

AAA

Adolescents & Adults with Autism A Study of Family Caregiving



Report #18 Language Outcomes in Adults with Autism Spectrum Disorder

- Principal Investigators -

**Marsha R. Mailick, Ph.D.
Leann S. DaWalt, Ph.D.**

**Waisman Center
University of Wisconsin – Madison**

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Table of Contents

	<u>Page</u>
<u>Section I:</u> Introduction	1
<u>Section II:</u> Background Information on Communication Skills of Individuals with ASD during Adulthood	2
<u>Section III:</u> How Communication Changes for People with ASD from Childhood to Adolescence and Adulthood	4
<u>Section IV:</u> Profiling Conversation Skills and Vocabulary in Adults with ASD	6
<u>Section V:</u> Language and Vocational Independence and Friendship Outcomes in Adults with ASD	9
<u>Section VI:</u> Summary and Conclusions	14

Section I: Introduction

Your participation in the Adolescents and Adults with Autism (AAA) study over the past two decades has provided valuable information on the development of people with autism spectrum disorder (ASD) across the lifespan and how ASD impacts families. We are grateful for your support, interest, and commitment to advancing the understanding of autism and family life.

In this report, we are very pleased to share with you recently published findings from the AAA study that addressed three topics:

- How communication abilities continue to change from childhood to adulthood for individuals with ASD
- The language abilities of individuals with ASD during adulthood
- How language is related to two important adult outcomes – friendship and employment

For this report, we analyzed descriptions you provided of your son or daughter's language during childhood, adolescence, and adulthood. We also looked at samples of language from an interview we conducted with some of the adults with ASD in our study in 2004 – 2005.

We hope that these findings will inform public policy, interventions, and services to promote successful communication for adults with ASD.

Section II: Background on Communication Skills of Individuals with ASD during Adulthood

Communication is a central part of daily life. We use communication to interact with our friends, family, employers, doctors, and cashiers. Although the ability to communicate is an essential adult skill, language research in autism has mainly focused on the communication of young children, and only a few studies have been conducted about language skills in adults with ASD. In this report we focus on our study's results that relate to communication during adult life.

Language and Communication

To learn about **how communication changes over the life course**, we posed the following question to all families at the beginning of the AAA study in 1998:

- 1) At the present time, what sort of language does [your son or daughter] typically use? How does he or she communicate?
- 2) What was his/her language like at 4-5 years of age?

We also asked follow-up questions to provide a clear picture of communication both currently (average age was 21 years old at the time of our interview) and when the individual with ASD was 4 or 5 years old. For example, parents were asked to describe their child's use of words and phrases and how well others understand his or her speech. These specific examples of spoken language helped the research team code the communication level of each individual with ASD in our study. **Section III** (page 4) shows what we learned from this part of the study.

To learn about **how communication in adulthood is related to friendships and employment**, we interviewed a group of individuals with ASD in our study who had reached adulthood in 2004 and were willing to participate in an in-person interview. A total of 84 adults with ASD participated. The interviews were audio-recorded and responses were recorded.

During this interview, the adults were asked five questions:

- 1) Can you tell me a bit about yourself and what kinds of things you like to do?
- 2) What do you feel people should know about what it is like to have an autism spectrum disorder?

- 3) What advice do you have for other people your age with an autism diagnosis?
- 4) What advice do you have for parents with a child with an autism diagnosis?
- 5) Is there anything else you would like to tell us?

Section IV (page 6) shows what we learned from this part of our study.

Section III: How Communication Changes for People with ASD from Childhood to Adolescence and Adulthood

In this section of the report, we share information from all participating mothers and their adolescent and adult children with ASD.

Verbal Communication

Mothers were asked to describe their child's current and past verbal communication (communication using spoken words) as either:

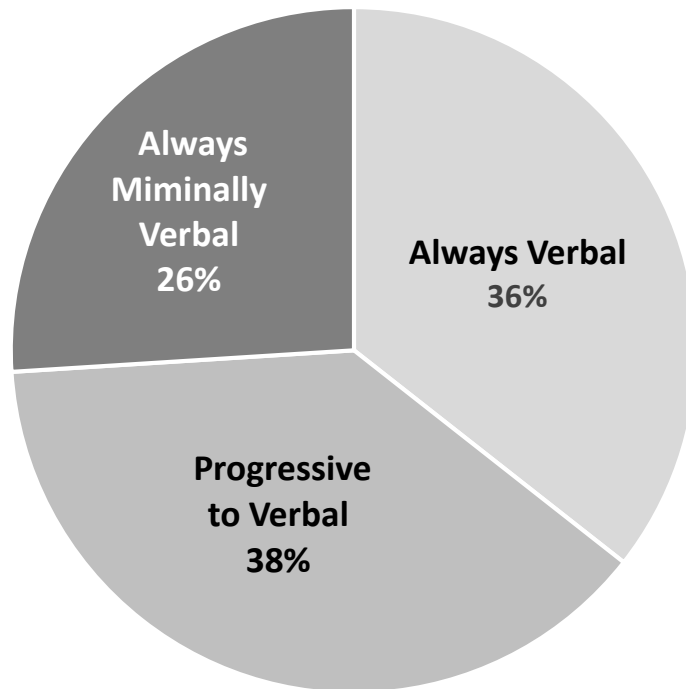
- ❖ The son or daughter with ASD uses verbal communication (e.g., spoken sentences) daily that are understood by others.
- ❖ The son or daughter has limited use of verbal communication (e.g., no spoken sentences but uses at least five words daily).
- ❖ The son or daughter has minimal verbal communication (e.g., less than five words used daily).

The goal of this part of the study was to use mothers' reports of their child's communication skills to examine changes in verbal communication from childhood to adolescence and adulthood.

To meet this goal, we divided the individuals with ASD in our study into three verbal communication groups reflecting how their spoken language changed over time:

- ❖ Individuals with ASD who were always verbal, meaning the person with ASD spoke in sentences in childhood *and* adolescence/adulthood.
- ❖ Individuals with ASD who progressed to verbal, meaning the person with ASD did not speak in sentences in childhood but developed verbal communication abilities by adolescence and adulthood.
- ❖ Individuals who were always minimally verbal, meaning the person with ASD had limited or minimal verbal communication at both time periods.

The pie chart below shows how many sons and daughters with ASD in our study were in each of these three groups.



As shown above, over a third of the *entire group* (36%) were verbal both during childhood and during adolescence and adulthood. About 38% of the group progressed from having limited or minimal verbal communication during childhood to having verbal communication by adolescence and adulthood. Slightly over a quarter of the group (26%) had limited/minimal verbal communication in childhood and continued to have that same level of language during adolescence and adulthood.

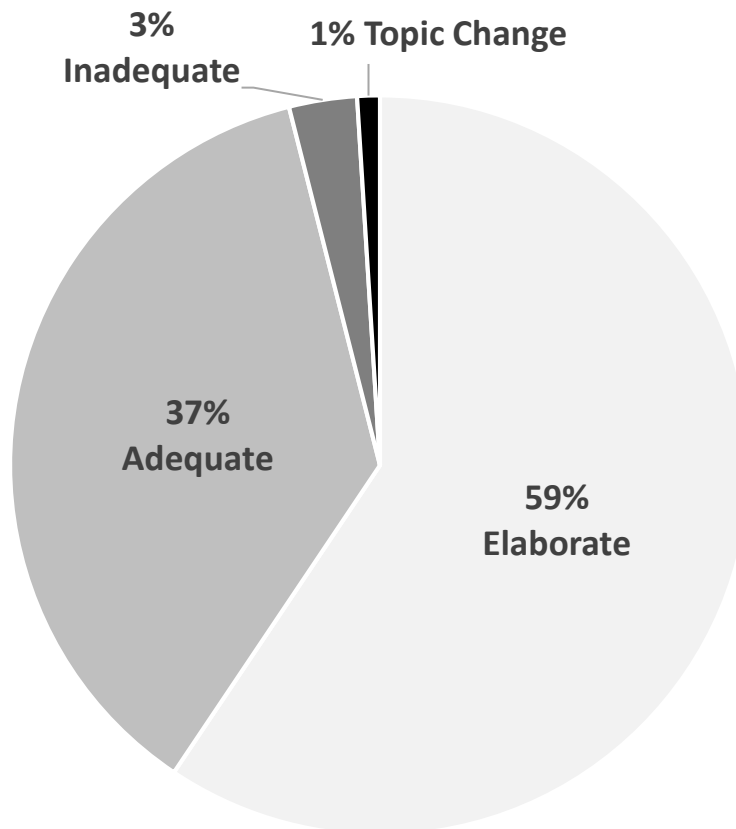
Section IV: Profiling Conversational Skills and Vocabulary in Adults with ASD

In this section of the report, we describe the conversation skills and vocabulary of 84 adults with ASD based on their communication during the interview. Each statement made by an adult was categorized into one of four levels of conversation skills:

- ❖ **Elaborate** – the adult’s comment added or asked for significant new information. For example, if the examiner asked “Do you ride your bike on the trail?” the adult could answer and elaborate by saying “I sometimes ride on it to get to my friend’s house.” The adult added new information about visiting a friend.
- ❖ **Adequate** – the adult’s comment did not add new information. For example, it would be adequate if the examiner asked, “Is there anything else you like to do besides go bowling?” and the adult said, “Go to the movies.” Here, the adult adequately answered the question without elaborating further.
- ❖ **Changed the topic** – the adult abruptly changed the topic of the conversation. For example, if the examiner said, “Tell me about your job,” the adult could abruptly change the topic by saying, “I mop and sweep. I’m going to church on Sunday.”
- ❖ **Inadequate** – participant stayed on topic but did not accurately respond to interviewer. For example, it would be inadequate if the interviewer asked, “Where did you get that?” and the adult said, “Because I liked it.”

During the interviews, adults with ASD produced **elaborate** sentences 59% of the time on average, meaning that they were primarily adding new information to the conversation. **Adequate** sentences were the second most common type of utterance, occurring 37% of the time. **Inadequate** sentences and **topic changes** were very rare, occurring 3% and 1% of the time, respectively. The figure on the next page shows the percentage of each social language type produced by these adults.

Social Language Types



We also measured the vocabulary used by the adults during the interview by examining the number of different words produced during the conversation. The number of different words ranged from 1 to 306 (average = 90.70). During the conversation, 34 adults (40%) said over 100 unique words across the 5 interview questions. Another 38 adults (45%) said between 10 and 100 unique words and 12 adults said less than 10 unique words. There were two adults who only said one unique word during the conversation both responding, “Yeah” when prompted to talk about specific things they like to do.

These findings provide a hopeful message, suggesting that adults with ASD who are able to participate in an interview can display good social language strategies such as speaking with elaborate exchanges and with a variety of different words. Many adults can “keep the conversation going” by asking at least some follow-up questions or making new statements. The adults are also keeping the conversation interesting by varying their words. The findings are encouraging as they suggest

that by adulthood many individuals with ASD are able to have a back and forth conversation with an unfamiliar person.

In addition to these findings, it is important to note that we observed a wide range in abilities in the group who participated in the interview. Although significant social communication challenges (e.g., abrupt topic change or not answering questions) were uncommon, over a third of the time responses to questions failed to build on the conversation. Similarly, a small group of adults were using the same few words repeatedly throughout the conversation. These challenges in the social aspects of communication, even for those who could participate in an interview, highlight how ongoing speech and language services targeting specific conversation strategies could be beneficial during adulthood.

Section V: Language and Vocational Independence and Friendship Outcomes in Adults with ASD

We next examined how the conversation skills and vocabulary, as measured in the interview, were associated with vocational and friendship outcomes five years later.

Language and Vocational Independence

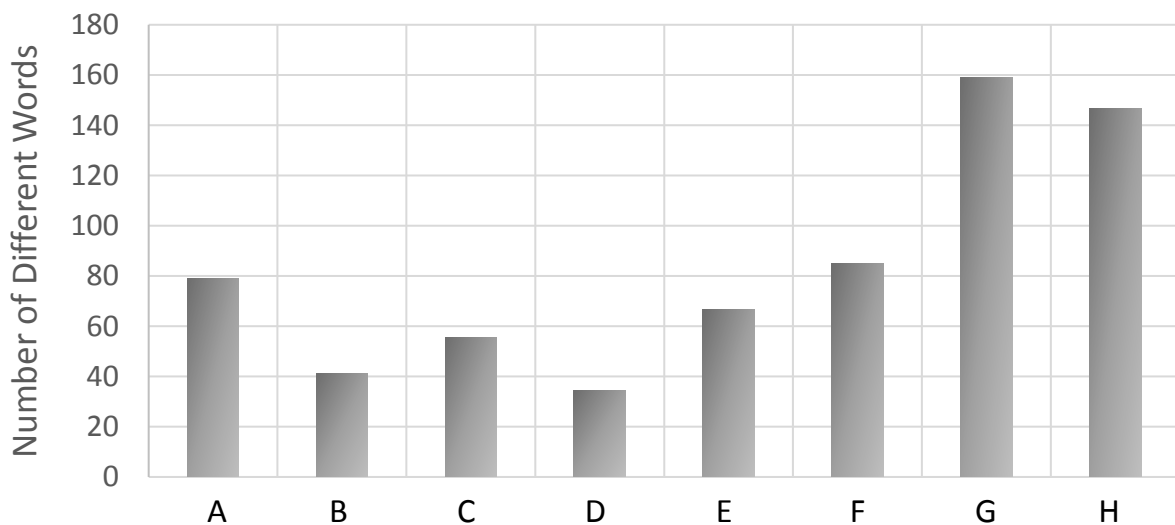
We measured vocational independence using the Vocational Index, an indicator of the independence of vocational activities that was developed as part of the AAA study. This index considers time spent in employment or educational activities each week, as well as the level of independence in these activities. The table below outlines each vocational independence code, and the number of adults who participated in the interview included in each category.

The Vocational Index rating	Number of adults (%)
1 no vocational or educational activities	6 (7.1%)
2 volunteering with no other activities or post-secondary non-degree seeking education with no other activities	6 (7.1%)
3 sheltered vocational setting – total activities less than 10 hours per week	0 (0.0%)
4 sheltered vocational setting with no community employment/volunteering or sheltered vocational setting and volunteering in the community– greater than 10 hours per week	19 (22.6%)
5 sheltered vocational setting and supported community employment – total activities greater than 10 hours per week	8 (9.5%)
6 employed in the community with supports; no time spent in sheltered settings – total activities 10 hours per week or less	4 (4.8%)
7 employed in the community with supports- greater than 10 hours per week; no time spent in sheltered settings	13 (15.5)
8 postsecondary, degree-seeking educational program or employment in the community without supports – total activities 10 hours per week or less	7 (8.3%)
9 postsecondary, degree-seeking educational program or employment in the community without supports – greater than 10 hours per week	21 (25.0%)

Having measured vocational activities, we next turned to the question of whether conversation skills and vocabulary were likely critical factors in vocational independence.

We learned from statistical analysis of the information you provided that vocabulary, as measured by the number of different words, significantly impacted later vocational independence. Adults who used a greater number of different words during their interview tended to be employed in the community or were enrolled in an educational program.

The figure below shows the relationship between number of different words and vocational independence. Individuals with better vocabulary skills had higher levels of vocational independence, even for those with intellectual disability. This finding is promising, given that vocabulary is something that can be learned throughout our lives.



A: No activities

B: Volunteering or non-degree seeking education

C: Sheltered settings – less than 10 hrs/week

D: Sheltered settings – more than 10 hrs/week

E: Community employment with support – less than 10 hrs/week

F: Community employment with support – more than 10 hrs/week

G: Degree-seeking education/community employment, no support–less than 10 hrs/week

H: Degree-seeking education/community employment, no support–more than 10 hrs/week

Vocational Independence Rating

Language and Friendships

We measured friendships using the following question: “At the present time, does (NAME) have any particular friends or a best friend?”

Interviewers asked mothers to categorize their adult son or daughter into one of four groups:

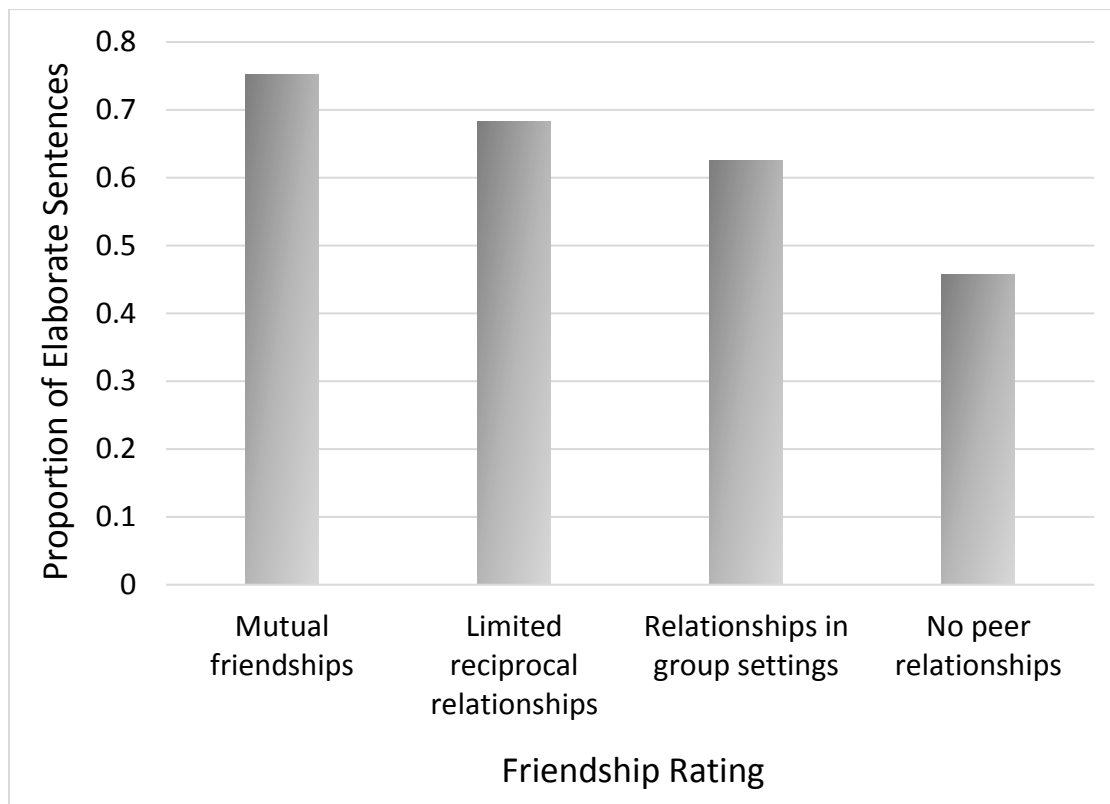
- ❖ Mutual friendships – one or more relationships with another person in son or daughter’s age group with whom they share a variety of activities and interests, are seen outside of a prearranged activity (e.g., school or work), and the friendship is mutual.
- ❖ Limited reciprocal relationships – one or more relationships that involve some personal shared activities outside a prearranged situation, with some initiative taken by son or daughter, but that is limited in terms of interests or reciprocity.
- ❖ Relationships in group settings – people with whom son or daughter has a personal relationship involving seeking out interactions, but *only* in a group situation (e.g., school or work).
- ❖ No peer relationships – no peer relationships that involve selectivity and sharing.

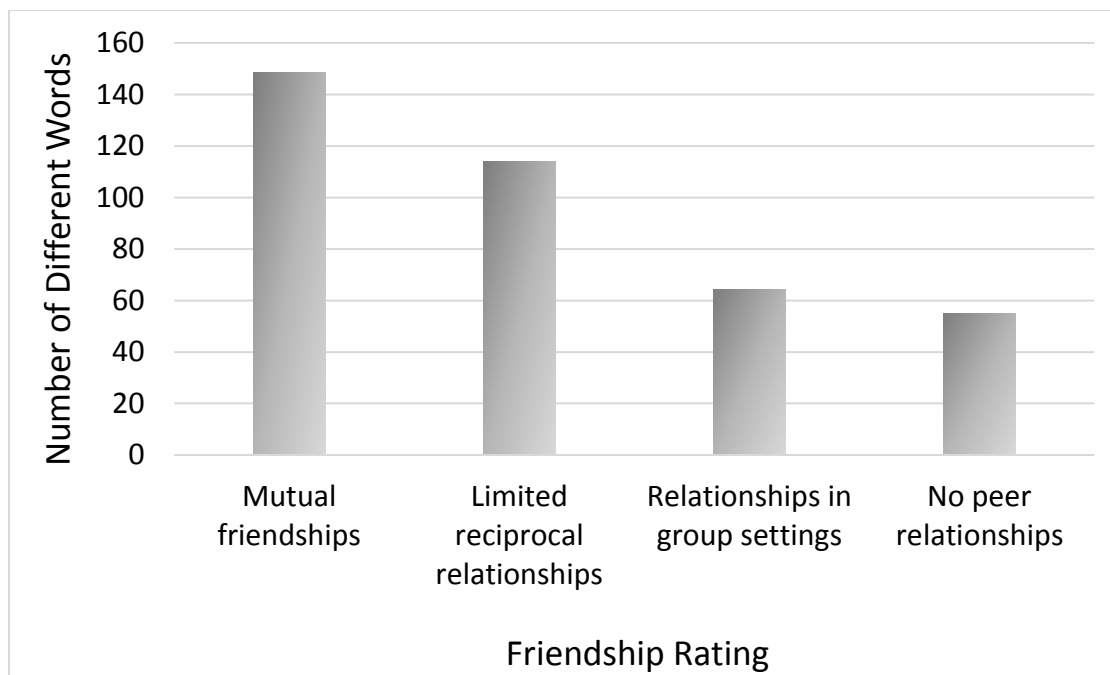
This table shows the number of participants who were categorized into each friendship category.

Friendship rating from Autism Diagnostic Interview – Revised	Number of adults (%) (Total <i>n</i> =84)
mutual friendships	22 (26.2%)
limited reciprocal relationships	14 (16.7%)
relationships in group settings	13 (15.5%)
no peer relationships	19 (41.7%)

Individuals who had better conversation skills (more elaborate words) and better vocabulary (variety of words) during their interviews had more friendships. Those adults who used a wide range of unique words during the interview were more likely to have mutual friendships, whereas those who used fewer words were more likely to have few peer relationships.

The figures below show the relationship between elaborate sentences and friendships, and the relationship between unique words and friendships for each participant.





Although we found that conversation skills had an impact on vocational independence and friendships in adulthood, it is worth noting that many adults in this sample achieved positive outcomes despite challenges with communication. There are many other factors, including daily living skills and the level of family support, that play an important role in vocational independence and friendship outcomes.

Section VI: Summary and Conclusions

This report highlighted the importance of communication in adulthood. We described the language profile of adults with ASD. We also provided new information about how language skills change from childhood to adulthood, and how these skills impact vocational independence and friendship outcomes. In summary, we learned:

- The majority of individuals who did not use verbal communication in childhood went on to gain this skill by adolescence and adulthood.
- The language profile of adults with ASD is varied. In our sample, adults had a range of vocabulary skills as measured by the number of different words they use during conversation. Importantly, most adults used elaborate sentences, meaning that they spent most of the conversation adding new, relevant information when they spoke.
- A rich vocabulary was related to greater levels of vocational independence.
- Both a rich vocabulary and strong conversation skills were related to adult friendships.

Findings in this report have important implications for services in adulthood. Since communication may improve outcomes for vocational independence and friendships, continued speech and language services should be provided to adults with ASD.

We would like to emphasize that this report only covers verbal language abilities. The use of language produced through alternative communication strategies (such as communication software on an iPad) and its impact on outcomes has not yet been studied in our research, although it is an important next step.

We hope that this report informs how communication can change over the life course for individuals with ASD and how language skills can promote improved vocational independence and friendship outcomes. We also hope that our findings can help inform policies and interventions that can support continued services for adults with ASD and their families.