AAA

Adolescents & Adults with Autism
A Study of Family Caregiving

Report #10
A Profile of Adolescent and Adult Siblings

- 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

Acknowledgements

This project is supported by grants from the National Institute on Aging (R01 AG08768) and the National Institute on Child Health and Human Development (R03 HD039185 and P30 HD03352). We gratefully acknowledge the support from the Graduate School and the Waisman Center at the University of Wisconsin-Madison, and Sargent College of Health and Rehabilitation Sciences at Boston University. We are also extremely grateful to the mothers, fathers, adolescents and adults with an autism spectrum disorder, and siblings who have given so generously of their time and shared their lives with us.

Cover Art: *Spaceship* by Ralf from Germany. From the Harvey A. Stevens International Collection of Art by People with Developmental Disabilities, sponsored by the Friends of the Waisman Center.

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

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Section I: Context for the Findings

Introduction

In 1999, we began this study to investigate the changes and challenges faced by adolescents and adults with autism spectrum disorders (ASDs) and their families. We have been following the lives of over 400 families over an 8-year period, collecting data every 18 months from the primary caregivers, and occasionally from fathers and siblings. When the study began, the individuals with ASD ranged in ages from 10-53, averaging 22 years of age. They now range in age from 17 to 64! We have learned much about how raising a child with an autism diagnosis impacts family life.

One of our primary questions throughout this study has been, "How does having a family member with a disability impact the family and their well-being?" When thinking about the family, one's attention immediately is drawn to the parents, as they are primarily responsible for the child's well-being and care. The sibling relationship, however, is often the longest-lasting relationship in a person's life. Siblings help us learn about ourselves and the world. They can teach us how to love, negotiate, and resolve conflicts. They are also sources of support and friendship.

When a person has a disability, his or her siblings might become extremely important, especially in adulthood and in later life. Siblings often take on some responsibility for supporting the well-being of their brother or sister after the parents can no longer do so. Thus, we felt it was important to learn from both the adolescent and adult siblings in our study and consider how these types of relationships develop and change as the family grows older.

Siblings in Our Study

Adult Siblings: Early on in our study we decided to collect data about the extent to which adult brothers and sisters of persons with an autism spectrum disorder (ASD) felt their childhood was different from their peers, how their adult lives were different because of having a sibling with a disability, and the extent to which they felt emotionally and physically connected to their sibling. Before our study, almost no research on adult siblings with a brother or sister with an ASD had been conducted.

It was during our second round of visits with families that we invited all eligible adult siblings (ages 18 and older who did not have a significant cognitive disability) to complete a mailed survey; 244 siblings participated. We were very pleased with the results as we were able to learn about each sibling's past experiences and ongoing concerns for his or her family. The uniqueness of each person's life and the extent to which each sibling had felt that he or she had been affected was clearly evident.

Adolescent Siblings: After collecting data from adult siblings, it was apparent how much they appreciated having the opportunity to share their stories, both with respect to the special challenges they have faced and the ways that they had grown and benefited from the relationship with their brother or sister with an ASD. Thus, we felt that it was essential to include adolescent siblings in our study and bridge the gap between adolescent and adult sibling experiences across the lifespan.

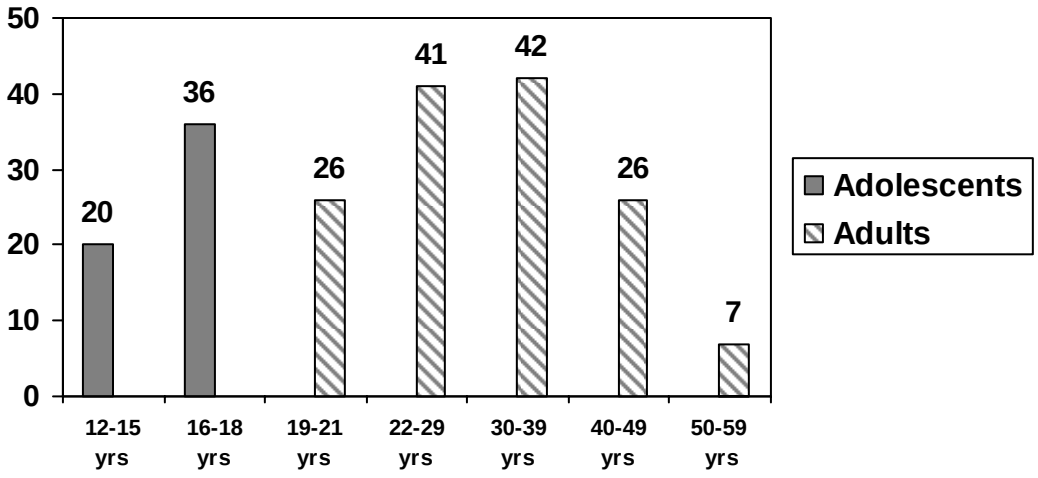
During the fourth round of visits, we received a special grant to conduct phone interviews and mailed surveys with adolescent siblings (12-18 years old). We invited one sibling per family to participate – the one closest in age to the brother or sister with an ASD; 57 siblings participated. As a result we were able to learn about their current life with a brother or sister with an ASD and how they have adapted to this unique experience.

Section II: Description of Adolescent and Adult Siblings

Who are the siblings who participated?

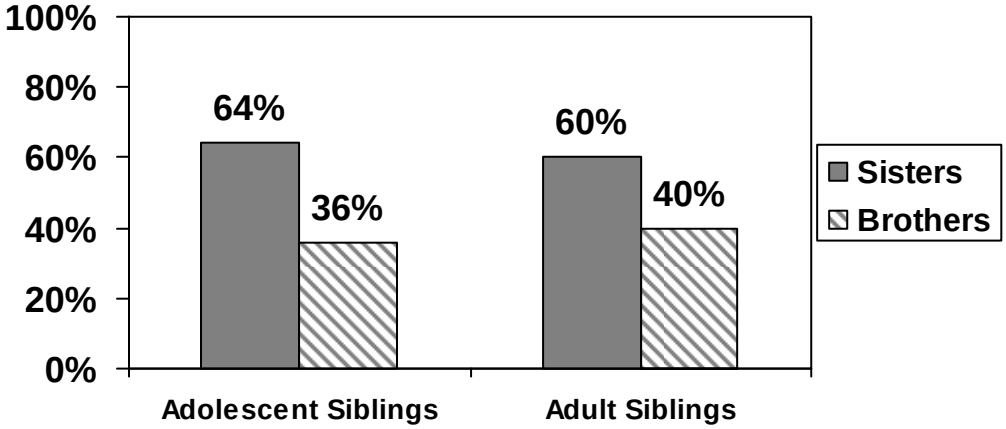
- Figure 1 shows the number of siblings in each age group. Adolescent siblings ranged in age from 12-18 years, with the average age being 16 years. Adult siblings ranged in age from 19 to 55 years, with the average age being 32 years.

Figure 1. Age distribution of siblings



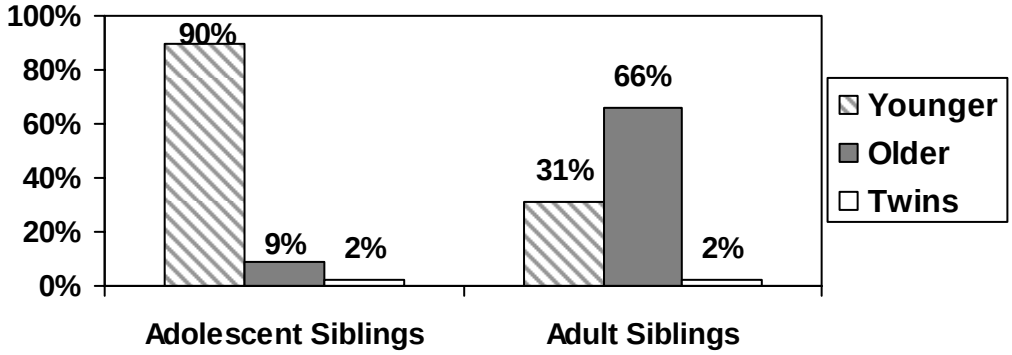
- Most of the adolescent and adult siblings who participated were sisters. Figure 2 shows the percentage of sisters and brothers in each age group of siblings.

Figure 2. Gender of siblings



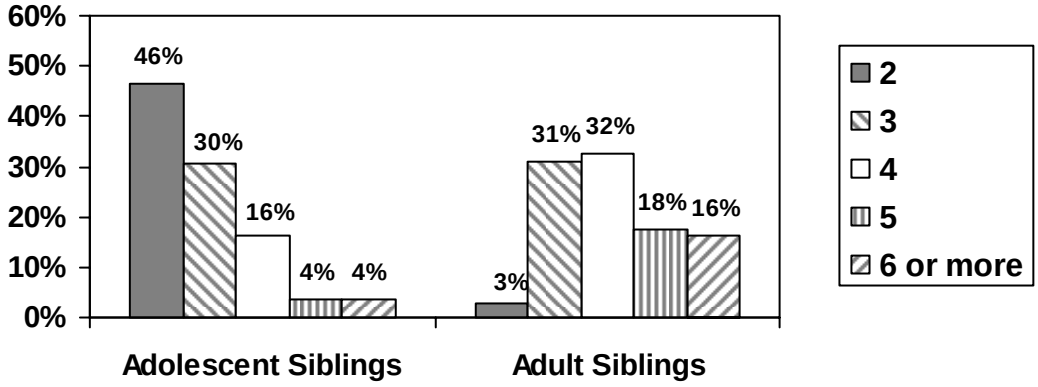
- Most adult siblings were older than their brother or sister with an ASD, while almost all adolescent siblings were younger. A few siblings were twins. Figure 3 shows the percentage of siblings who were older, younger, and the same age as their brother or sister with an ASD.

Figure 3. Birth order of siblings



- Adolescent siblings came from smaller families than adult siblings. As shown in Figure 4, adolescent siblings were most frequently the only other sibling in the family, whereas adult siblings frequently had one or two other siblings, in addition to their brother or sister with an ASD.

Figure 4. Number of children per family

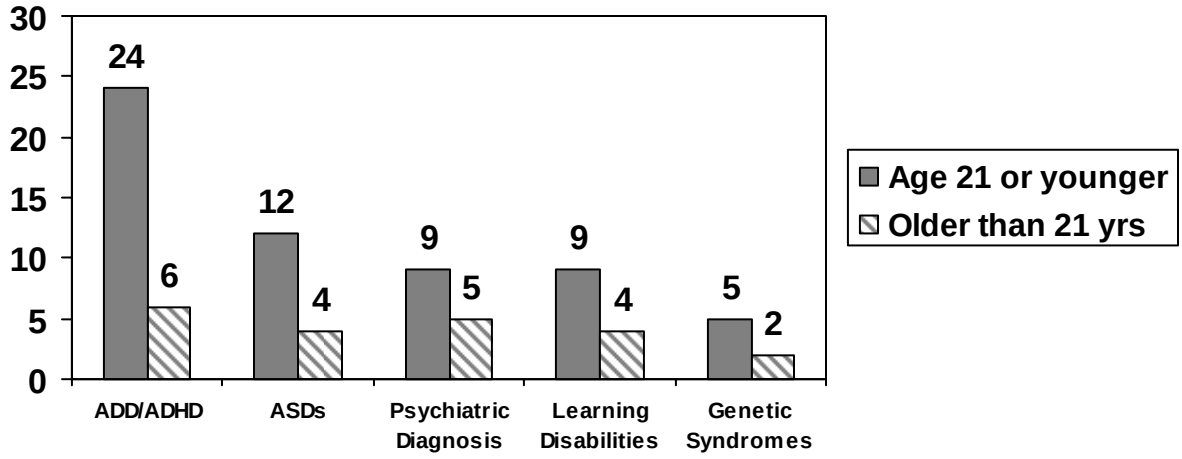


- Only a few (6%) of the adult siblings, but a majority (77%) of adolescent siblings, currently lived in the same household as their brother or sister with an ASD.

- We had some additional demographic data available on adult siblings. Almost two-thirds (62%) are married, and 52% have children. They have relatively high levels of education (22% are college graduates, 10% have taken some graduate level classes, and 26% have a graduate degree). Most (83%) are working and almost one-half (42%) have a household income of $60,000 or more per year. Almost two-thirds (61%) live less than 1 hour away from their brother or sister with an ASD.

- A number of the siblings also had disabilities. Figure 5 shows the number of adolescent and adult siblings with different types of disabilities as reported by the mother. As you can see, attention deficit/hyperactivity disorders (ADD/ADHD) were the most common, followed by ASDs. All of these disorders were more common among siblings age 21 or younger.

Figure 5. Number of siblings in each age group with specific disabilities



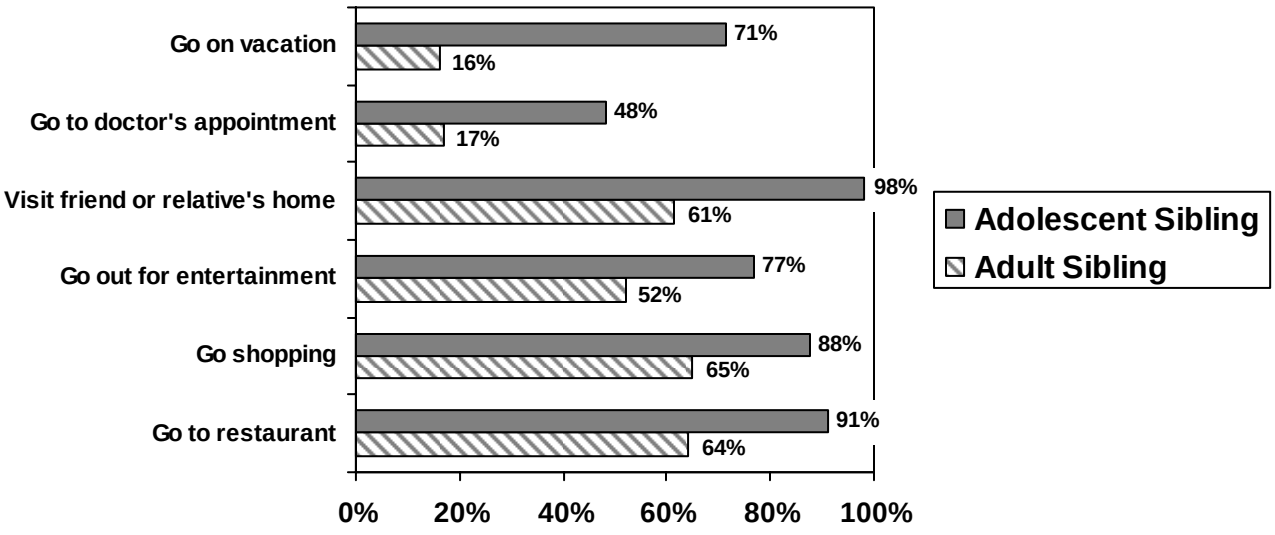
- Having two or more children with a disability in the family posed challenges to the mother and the family. These mothers reported more symptoms of depression and anxiety, and felt that their family was less cohesive and less adaptable to change, than mothers who had one child with a disability.

How close are sibling relationships in adolescence and adulthood?

We also sought to understand sibling patterns of joint activities and feelings of closeness. Here is what we found:

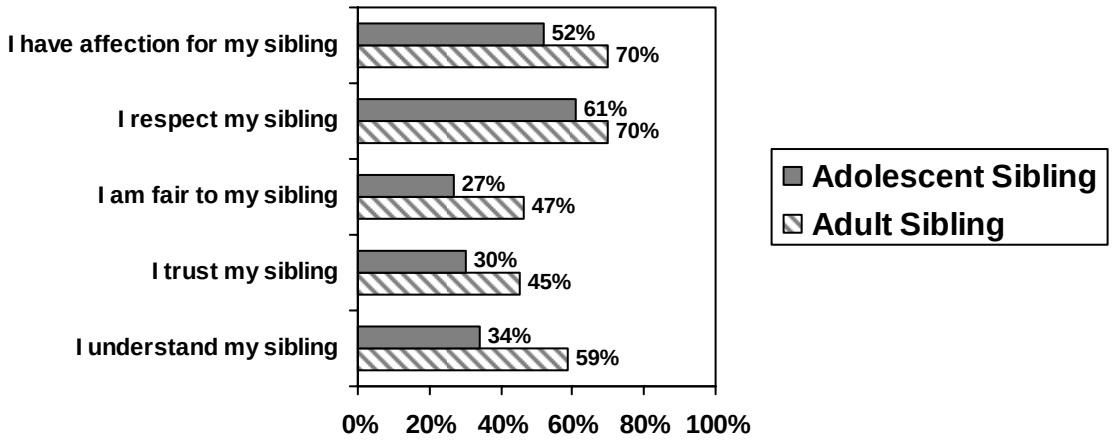
- Figure 6 shows the percentage of siblings who participated with their brother or sister with an ASD in each type of activity in the past year on at least one occasion. As expected, adolescent siblings participated in more activities with their brother or sister with an ASD than did adult siblings. The majority of siblings engaged in a variety of activities with their brother or sister, particularly visiting friends' or relatives' homes, going out for entertainment or recreational activities, going shopping, or going to restaurants. Over three-quarters of adolescent siblings and over half of adult siblings engaged in these activities with their brother or sister in the past year.

Figure 6. Percent of siblings who did each activity in past year



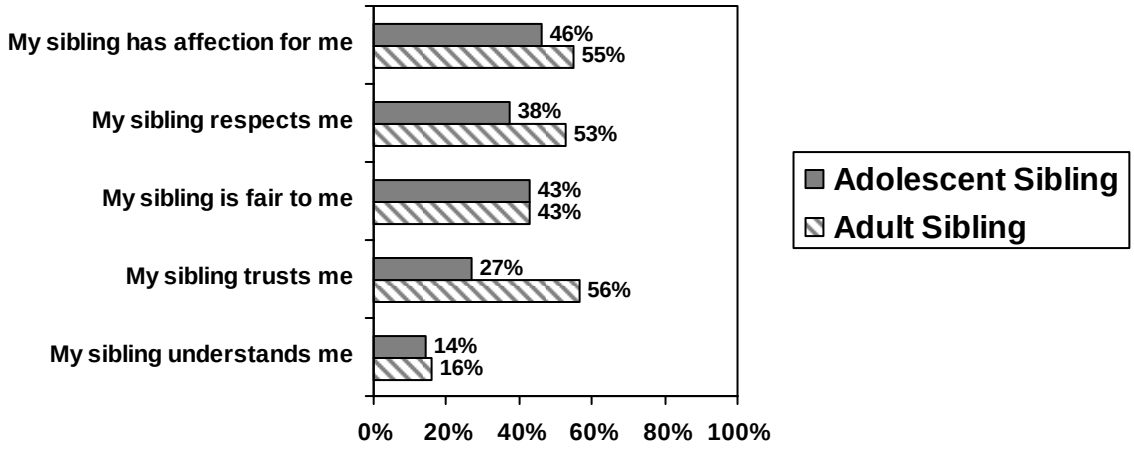
- Figure 7 shows how close siblings felt toward their brother or sister with an ASD. Adult siblings tended to report somewhat closer sibling relationships than adolescent siblings, but siblings of all ages reported high levels of affection and respect for their brother or sister.

Figure 7. Percent of siblings who reported high levels of emotional closeness



- Figure 8 shows how siblings thought their brother or sister with an ASD felt about them. Notably, about half of the siblings felt that their brother or sister had high levels of affection for them. Adult siblings tended to report more reciprocated respect and trust than did adolescent siblings. Few siblings felt that their brother or sister with an ASD understood them well.

Figure 8. Percent of siblings who reported high levels of emotional closeness



- There were several other conclusions we reached regarding adolescent and adult siblings.

    - Both adolescent and adult siblings reported a more distant relationship when their brother or sister with an ASD had significant behavior problems. Therefore, high levels of behavior problems can jeopardize the sibling relationship.

    - Adult siblings tended to use more effective coping strategies than adolescent siblings. In general, coping strategies that directly address the problem are more effective than just ignoring or venting about the problem. The patterns we saw reflect what is seen in the general population. Adults tend to use coping strategies that directly address the problem more frequently than do adolescents. Conversely, adults use fewer strategies such as venting their emotions or avoiding the problem, while adolescents tend to use more of these strategies. We also found that adolescent siblings who were good problem solvers had a closer sibling relationship.

    - Adult siblings who received high levels of support from their parents had a closer sibling relationship. This shows us that support from parents, even in adulthood, is very important and may promote a more positive sibling relationship over the life course.

How has having a sibling with an ASD influenced adult lives?

- We also asked adult siblings how they thought different aspects of their lives had been affected by growing up with a brother or sister with an ASD. Table 1 shows their responses.

Table 1. How having a sibling with an ASD affected adult lives

	No Effects	Mainly Positive Effects	Both Positive and Negative Effects	Mainly Negative Effects
Relationship with Mother	19.5%	33.8%	33.8%	11.7%
Relationship with Father	37.7%	27.3%	19.5%	14.3%
Relationship with Spouse/Significant Other	46.8%	15.6%	26.0%	9.1%
Thoughts about Having Children	54.5%	2.6%	18.2%	29.0%
Feelings about Self	26.0%	32.5%	28.6%	11.7%
Plans for the Future	39.0%	7.8%	40.3%	10.4%
Career	68.8%	22.1%	5.2%	2.6%
Choices about Where to Live	64.9%	10.4%	15.6%	5.2%

- Most adult siblings felt that their relationship with their mother had been affected, and most described mainly positive or both positive and negative effects. Few described mainly negative effects.

- The majority of adult siblings also felt their relationship with their father had been affected. Again, most felt the effects had been either positive or both positive and negative. Few reported mainly negative effects.

- About half of the adult siblings said that their relationship with their spouse or significant other had been affected. Most of these siblings reported both positive and negative effects and few reported mainly negative effects.

- About half of the adult siblings said that their thoughts about having children had been affected. Almost one-third of adult siblings reported that their thoughts about having children had been negatively affected.

- Almost three-quarters of siblings said their feelings about themselves had been affected. One-third of siblings said the effects had been mainly positive, and slightly over one-quarter said the effects had been both positive and negative.

- Almost two-thirds of adult siblings said their plans for the future had been affected. They primarily reported that the effects had been both positive and negative.

- Only one-third of adult siblings reported that their career had been affected. But, of this group, most siblings said their career had been positively affected. Few siblings reported mixed or negative effects on their careers.

- Finally, almost one-third of adult siblings reported that their choices about where to live had been affected. These siblings reported primarily positive effects or both positive and negative effects.

Section III: Conclusions

This report has presented information about the adolescent and adult siblings who participated in our study, focusing on the closeness between siblings and how their lives have been influenced by growing up with a brother or sister with an ASD. Siblings shared rich and detailed information about their lives, and therefore we can draw several important conclusions.

- Siblings had less contact when they were adults than during adolescence, but the emotional aspects of the sibling relationship were stronger in adulthood than in adolescence.

- Sibling relationships were closer when the brother or sister with an ASD had fewer behavior problems, when the sibling used more effective coping strategies, and when the sibling received high levels of support from the parents.

- A number of siblings had disabilities themselves. The most frequent were attention deficit/hyperactivity disorders (ADD/ADHD) and ASDs. The rate of ADD/ADHD in siblings was similar to the general population, but ASDs were more frequent.

- Adult siblings felt that their lives had been affected in several ways by growing up with a brother or sister with an ASD. Most reported that the effects on their feelings about themselves and their relationships with their parents had been positive or mixed. A number of siblings reported negative effects on their thoughts about having children, possibly because of the genetic risks associated with ASDs. Seeking genetic counseling may be helpful.

Finally, family members frequently ask for resources for themselves and siblings. Don Meyer from the University of Washington has an excellent website for siblings with special health, developmental or mental health concerns, the Sibling Support Project (http://www.siblingsupport.org/). The website includes listings of sibling support groups, lists of books written by and about siblings, and other Internet resources that siblings can utilize. We feel you may find this resource very useful.

We hope the information that we have shared is interesting and shows how much we have learned from siblings participating in our study. Again, we wish to express our gratitude to all the family members who continue to participate in this ongoing study. Your willingness to share your insights and experiences helps us to better understand family life when the family includes a person on the autism spectrum. We thank you for your continued support of our research.