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Adolescents & Adults with Autism A Study of Family Caregiving



Report #16 Characterizing Quality of Life in Adults with Autism Spectrum Disorder

- Principal Investigators -

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Section I: Introduction

The growing number of adults with autism spectrum disorder (ASD) has led to increased interest on the part of researchers, policymakers, and families to better understand adult outcomes and quality of life for this population. The current knowledge in our field tells us that many adults with ASD do not fully achieve the conventional markers of adulthood (e.g., becoming self-supporting, living independently).

However, there is more to having a good quality of life than these conventional markers of adulthood. Fully understanding the complex nature of adult life for all people, including adults with ASD, goes beyond these conventional markers of adulthood to include other aspects of quality of life. These other aspects include one's own feelings about life as well as having good physical and mental health, adequate living conditions, and supportive and fulfilling social relationships.

In our last report, we detailed preliminary findings about quality of life in adults with ASD who participated in our 15-year study. This report presents new findings on outcomes and quality of life from two recently prepared articles, with a specific emphasis on factors that are associated with good outcomes and quality of life. We also provide narratives in order to better illustrate the wide range of ways in which adults with ASD and their families construct a good life in adulthood.

Note: All names throughout this report have been changed to protect the identity of those participating in the study. In addition, we present a number of anonymized case studies that represent multiple adults with ASD in our sample.

Section II: Defining Adult Outcomes and Quality of Life

The research literature includes a number of different definitions of outcomes and quality of life for adults with ASD. This section will outline how we have defined adult outcomes and quality of life in our study.

DEFINING ADULT OUTCOMES

Researchers who focus on adults with ASD or other developmental disabilities often define outcomes based on a comparison to adults without disabilities. Past research has defined “good” outcomes as becoming self-supporting, living independently, and developing a network of friends. This means that many adults with ASD and their families are encouraged to define “success” in adulthood by living on one’s own, having a paying job, and finding friendships that provide social support. Because so much research has conceptualized “good” outcomes in this manner and because many adults with ASD report that they want to work, live independently, and spend time with friends, we include this definition of *adult outcomes* in our research studies.

DEFINING QUALITY OF LIFE

There are diverse ways in which an individual can construct a good life. In many respects, there are commonly shared ideas about what a good life includes – such as good health, a safe place to live, and social relationships. In other respects, a good life is subjectively defined by each of us – what makes each of us feel happy or satisfied. Yet very little research to date has explored how these ideas apply to adults with ASD. Therefore, for this research, we incorporated definitions of both *objective and subjective quality of life*.

Objective Quality of Life

Objective quality of life refers to how *someone would define another person’s quality of life* if looking in from the outside. Examining objective quality of life gives us an opportunity to go beyond the definitions of outcomes that are typically used by researchers to include other components needed to construct a good life. The components of objective quality of life that we examined, as well as the central question for each component, are detailed on the next page:

❖ Physical health

Is the adult in excellent health, as rated by his or her mother?

❖ Mental health

Does the adult have good mental health, such as the absence of significant symptoms of depression, anxiety, bipolar disorder, or schizophrenia?

❖ Neighborhood quality

Is the adult's home or apartment located in a neighborhood with adequate resources and low crime?

❖ Relationships with siblings and extended family

Does the adult see his or her siblings and/or extended family at least once per week?

Subjective Quality of Life

Subjective quality of life refers to *how an individual feels about his or her own quality of life*. Feelings about one's own quality of life can be divided into different categories, including physical health, psychological health, social relationships, and environment. In our study, we asked about subjective quality of life in three ways. First, we asked mothers to report *how they feel about their son or daughter's quality of life* ("mother report"). Then, we asked mothers to report *how they think their son or daughter feels about his/her quality of life* ("mother proxy-report"). Finally, we interviewed 67 adults with ASD about *how they feel about their own quality of life* ("adult self-report"). We asked the same questions to mothers and adults with ASD, with slight differences in wording based on who the question was asking about. For example, we asked mothers "How much *do you think* your son or daughter enjoys life?" ("mother report"), and then "How much does your son or daughter enjoy life?" ("mother proxy-report"). We asked adults with ASD "How much do you enjoy life?" ("adult self-report").

Below are some of the questions that were asked to adults with ASD (and their mothers):

Physical Health

- ❖ “Do you have enough energy for everyday life?”
- ❖ “How much do you need any medical treatment to function in your daily life?”
- ❖ “To what extent do you feel that physical pain prevents you from doing what you need to do?”

Psychological Health

- ❖ “How often do you have negative feelings such as blue mood, despair, anxiety, or depression?”
- ❖ “To what extent do you feel your life has meaning?”
- ❖ “How well are you able to concentrate?”

Social Relationships

- ❖ “How satisfied are you with the support you get from your friends?”
- ❖ “How satisfied are you with your personal relationships?”

Environment

- ❖ “How satisfied are you with the conditions of your living place?”
- ❖ “How safe to you feel in your daily life?”
- ❖ “Do you have enough money to meet your needs?”

Quality of life ratings ranged from very dissatisfied to very satisfied on these and other questions.

In addition, we asked adults with ASD and their mothers to describe quality of life during an interview. Overall, most families reported positive aspects about life for their son or daughter, although many families noted a number of challenges that their son or daughter experienced. On the next page, we present selected quotes representing the range of perspectives that families reported.

QUOTES FROM FAMILY MEMBERS

Thoughts on Positive Aspects of Quality of Life

I'm very happy with his life, I think he is. I asked him not long ago, I think when he was home last week, and he said he's quite satisfied with his life, and I think it shows in his behaviors and his attitude. After years of thinking that he was never going to fit in anywhere and never be safe anywhere unless he was under supervision all the time, I think he's doing very well.

She is, I think, accepted where she lives. She knows she can come home anytime. I think she's pretty happy. I know she's very healthy. I wish she would have more things to do socially, and recreationally, but as of right now, I just don't know what they would be.

He has good people around him that love him and support him. He lives in an atmosphere of love and support. He has some funding to support daily living and community living. His health is good.

I think he enjoys going off to his daily activities, feels like he's doing something productive. Going to a place where he wants to be. I think he enjoys living with us, although I think he's feeling a little restless now, he's ready to move into a group home. And he feels safe and valued. He seems pretty happy.

She has a job; she has a nice place to live. She's self-sufficient. She seems happy. That's as much as you can hope for.

I believe that he is very happy. He's pretty healthy. He is positive. He has a zest for life. And there's always things that he's going to want because he is challenging. But that's what makes him interesting is that he's always looking for more, he's exciting. And I think that he's quite happy with this life, although he does get frustrated, but so do the rest of us. He's frustrated because he thinks he needs a girlfriend; where can I find a girlfriend. That's his big thing now.

Thoughts on Challenges to Quality of Life

I worry about his quality of life because when you do get [mental health issues] under control and then something else acts up how is he gonna handle that? So that's probably the biggest thing, is trying to be able to keep [his mental health issues] from ruining his life.

I think she'd be happier if she could have at least one or two good friends, but I'm optimistic that that will happen.

I would like to see him a lot more independent. There are things I'd like to be able to do differently that I can't, but we'll deal with it. If, for example I could drive, I would take him on a trip to the Baseball Hall of Fame. If I had the money, I would get more get more help. If he gets a full time job I will be very, very happy to set him up in his own living situation. If he winds up doing it with three part time jobs so we can keep his Medicaid, he could still become independent. My objective is to get this kid independent and it's gonna take a lot of extra doing.

I think he really would like to be able to have some folks to do other kinds of activities with, but sometimes I think that people tire him out. He has been checking out dating sites. He would like to have a girlfriend. It's not working out as well as he had hoped. But I always tell him that this just isn't his time yet. But he may meet someone when he's not even looking to find someone.

Is it what I would really ideally want for her life? No. Ideally I would still like her to be able to function at a work site for a couple hours a week. I'd like her to be more independent than she is. I wish she had fewer negative behaviors, which hold her back, and hold the group home back from letting her be included in things.

Section III: Findings on Adult Outcomes and Objective Quality of Life

As part of our interviews, we asked mothers to report on a number of factors related to adult outcomes and objective quality of life in their adult son or daughter with ASD. We conceptualized three indicators of outcomes (social engagement, competitive employment, independent or semi-independent living) and four indicators of objective quality of life (good physical health, good mental health, good quality of neighborhood, frequent contact with siblings and extended family).

DESCRIPTION OF ADULT OUTCOMES AND OBJECTIVE QUALITY OF LIFE

We found that adults with ASD generally faced challenges achieving outcomes that are thought of as "good" outcomes. More specifically, only 20.0% were competitively employed for 10 or more hours per week, 21.1% lived independently or semi-independently, and 27.8% socialized with friends or neighbors once a month or more often, all indicators of normative adult outcomes. Overall, only 2.8% of the adults with ASD who participated in this study achieved all three of these "good" outcomes.

We also examined the objective quality of life of adults with ASD in our study. We found that adults with ASD had relatively good objective quality of life. More specifically, 80.0% had good or very good physical health and an equal number lived in a good or very good neighborhood. However, only about half (47.8%) did not have a mental health condition. Also, fewer than half (47.2%) spent time with their siblings and extended family once a week or more often. Altogether, 13.9% of our sample of adults with ASD achieved all four of these indicators.

ADULT OUTCOME AND OBJECTIVE QUALITY OF LIFE GROUPS

We used a statistical technique to identify groups of adults with ASD who had similar outcome and objective quality of life profiles. We found three distinct groups –the Good Physical and Mental Health group, the Greater Dependence group, and the Greater Independence group. The characteristics of the three groups are described below, along with composite case studies that illustrate the unique strengths and challenges of representative individuals in each group.

Members of the Good Physical and Mental Health Group

- ❖ are physically healthy
- ❖ have few mental health conditions
- ❖ live in good neighborhoods
- ❖ experience greater warmth in the family environment
- ❖ continue to live with parents
- ❖ have good subjective quality of life

Alex, age 23, was diagnosed with autism at the age of five, although her parents first noticed that something was different around 18 months. She has an average IQ score. Alex's parents are well-educated: her father has a professional job and her mother stayed home in order to help manage her care. Alex was very involved in school as a child and adolescent, and served as the manager for the basketball team during high school, largely because of the high-quality special education services in her local school district. After graduating from high school, Alex attended the local community college where she is studying graphic design, and she spends her weekends working at a local bead store owned by a family friend. She lives with her parents, who help her eat healthy meals and get to and from work and school. Alex's parents are hopeful that she will be able to move to a four-year college after finishing her AA degree this year, and have plans to buy an apartment for her close to school that she can live in with a roommate.

Members of the Greater Dependence Group

- ❖ do not work in a competitive job
- ❖ live with family or in agency settings
- ❖ see friends less than once a month
- ❖ have poorer daily living skills

Jacob, age 44, was diagnosed with an intellectual disability at two years, and was given an autism diagnosis at age six. He is able to respond to questions with one-word answers and point to things that he wants, although his parents describe him as being more aware of the world than he is able to verbalize. Jacob is very interested in watches and has a difficult time focusing when someone in the room is wearing a watch that he has not examined before. He enjoys participating in recreational activities with other individuals with disabilities several times per week. Jacob also attends church services and sees his sister and extended family several times per month. He currently participates in an adult day program and a sheltered workshop, and he lives with his parents.

Members of the Greater Independence Group

- ❖ are employed in competitive jobs
- ❖ live independently
- ❖ have similar subjective and objective quality of life to Greater Dependence group
- ❖ more mental health diagnoses

Rich, age 31, was diagnosed with Asperger's disorder at the age of seven after struggling with behavioral control and social interaction for much of his early childhood. He also struggles with anxiety and depression. While Rich has an IQ over 130, graduated from college, and completed a Ph.D. in Medieval Studies, he moved back home after finishing his education and was unable to find a job for a year. He now lives on his own in a studio apartment close to downtown and works full-time at a bank as a data management specialist, making slightly above minimum wage. Although Rich was able to establish some friendships with individuals living in his dorm in college, he was unable to maintain those friendships after moving out of the dorm. In his free time, Rich travels to gaming conventions and is trying to find a girlfriend who shares his interests in role-playing games (specifically, Dungeons and Dragons).

FACTORS ASSOCIATED WITH MEMBERSHIP IN GROUPS WITH BETTER OUTCOMES AND OBJECTIVE QUALITY OF LIFE

After identifying groups of adults with ASD who were similar in their outcome and objective quality of life profiles, we identified factors that were associated with belonging to a group that had overall better outcomes and objective quality of life.

We found that individuals with better daily living skills were more likely to belong to either the Good Physical and Mental Health group or the Greater Independence group. In addition, adults with ASD who had a more positive and supportive relationship with their families were more likely to belong to the Good Physical and Mental Health group.

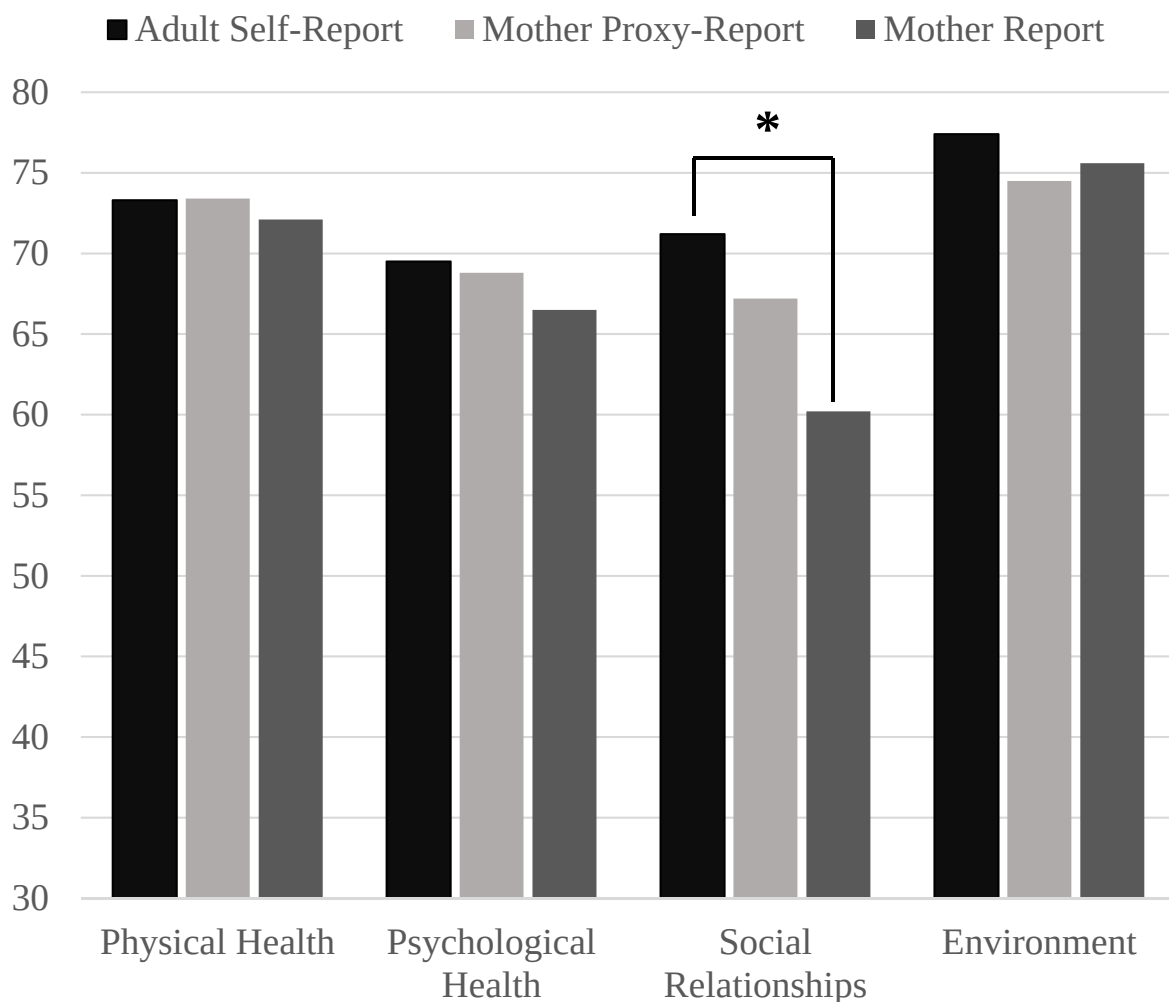
It is important to note that having intellectual disability was NOT associated with belonging to a better outcome or quality of life group for adults with ASD. This means that having strong daily living skills and a positive relationship with one's family are important factors that can lead to the ability to have a high quality of life for adults with ASD, regardless of intellectual ability.

Section IV: Findings on Subjective Quality of Life

In our interviews, we asked mothers to report on *how they feel* about their son or daughter’s subjective quality of life (“mother report”) and *how they think their son or daughter feels* about their own quality of life (“proxy report”). We also asked adults with ASD *how they feel* about their own quality of life (“adult self-report”).

Figure 1 displays the average of subjective quality of life in each of the four domains, as reported by mothers and adults with ASD. The highest possible score for each domain was 100.

Figure 1. Subjective Quality of Life of Adults with ASD



As shown in Figure 1, both mothers and adults with ASD rated subjective quality of life as relatively high, and they mainly agreed with each other.

Notably, the only significant difference between ratings from mothers and adults was that mothers rated their son or daughter's subjective quality of life in the social relationships domain as poorer. As shown in Figure 1, mothers rated their son or daughter's quality of life in this domain more negatively than their adult child rated it, with maternal-proxy ratings in the middle.

There were no other significant differences between mother report, mother proxy-report, or adult self-report ratings in the domains of physical health, psychological health, or environment. This means that mothers and their adult children rated subjective quality of life similarly in all of these domains.

FACTORS ASSOCIATED WITH GOOD SUBJECTIVE QUALITY OF LIFE IN ADULTS WITH ASD

In addition to examining the level of subjective quality of life in each of these domains, we also were interested in the extent to which life experiences and characteristics of the adult with ASD were associated with good subjective quality of life. Beyond this, we were interested in whether there were differences when we separately considered factors associated with the adult's self-report of subjective quality of life and the mother's report of quality of life. We considered a number of factors that might be associated with better subjective quality of life, including adult health, daily living skills, mental health, extraversion, perceived stress, and history of being frequently bullied.

Adult Reports

When quality of life was rated directly by the adult with ASD, two factors consistently predicted all four domains of subjective quality of life: perceived stress and the experience of frequently being bullied. Adults who reported higher levels of perceived stress or frequent experiences of being bullied at some point in their life reported worse subjective quality of life than those with lower levels of perceived stress or with fewer experiences of being bullied. In addition, adults with ASD who were more extraverted were more likely to have better subjective quality of life in the domains of psychological health and social relationships than adults with ASD who were less extraverted.

Mother Report

When subjective quality of life was based on reports by mothers about how they believed their son or daughter felt about their own quality of life *and* about their

own beliefs about their son or daughter's quality of life, adults with ASD who were more independent in daily living skills were more likely to have better subjective quality of life in the physical health, psychological health, and social relationships domains. In addition, adults who have lower perceived stress were more likely to have better subjective quality of life in the domains of physical health, psychological health, and environment, as proxy rated by their mother. Finally, adults who reported frequent experiences of being bullied at some point in their life were more likely to have worse subjective quality of life in the physical health and psychological health domains, as rated by their mothers.

Section V: Summary and Conclusions

This report has highlighted our findings about quality of life during adulthood for individuals with ASD. We shared new information about adults' quality of life in several important domains, including subjective quality of life, objective quality of life, and adult outcomes. Finally, we provided information about factors that are associated with good outcomes and quality of life in adults with ASD. In summary, we learned that:

- ❖ Adults with ASD in our study struggled to achieve “good” outcomes in adulthood of becoming self-supporting, living independently, and developing a network of friends. They did, however, have a high level of objective quality of life in terms of having good physical and mental health, adequate living conditions, and supportive and fulfilling social relationships.
- ❖ There are three distinct groups of adults with regards to their outcomes and objective quality of life profiles: Greater Dependence, Good Physical and Mental Health, and the Greater Independence.
- ❖ Adults with ASD were likely to be classified into better outcome and quality of life groups if they had better daily living skills and more positive and supportive relationships with their families.
- ❖ From the perspective of the adults with ASD, having lower levels of perceived stress and not having a history of frequent bullying were associated with the best overall subjective quality of life. When mother reported about their son or daughter's subjective quality of life, better daily living skills emerged as the most important factor that was associated with her perception of a better overall subjective quality of life.

We are excited to continue to study factors that promote good adult outcomes and a high quality of life for all individuals with ASD. We hope that this work can help inform policies, interventions, and services for individuals with ASD and their families.

Thank you again for your partnership in this work.