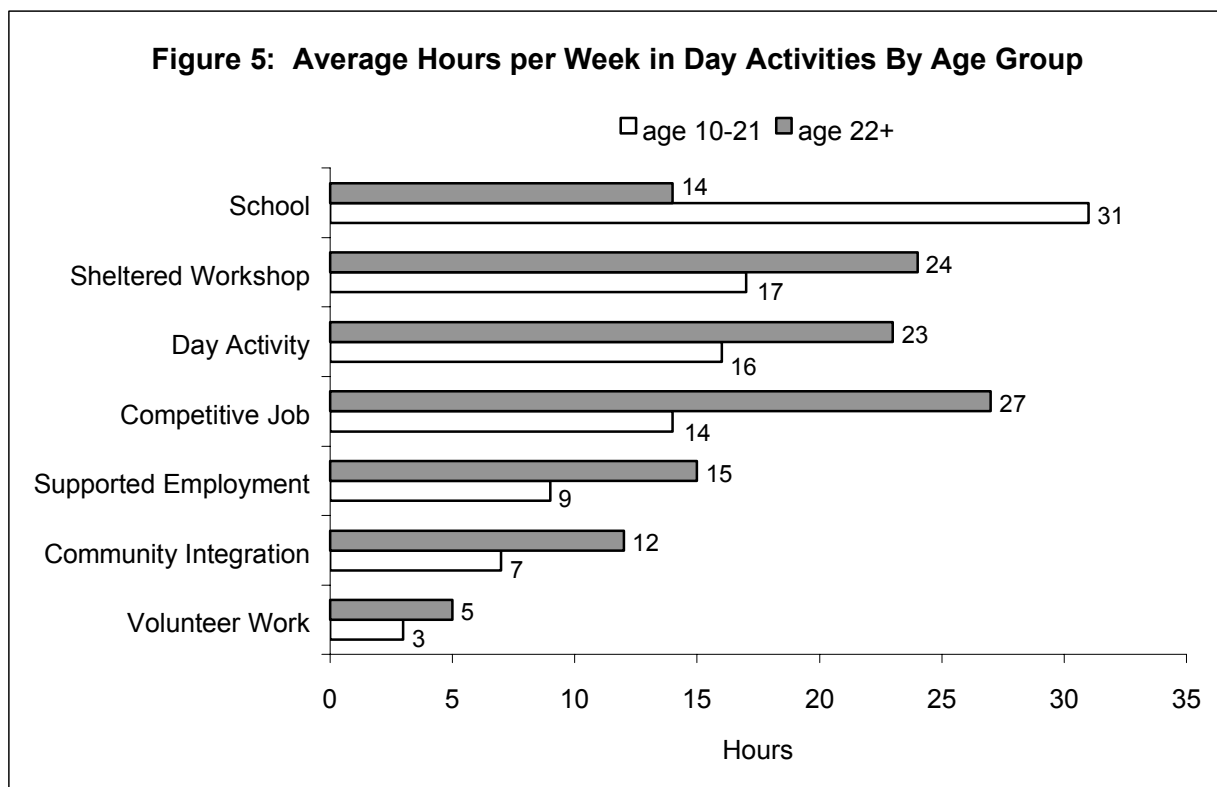
Individuals with autism spectrum disorders spend their days in a variety of settings and many engage in multiple activities on any given day. Figure 4 shows how members of each age group (10 to 21, 22 and older) spend their days.



- The vast majority (90%) of individuals in the 10 to 21 age range spend at least part of their day in a school setting. About 20% of the 10 to 21 year olds have some kind of job (competitive, supported, or sheltered employment).
- The majority (approximately 60%) of the adults have some kind of job (competitive, supported, or sheltered employment).
- Although not shown directly in Figure 4, most (95%) of the adults age 22 and older are involved in at least one type of daily activity.

Figure 5 portrays the average amount of time per week that individuals in each age group spend in various activities.

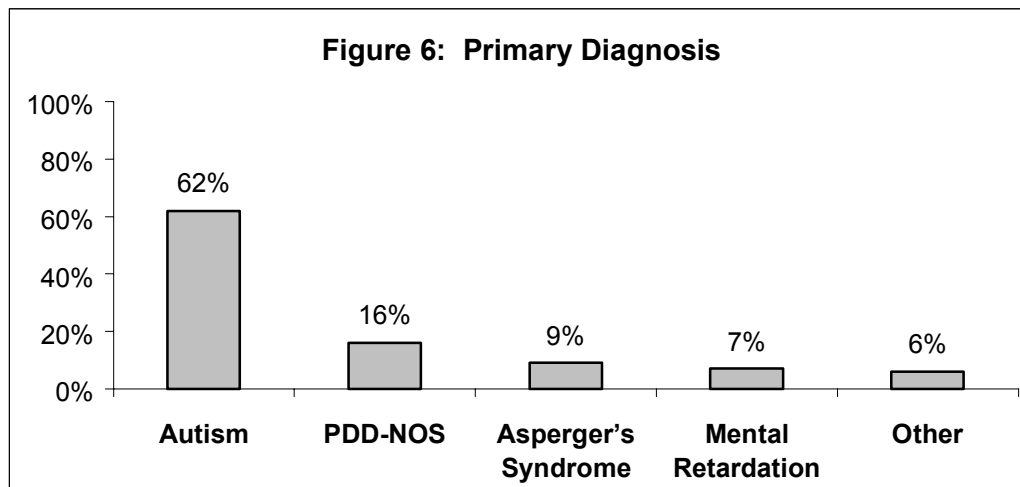
- Individuals in the 10 to 21 age range who attend school typically spend about 31 hours per week there.
- Adults who attend school spend only 14 hours per week in a school setting.
- Competitively employed adults spend roughly 27 hours per week at their jobs.
- Competitively employed teens spend an average of 14 hours per week at their jobs.



What are their diagnoses?

Much of the research on autism spectrum disorders has been conducted by examining the symptoms of young children. One of the main reasons we began this study was to learn how symptoms change over the course of time as people grow up and become adults. A first step in this direction involves documenting the types of diagnoses and symptoms individuals on the autism spectrum manifest.

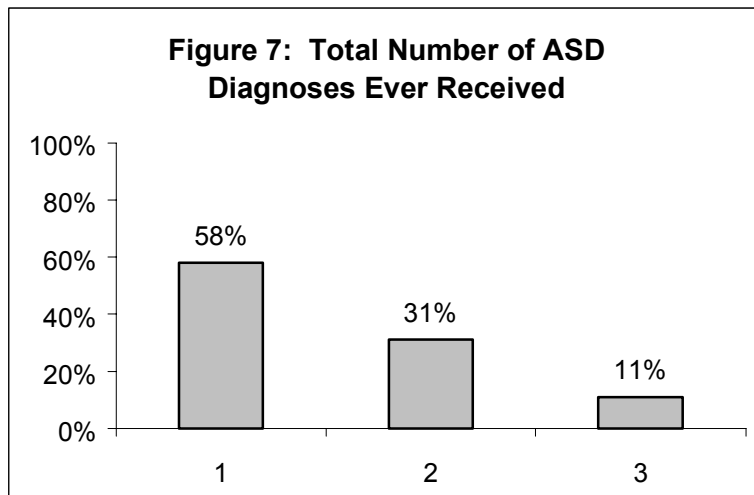
Figure 6 below describes the primary diagnoses of the sons and daughters in our study. All of the individuals in our study have an autism spectrum diagnosis - either Autism, Asperger's Syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). However, many individuals with an autism spectrum disorder also have other health conditions and diagnoses. So, we asked parents to tell us what they consider their son or daughter's primary diagnosis to be.



- As Figure 6 portrays, almost two-thirds (62%) of the sons and daughters in the study have a primary diagnosis of autism.
- Less than a fifth (16%) have a primary diagnosis of Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS).
- Less than a tenth have a primary diagnosis of Asperger's Syndrome (9%), Mental Retardation (7%), or 'Other' (6%).

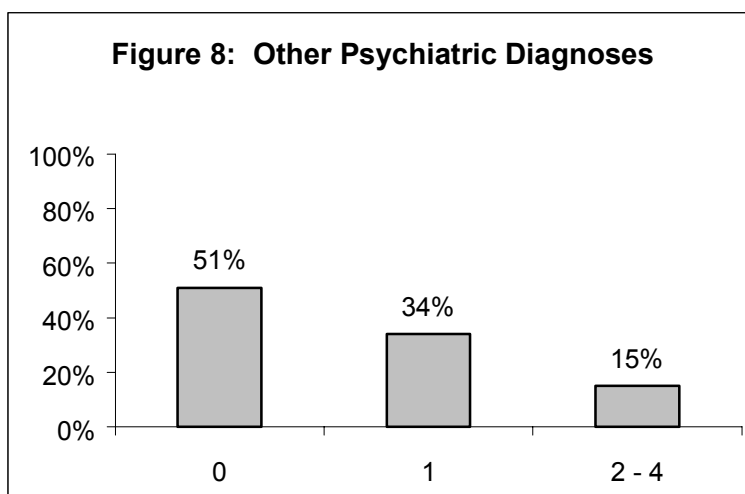
The criteria and practices for diagnosing autism spectrum disorders have changed over the past several decades. Sometimes individuals receive different diagnoses from different professionals or at different points in their lives.

- As shown in Figure 7, among the people in our study, 31% received two different autism spectrum diagnoses over the years. Eleven percent had received all three diagnoses (Autism, Asperger's Syndrome, and PDD-NOS).



We also asked parents whether their son or daughter had ever been diagnosed with any of four other relatively common psychiatric conditions: Attention Deficit Disorder, Obsessive Compulsive Disorder, Schizophrenia, and Bipolar Disorder. The results are displayed in Figure 8.

- Half the individuals in our study had never received any of these other diagnoses.
- One third had received one of these four diagnoses at some point during their lifetime.
- About 15% had received two or more of these diagnoses.



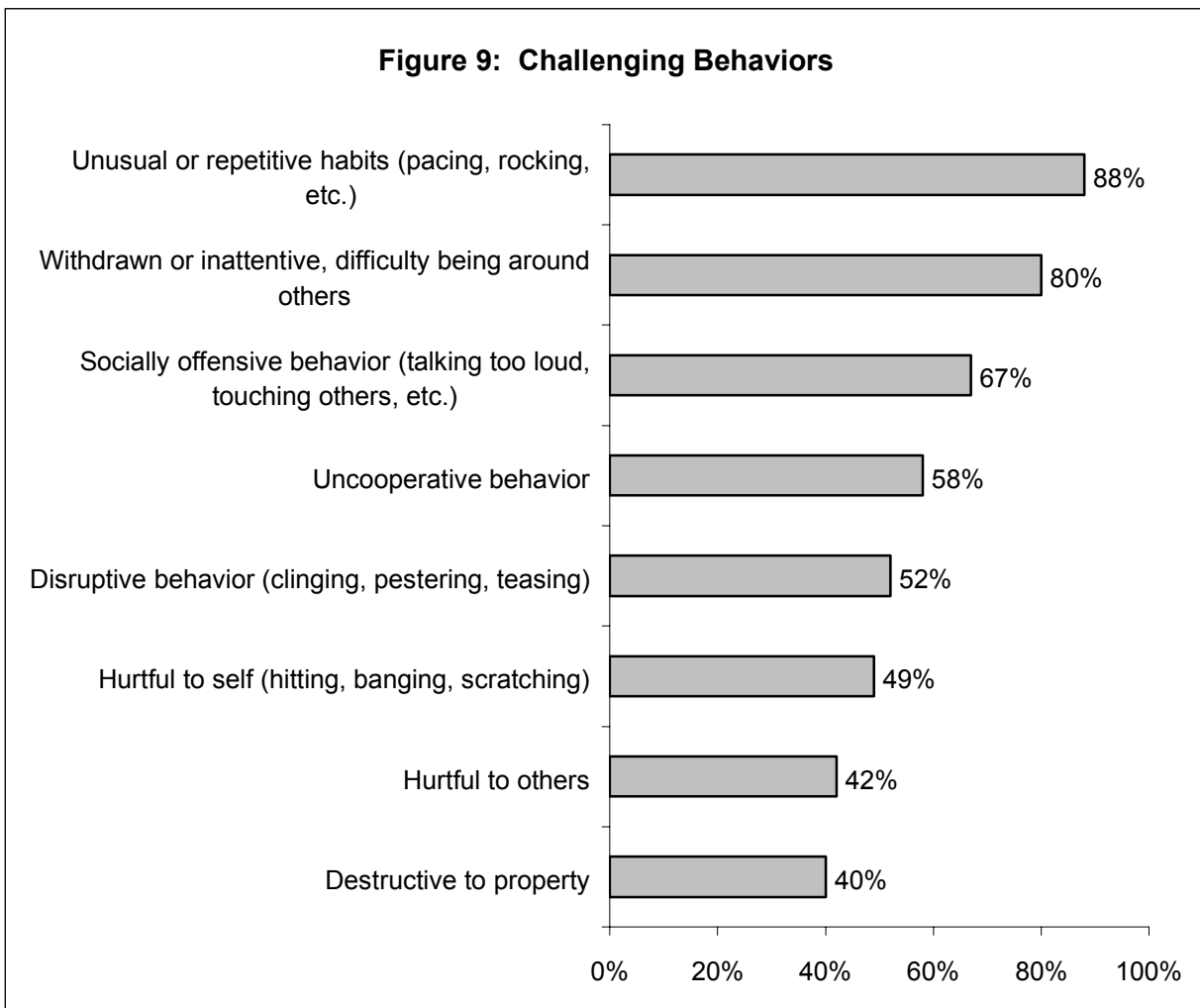
- The most commonly received diagnoses were Attention Deficit Disorder (nearly 33%) and Obsessive Compulsive Disorder (almost 25%).

Finally, we also asked about other aspects of health.

- Nearly one-quarter (23%) also have a seizure disorder.
- Altogether, 85% of parents rate the physical health of their son or daughter with ASD as either good or excellent.

What are their challenging behaviors?

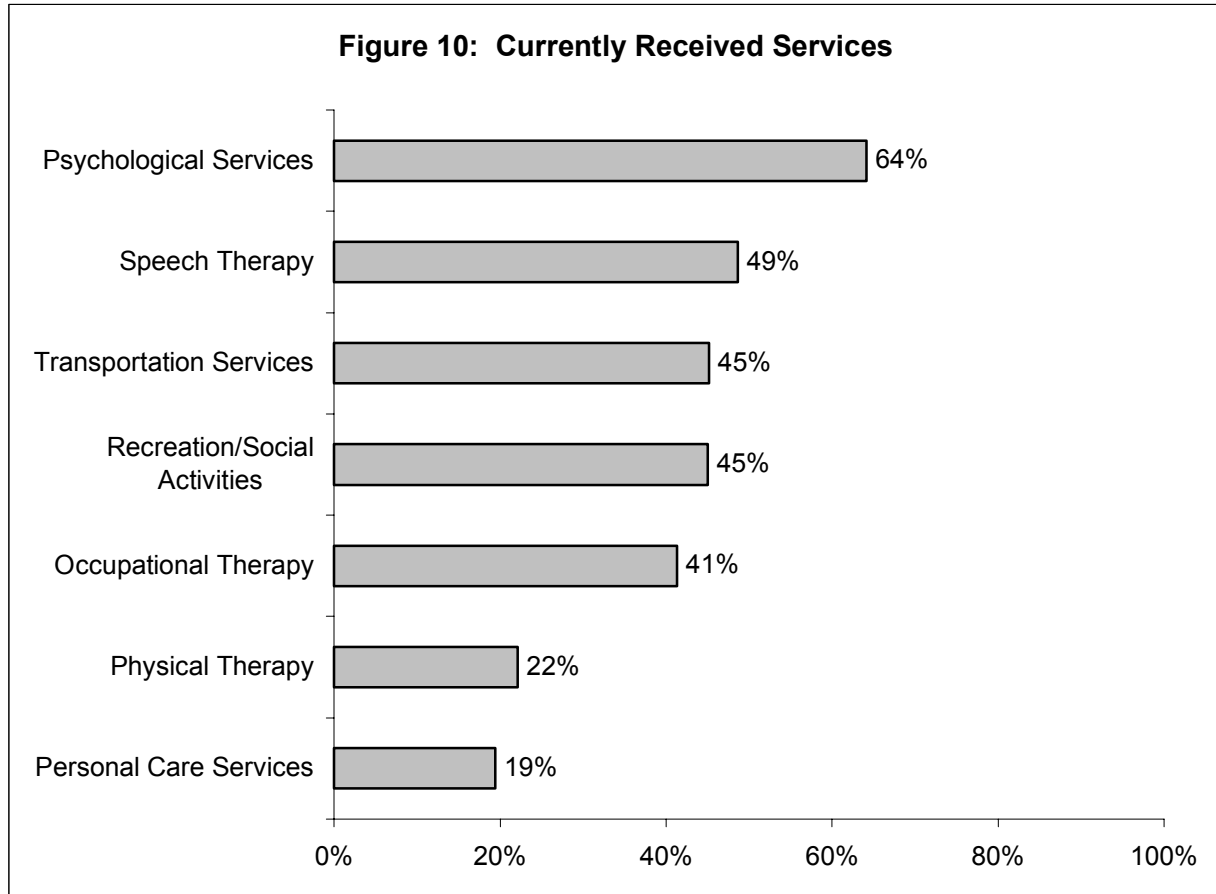
We asked parents questions about whether their son or daughter had eight types of behavior problems that can be especially challenging for families. Figure 9 reports the percentage of individuals who had each of these behavior problems at the time of our first round of data collection.



- The most common types of challenging behaviors are unusual or repetitive habits (88%) and withdrawn or inattentive behaviors (80%).
- Fully 98.8% of the adolescents and adults with ASD had at least one of these eight types of behavior problems. The average number was five per person.

What kinds of services and treatments do they receive?

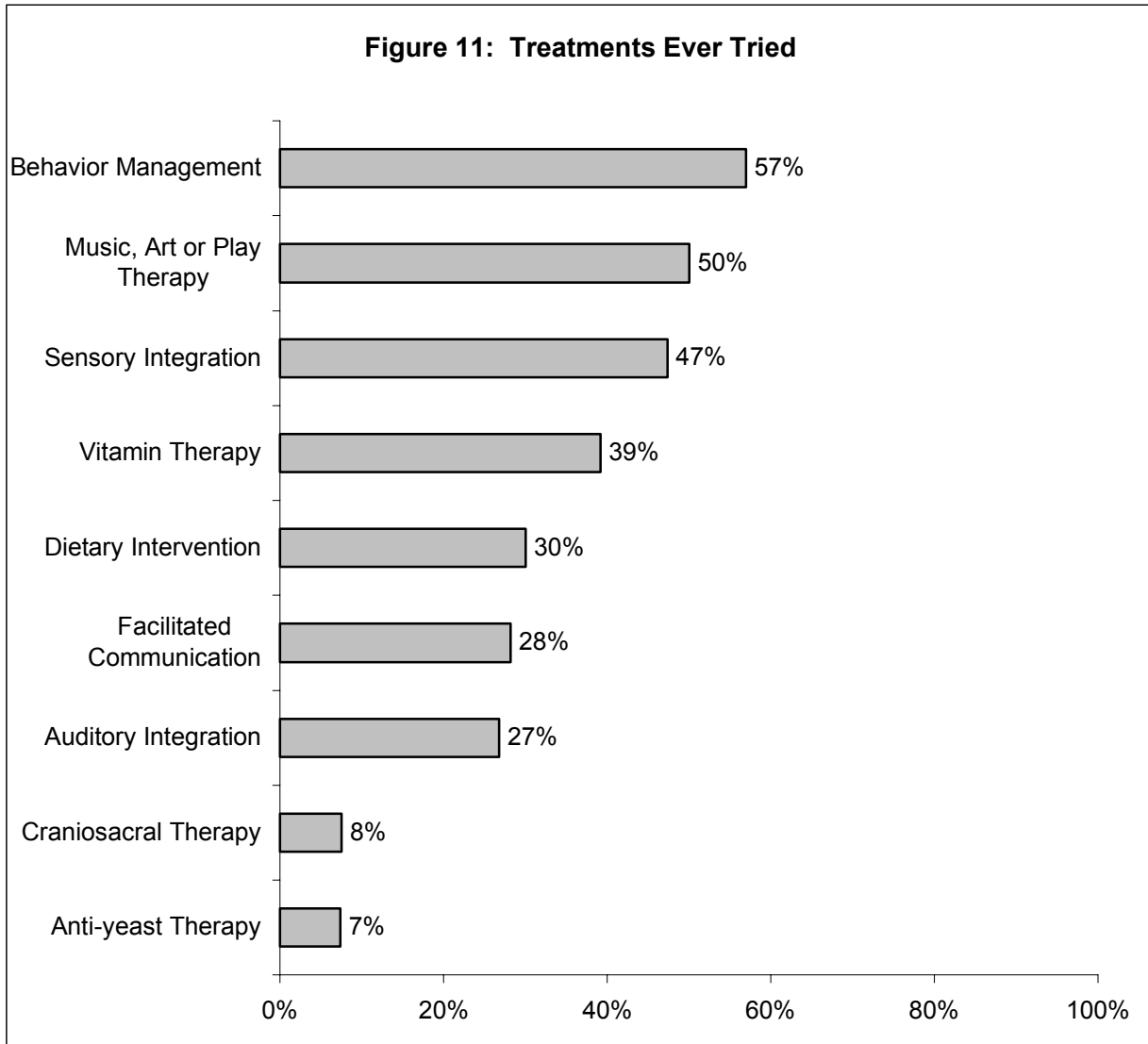
We asked questions about what kinds of services the son or daughter with ASD is currently receiving. These findings are reported in Figure 10.



- About two-thirds (64%) of the adolescents and adults with ASD receive psychological services, and nearly half (49%) receive speech therapy, transportation and recreational/social activities.
- Nearly all (92.3%) of the sons and daughters are receiving at least one of these services. The average number of services received is three per person.

Medication is another kind of treatment. Fully 70% of the sons and daughters take prescription medications. The total number of medications taken ranged from 0 to 13. Among those on medication, the average number taken is about three.

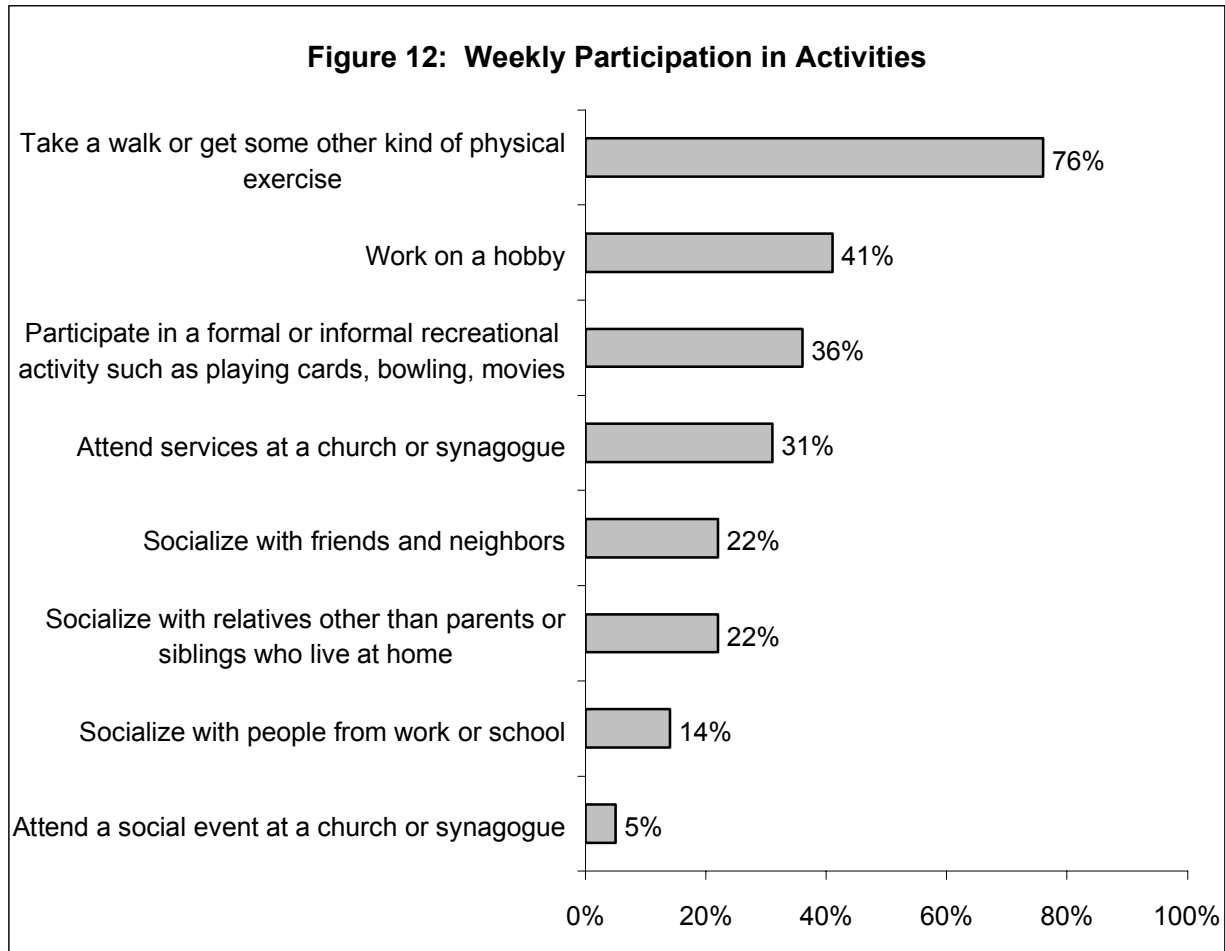
We also asked questions about what kinds of treatments families have ever tried at some point. Figure 11 lists the percentage of adolescents or adults who have ever received each listed treatment. This does not represent how many individuals are currently using each type of treatment.



- Fully 90.9% of the families had tried at least one of these types of treatments. The average number was three per person.

What social and recreational activities do they enjoy?

We asked parents whose son or daughter lived at home (a total of 263 individuals) to tell us about their child's involvement in social and recreational activities. Figure 12 below summarizes the responses regarding involvement in nine different kinds of activities. The bars represent the percentage of individuals who engage in a given activity on at least a weekly basis. So, for instance, 76% take a walk or get some other kind of exercise at least once a week.



- Fully 60.2% of the adolescents and adults participate in at least one of these activities on a weekly basis. The average number of weekly social activities is two per person.

How have their symptoms changed over time?

The symptoms of autism spectrum disorders are not constant over time. For any given individual, some symptoms may subside, or even disappear altogether. Other symptoms may become more pronounced. Changes in symptoms over time may be due to specific interventions, to changes in the child's environment, or to maturation and development.

The parents in our study answered a number of questions about their child's current symptoms. Other questions asked about the child's symptoms when he or she was 5 years old. Still, other questions asked about the most severe symptoms the child ever had. Thus, based on parents' descriptions of the severity of symptoms in the past, we are able to make some very broad generalizations about the tendencies of specific symptoms to change or remain stable over time.

The information presented below divides symptoms into three categories:

- Communication
- Social Skills
- Repetitive Behaviors and Stereotyped Interests

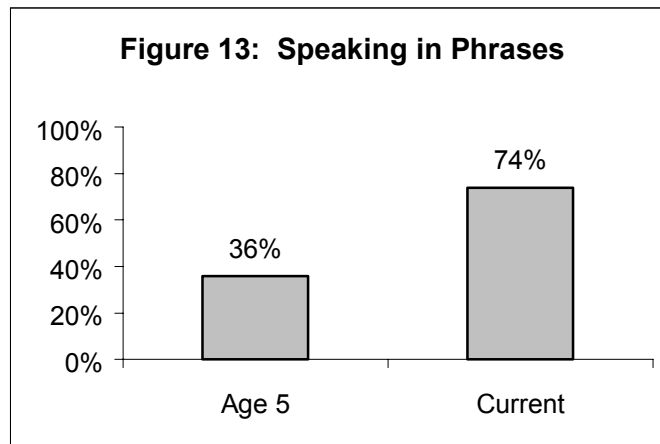
This division matches the diagnostic criteria used by most professionals, detailed in the Diagnostic and Statistical Manual of the American Psychiatric Association.

We found that, on average, all symptoms of autism improved or became less severe over time. Some symptoms improved considerably more than others, and the rate of improvement varied from person to person. In rare instances, some individuals had symptoms that grew worse over time. We describe the two symptoms in each category that improved the most and the two symptoms that improved the least among the 405 individuals with ASD in the study.

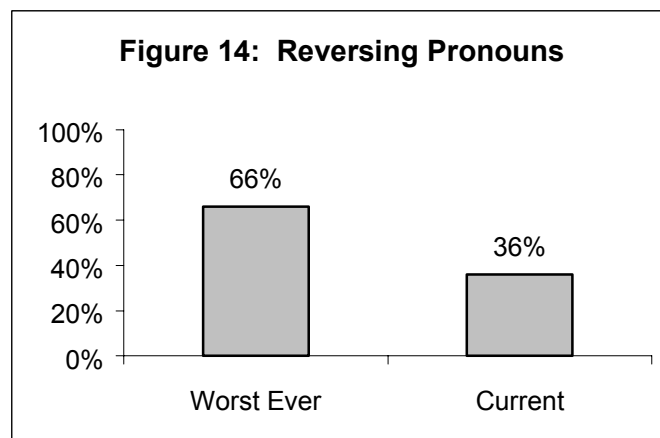
Communication

Most Improvement in Communication

- *Speaking in 3+ word phrases* – Language development is something many individuals with autism spectrum disorders struggle with. At age 5, only 36% of the individuals in the study could communicate using three-word phrases on a daily basis. However, by the time of the first interviews with families, fully 74% were able to communicate using phrases at least three words long. So, 38% gained this skill during the intervening years.

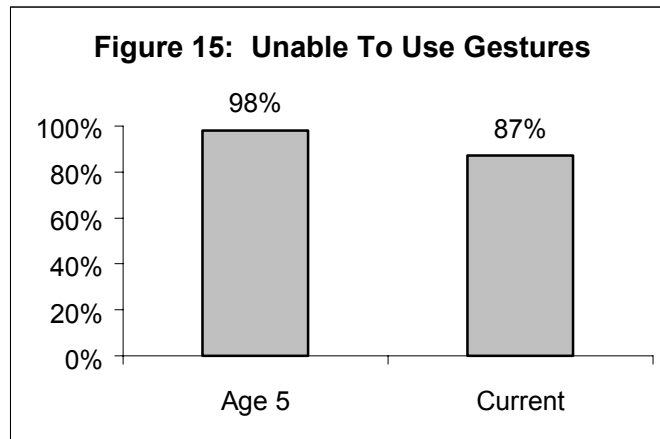


- *Reversing Pronouns* – Some people with autism spectrum disorders confuse pronouns – mixing up “you” and “I”, or saying “he” or “she” instead of “I.” At some point in their lives, 66% of the individuals who could talk had some degree of pronoun reversal. However, by the time of the first interviews, only 36% were having difficulty with this. So, 30% improved during the intervening years.

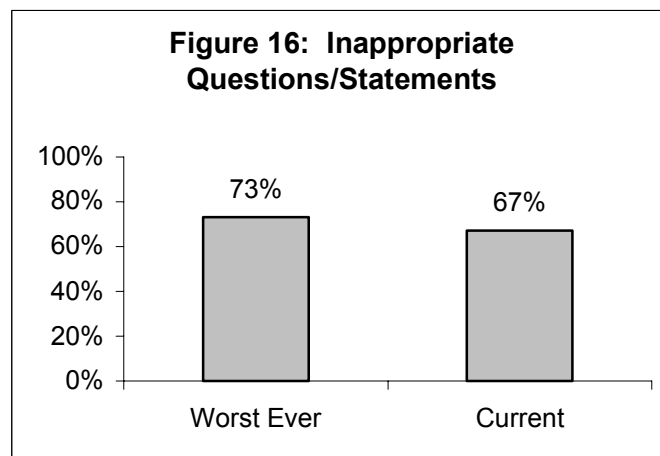


Least Improvement in Communication

- *Using Gestures* – Some people with autism spectrum disorders have trouble using gestures (such as hand or arm movements that convey a message) in a socially appropriate way. At age 5, fully 98% were not able to use gestures as a means of communication. And, at the time of the first interviews, 87% were still not able to use gestures appropriately as a form of communication. So, only 11% gained this skill during the intervening years.



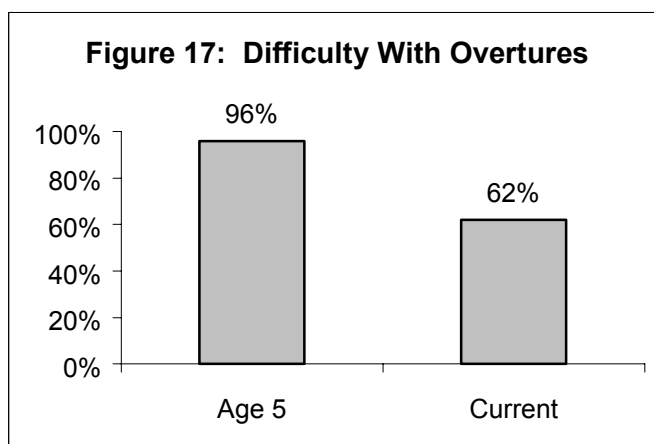
- *Inappropriate Questions/Statements* – Some people with autism spectrum disorders may ask questions that are odd or inappropriate because the questions are too personal, or they make inappropriate statements not related to the topic of conversation. At some point in their lives, 73% of individuals who could talk tended to ask inappropriate questions or made inappropriate statements. And, at the time of the first interviews, 67% were still asking inappropriate questions or making inappropriate statements. So, only 6% improved during the intervening years.



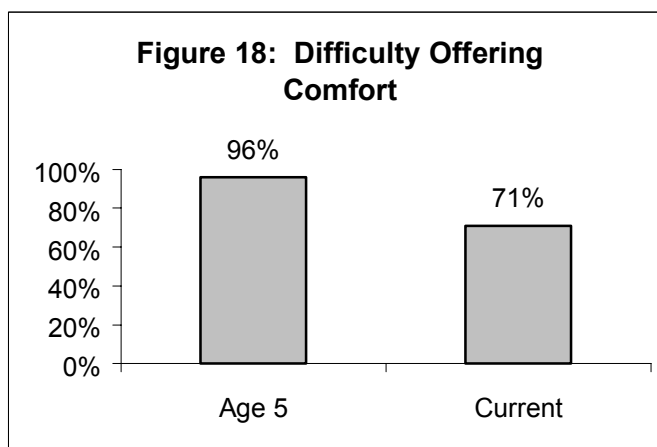
Social Skills

Most Improvement in Social Skills

- *Quality of Social Overtures* – Some individuals with autism spectrum disorders have trouble signaling to other people when they need assistance. For instance, some individuals may fail to look at someone when attempting to get his/her attention. At age 5, 96% of the individuals in the study had some degree of trouble with making social overtures. By the time of the first interviews, however, only 62% were having trouble making social overtures. So, 34% gained this skill in the intervening years.

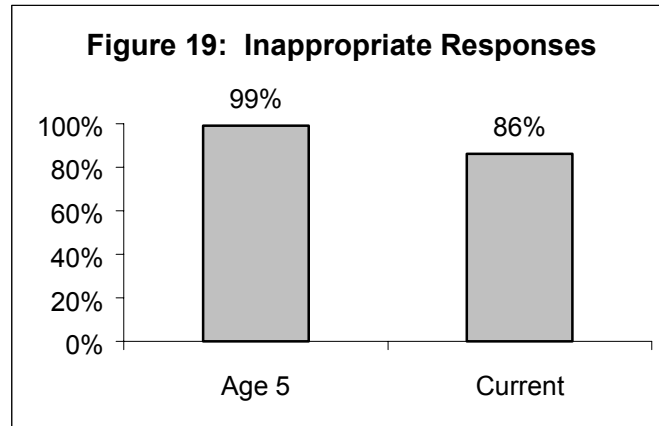


- *Offering Comfort* – This refers to the use of spontaneous gestures (such as touch, facial expression, offering an object, etc.) directed to someone who is sad or hurt in an attempt to help him or her feel better. At age 5, virtually all (96%) of the sons and daughters in the study were not spontaneously able to offer comfort. By the time of the first interviews, however, 71% were not offering comfort spontaneously. So, 25% gained this skill during the intervening years.

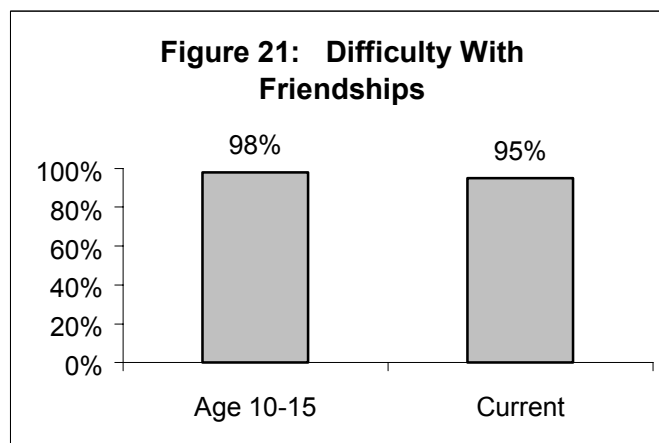


Least Improvement in Social Skills

- *Appropriateness of Social Responses* – Many individuals with autism have difficulty responding appropriately when others try to interact with them. At age 5, virtually all (99%) of the people in the study had difficulty with this. And, at the time of the first interviews, 86% were still having difficulty responding appropriately to others. So, only 13% gained this skill during the intervening years.



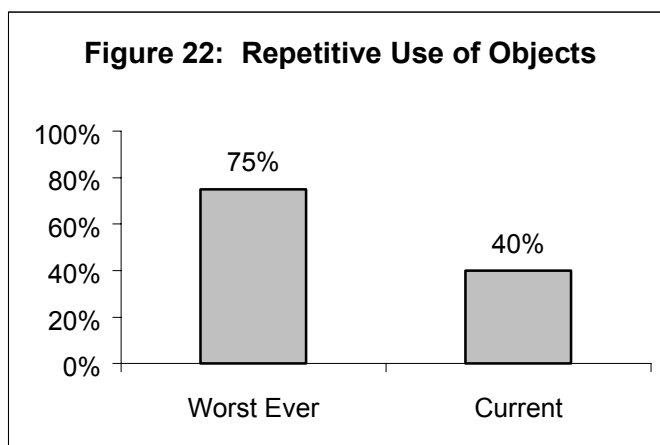
- *Friendships* – Many individuals with autism spectrum disorders have difficulty making or maintaining friendships. Friendships are defined as selective, two-way relationships between two persons of approximately the same age who seek each other's company and share activities and interests. At age 10 to 15, 98% of the individuals in the study who were 16 or older had trouble developing and maintaining friendships. By the time of the first interviews, fully 95% still had significant difficulty with making and keeping friends.



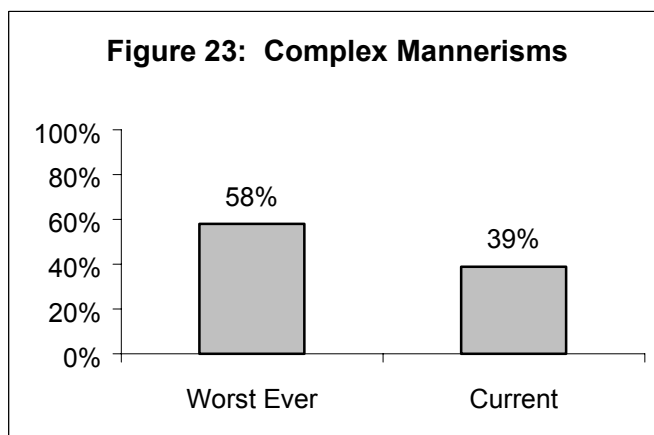
Repetitive Behaviors And Stereotyped Interests

Most Change in Behaviors

- *Repetitive Use of Objects* – Some individuals with autism spectrum disorders have behaviors that are stereotyped, repetitive, or serve no practical function. These behaviors and interests often focus either on parts of objects or using an object in a way that is different from how the object is supposed to be used. At some point in their lives, 75% of the individuals in the study displayed such behaviors or interests. But at the time of the first interviews, only 40% were still doing this. So, more than a third (35%) improved in this area overtime.

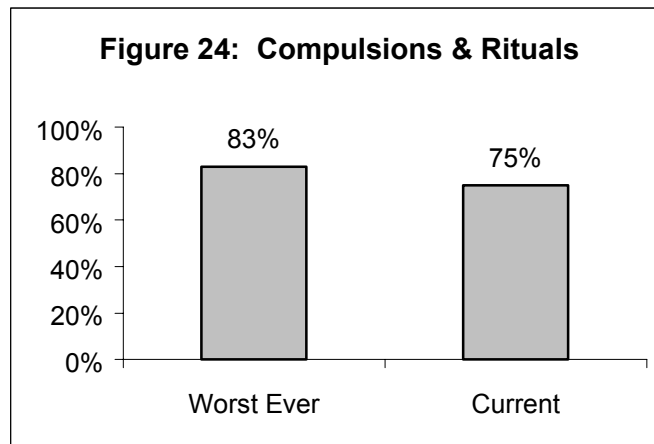


- *Complex Body Mannerisms* – Some individuals with autism spectrum disorders move their bodies in complex and stereotypic ways. Some examples include posturing or arm waving while rocking on their tiptoes. At some point in their lives, 58% of the individuals in the study had these types of complex body mannerisms. By the time of the first interviews, however, only 39% were still engaging in complex body mannerisms.

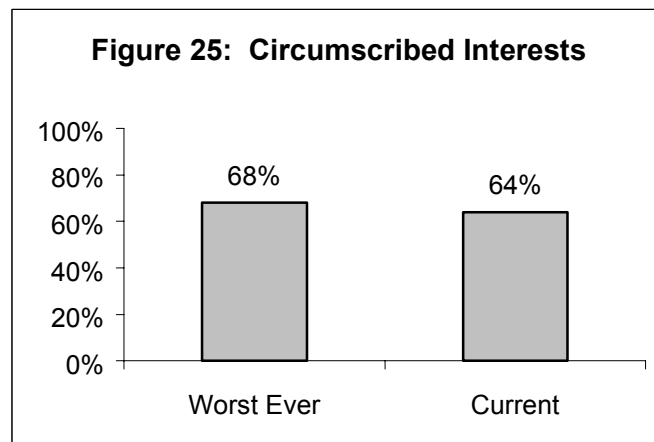


Least Change in Behaviors

- *Compulsions/Rituals* – Some individuals with autism spectrum disorders have compulsions and/or rituals that they engage in on a fairly regular basis. Rituals are activities the individual feels a need to complete in a particular order. Compulsions reflect a desire to place particular objects in an exact position, such as opening all doors at a certain angle or turning all lights off. At some point in their lives, 83% of the individuals in the study had compulsions and/or rituals. By the time of the first interviews, fully 75% were still symptomatic in this area. So, only 8% improved during the intervening years.



- *Circumscribed Interests* – Some individuals with autism spectrum disorders have what are known as circumscribed interests. A circumscribed interest differs from ordinary hobbies in its intensity and its tendency to be unusually focused. For example, an individual with a circumscribed interest may know the birth date of every president but may not be able to employ this knowledge in a useful manner. At some point in their lives, 68% of the individuals in the study had a circumscribed interest. By the first interviews, fully 64% continued to have circumscribed interests. So, only 4% improved during the intervening years.



Section III: Summary

This report describes the 405 adolescents and adults with an autism spectrum disorder whose families are participating in this research. Future reports will focus on other members of the family – parents and siblings – or other aspects of family life. Our study is the largest ever conducted about families of adolescents and adults with ASD. It provides important new information about their current lives and about how the symptoms of autism change over time.

We highlight four important themes from the information presented in this report:

- Many individuals with autism receive multiple diagnoses during their lifetime—including diagnoses on the autism spectrum and other diagnoses. This finding underscores the complexity of the disorder and the likelihood that, over time, its manifestations may change, leading to recurring efforts by families to obtain an updated or more precise understanding of their child’s condition.
- Most adolescents and adults with ASD participate in some social or recreational activities. While most get physical exercise at least weekly, the majority of these individuals have much more limited social interactions with family, friends, and neighbors. Both behavior problems and lack of opportunities may be responsible for this restricted social life.
- The range of treatments or interventions that have been accessed by families on behalf of their children with ASD is impressive. Nearly all individuals in our study are receiving at least one type of service, with the majority currently receiving a variety of services - including psychological services, therapies, and transportation.
- There is both stability and change over time in the manifestations of the core symptoms of autism across the life course - difficulties in communication, social skills, and behaviors. In some areas, a large number of individuals in our study have made significant gains compared to when they were youngsters. In other areas, there is a persistence of considerable difficulty in behaviors and skills.

These preliminary findings provide a portrait of a very complex group of individuals. A central purpose of this study is to document the changes in their lives—with respect to their functioning, the services they receive, and the support they get from their families. We are also interested in how mothers, fathers, and siblings are affected by their experience of having a family member with ASD, and how families change over time. Ultimately, we hope the findings from this study will be used to inform service providers, policy makers, and the general public about the capacities and needs of individuals with ASD as they mature and become adults.