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Adolescents & Adults with Autism A Study of Family Caregiving



Report #15

Quality of Life of Adolescents and Adults with an Autism Spectrum Disorder

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Section I: Introduction

Recent interest in the transition to adulthood in individuals with autism spectrum disorders (ASD) has been motivated in part by the surge of youth with these diagnoses currently exiting high school and entering adulthood. At the present time, there is little consensus about how best to assess the quality of life (QoL) of adults with ASD.

Past research has found that adults with ASD face many challenges in achieving the conventional markers of adulthood – becoming employed and self-supporting, living independently, establishing one’s own family, developing a network of friends, and contributing to the community. Some have called for a reconceptualization of QoL for adults with ASD, but little research has been conducted that can inform such a reconceptualization or identify strategies for improving the QoL of adults with ASD.

It is because of this lack of understanding of the adult population with ASD, and our collective knowledge based on our research over the past 14 years, that we are well positioned to trace trajectories of development during adulthood, as well as to identify factors that have the potential to improve QoL during the adult years.

Note: All names throughout this report have been changed to protect the identity of those participating in the study.

Section II: Descriptions of Son or Daughter's Quality of Life

As part of our ongoing study, we asked mothers to describe the quality of life of their adult son or daughter with ASD. Responses reflected the varied experiences of adults on the spectrum. The majority of mothers reported that the quality of life of their adult child was good or very good. Many mothers noted that the son or daughter often seems happy even if the mother might like the son or daughter to have more activities. A smaller proportion of mothers reported that the life of their son or daughter was very sheltered and that it could be enriched and more integrated with the community. Mothers provided interesting insights about how we define and understand quality of life, which are reported below. We grouped mothers' comments into 5 categories:

- My Son/Daughter Seems Happy
- Good Quality of Life, but Not as Active as I Would Like
- My Son/Daughter's Life is Safe and Sheltered
- My Son/Daughter's Quality of Life Could be Much Better
- What is Quality of Life?

MY SON/DAUGHTER SEEMS HAPPY

I think it's good. I think he enjoys going off to his daily activities, feels like he's doing something productive. . . . he feels safe and valued. He seems pretty happy.

His quality of life is quite good. He enjoys what he does; he's proud of his hobbies and his accomplishments. I'd say the biggest difficulty in his life is the anxiety he experiences over various things. Change, stuff like that. But he seems happy with what he's doing. He's busy. He seems content.

I think Cathy is very happy with her life now. She controls it. . . . We're both quite comfortable with our situation now.

I believe that Chris is very happy. He's pretty healthy. He is positive. He has a zest for life . . . 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. That's his big thing now.

I'd say it's very good. It's not excellent, but it's very good. . . He seems to be very satisfied with his life at this point in time. His behavior problems have disappeared to almost nothing, which basically shows that he's happy. Any time stuff happens that he doesn't like, the behaviors manage to sneak back in.

GOOD QUALITY OF LIFE, BUT NOT AS ACTIVE AS I WOULD LIKE

I think it's pretty good. I'd like to see him going on more outings, but I think it's pretty good. He seems to be pretty happy most of the time. He also seems bored at times.

I think it's pretty good. . . . 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 probably would describe it as perfect. I think it would be perfect if he had a little more socialization. But I think it's pretty good.

I think he has a very good quality of life. There are some minor places for improvement; more socialization and building on learning relationships with women, but he is very happy otherwise. So he enjoys life most days.

I would say it's pretty good. He can go on vacations with us and we go to restaurants and do different things and we encourage him to be as active as possible. He doesn't always choose to do things . . . I would say that he has opportunities open to him but whether or not he decides to do things, that's up to him. Sometimes I think he likes quiet time and just being able to watch TV in his room. . . . He's not one to be wanting to do things all the time.

MY SON/DAUGHTER'S LIFE IS SAFE AND SHELTERED

He's safe but his life is very mundane. As safe as I can make it for him. I wish that I could do a lot more.

His quality of life is very sheltered. His world is very small; that's what I want to say. He's happy. He's proud of what he does. He enjoys the few things that he engages in outside of the home. But he could be doing so much more to expand both his mind and his world. He used to love books. When he comes here he looks at books; he's never opened a book at his house, because the TV is always on. But that's his right.

I think that her world is too small, and I think she would really benefit from a job, which would make her world bigger, and use some of her abilities . . . I would say it has its positives, and it has its negatives; I don't know.

It's fairly limited. Physically she's well, and she can get around well. Her cognitive abilities limit her; she can't drive, and she can't go to college. . . . She has a roof over her head and plenty to eat, she has activities to engage her, and she has day programs that give her an out, so she's not stuck at home all the time. I think her quality of life is reasonable.

MY SON/DAUGHTER'S QUALITY OF LIFE COULD BE MUCH BETTER

It could be a lot better. I think we're doing the best we can with what we've got. I think having more people involved in his care, emotionally involved in him and his care, would be a good help. We do things he enjoys, like concerts, going for a hike or camping, but not often enough. He doesn't really indicate much of anything else that he wants to do. Other than going to see people a lot.

Not so good. I think it's very uncertain.

I'm not totally happy with it, I guess. I would like to see more for her. She just moved into the group home; maybe I need to give things a little more time.

It's lacking. He really needs more structure, more income, and more contact with people outside the household.

WHAT IS QUALITY OF LIFE?

I mean, that's all relative. Many, many people would consider him to be lonely or bored; a low quality of life. But I think he's actually doing very well given his circumstances.

I think it's excellent all things considered. You can always be sad and concerned about the fact that Kevin is not able to live the same kind of life that I live. But he also has his limitations and these things, so it depends. Your satisfaction is based on what you compare it against, right? So if you pine for things that are not reasonable then that's foolish, right? So if we say Kevin has a job, he has interests, he travels: he has a life. He has a fairly full life considering his disability and it could be much worse. So I would say I'm satisfied and happy with what Kevin is able to do and I believe he's happy too.

I just try to think positive, but sometimes when I'm really quiet and stop to think about it, I really do not know what he is thinking deep in his heart. I do not think he is happy, but he has said "I'm trying my best." So compared to himself, he is more open, and he can talk more, and express his feeling, or what he needs. So in that way, I think he feels better. But I think he will feel he's not as good, or not as able, as compared to people his age. I just don't know what else I can do. . . . I think I'm just learning too, along the way.

How would I describe it? You know, what is quality? I don't know. He's safe. So I'm happy; that's all I want. I want him safe.

Well, I'm not satisfied with it, but I think he is. I don't feel he's doing enough activities to exercise his mind or body. But I think that's probably my problem and not his.

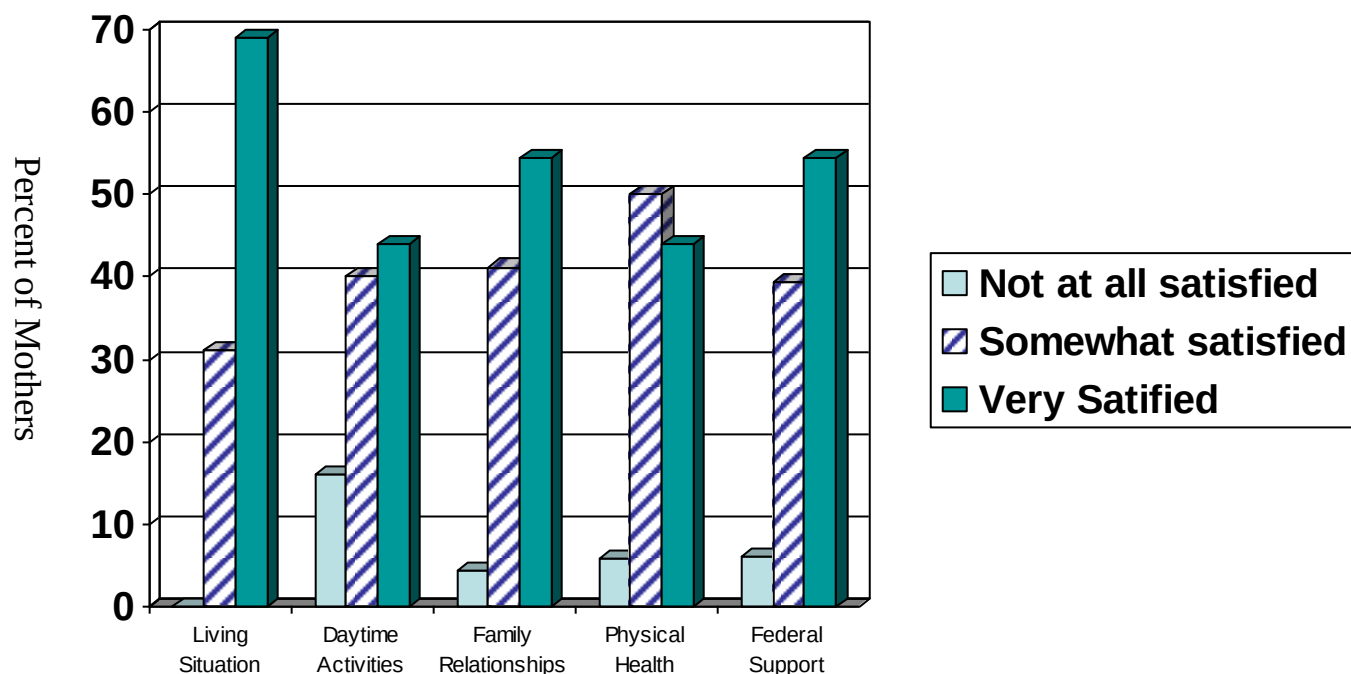
Section III: Ratings of Satisfaction with Different Areas of Quality of Life

As part of our interviews in 2011-2012, mothers were asked to rate their level of satisfaction with several areas of their son or daughter's quality of life. Specifically, mothers have indicated if they are "not at all satisfied," "somewhat satisfied," or "very satisfied" with their adult child's life in the following domains:

- Living situation
- Daytime activities
- Family relationships
- Physical health
- Federal support
- Emotional well-being
- Ability to communicate
- Recreational activities
- Services from agencies
- Friends

The data for the first five categories (living situation, daytime activities, family relationships, physical health and Federal support) are presented in Figure 1.

Figure 1. Ratings of Satisfaction with Living Situation, Daytime Activities, Family Relationships, Physical Health, and Federal Support

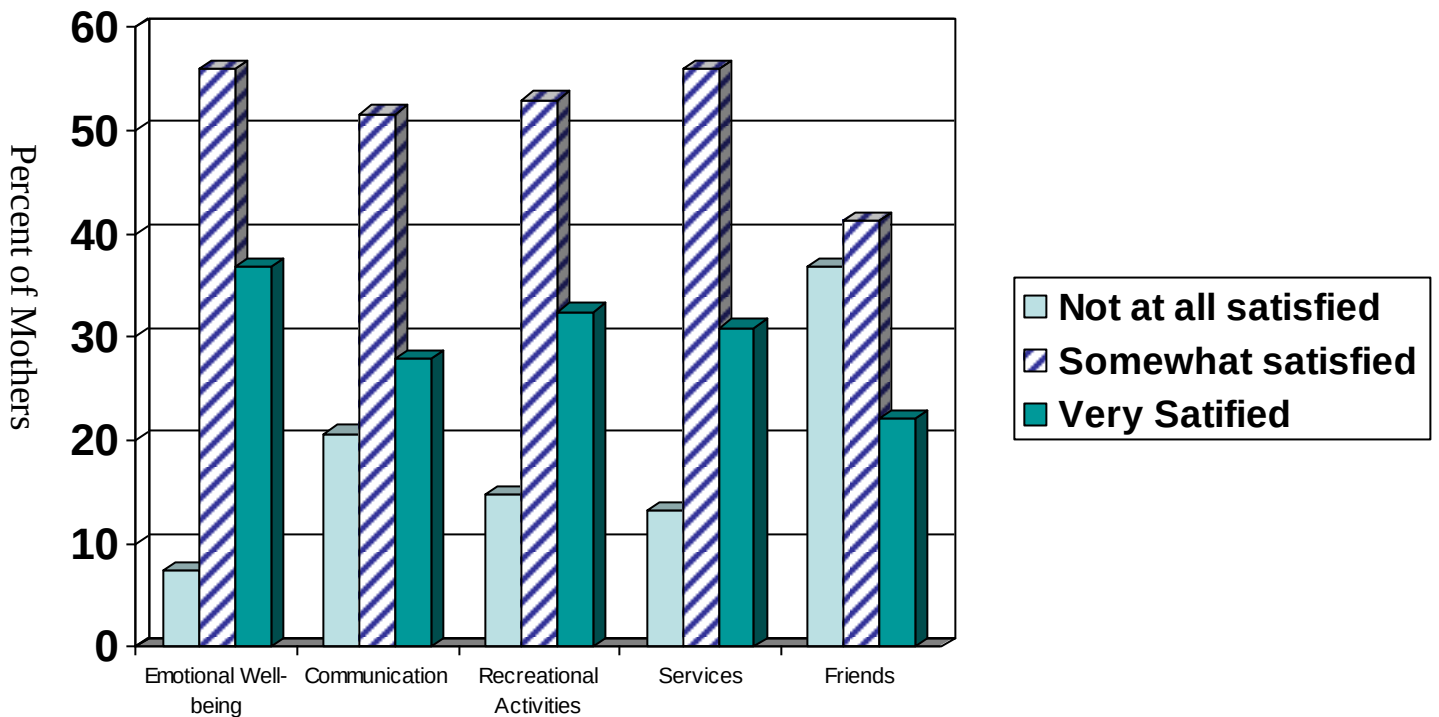


As shown in Figure 1, mothers were most satisfied with their son or daughter's living situation, with nearly 70% of mothers being "very satisfied" and very few mothers being "not at all satisfied."

Satisfaction was also high with respect to family relationships and Federal support; over 50% of mothers were "very satisfied" with their son or daughter's family relationships and level of Federal support.

Next, Figure 2 presents data showing ratings of satisfaction with quality of life in the second five categories: emotional well-being, communication, recreational activities, services, and friends.

Figure 2. Ratings of Satisfaction with Emotional Well-Being, Communication, Recreational Activities, Services, and Friends.



Mothers were least satisfied with the son or daughter's friendships, with 37% of mothers reporting being "not at all satisfied" with this aspect of quality of life and 40% being "very satisfied."

Less than one third of mothers were very satisfied with emotional well-being, communication, recreational activities, or services, but over 50% of mothers reported being “somewhat satisfied” in these domains of quality of life.

We also note that 21% of mothers were “not at all satisfied” with their son or daughter’s communication, indicating that even during adulthood at least 20% of mothers still would like to see better quality of life regarding their son or daughter’s communication.

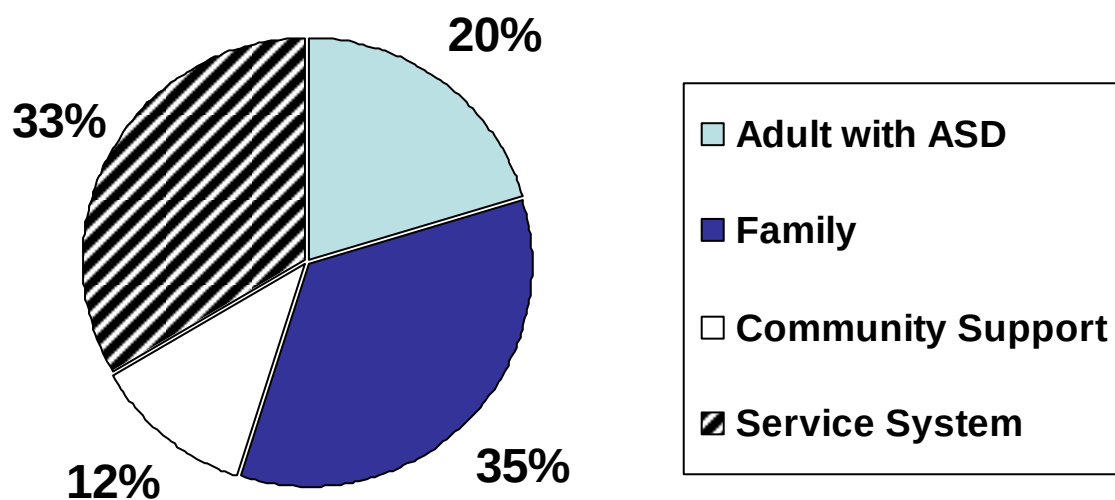
In addition to examining level of satisfaction in each of these domains, we also were interested in the extent to which satisfaction with QoL may differ based on residential setting of the son or daughter. We found very few differences in QoL between adults who were living at home and those who were not living at home in terms of the 10 QoL domains. There were two exceptions to this pattern of similarity: Mothers of a son or daughter who was living at home were more likely to report higher levels of satisfaction with communication than mothers of a son or daughter who was living outside the home. In contrast, mothers of a son or daughter living at home were more likely to report lower levels of satisfaction with Federal support than mothers of a son or daughter living outside the home.

Section IV: Factors That Contribute to Quality of Life

We asked mothers to describe three factors that contributed most to their son or daughter's quality of life. Responses clustered into four primary areas of support for adults on the spectrum:

- Characteristics of the Adult with ASD
- The Family
- Community Support
- Service System

Figure 3. Factors that Contribute to Son or Daughter's QoL



As shown in Figure 3, the most common response from mothers regarding the factors that contributed to the quality of life of adults was the family, followed by the service system. Quotes regarding each of these four areas that influence quality of life are presented below.

CHARACTERISTICS OF THE ADULT WITH ASD

The most important thing is his ability to communicate. I remember when he couldn't communicate and we never knew what was setting him off. Now he's able to sit and have a better conversation and he's actually able to come right up and tell you what the problem is. Like last week when he had a problem. He told me exactly what was wrong. We wrote it down and gave it to his case manager and they took care of it, whereas before you had to ask: you had to go through the 20 questions routine. We don't have to do that anymore.

Sam himself. He's an optimistic and ambitious person. I think if he was a more depressive character he would not be where he is.

He's in good health.

Her emotional well-being because that is her balance. If she's well mentally and feels good, it's everything to her day.

She's happy and confident. And that's basically half the battle. If she's happy she'll get up and go to work in the morning and her general outlook on life is good.

I think being able to communicate with others is really important for him.

FAMILY

Family relationships. I come from a big family and I think family is important to be around you to give you that support you need, to give you comfort.

The fact that the family has been on top of things and completely involved and set up the program and was tenacious enough to keep pushing to make it happen. All of that organizing was mainly done by me actually [laughing]. So me. His brother being close and being there when he's needed, most of the time. And his sister caring enough and having enough money to purchase a home for him.

She has her family. That's a support. If you have a hard day in the outside world, you can come home. I try to keep my house a nice, calm, and quiet place so it's a good environment.

I think her family relationships. It gives her a sense of security, knowing that she belongs and she is loved.

Having me as his primary caretaker because I take him out in the community and outdoors and because I'm not afraid to give him hugs.

Family. When it comes down to it, if she's really struggling, she needs the support of me and my husband to help her figure things out and just to be there for her no matter what.

COMMUNITY SUPPORT

His church and Special Olympics . . . The church . . . he feels comfortable there and they have Sunday School for just people with disabilities of all kinds. He sees the people. He says the teachers and helpers are nice. And with Special Olympics he gets exercise and it's a group activity. They have picnics. The church has activities too.

The community in which he lives. It's a special place.

Her membership in [special interest group]. It gives her a sense of purpose and a way for her to continue to learn. There's always more that she can learn and that's really important to her. Her friends provide her with an outlet for some of the darker sides of her personality. She also gets to do physical stuff and be active.

Her boyfriend really provides her a sense of companionship and makes her less lonely, and affords her the opportunity to go places because he drives. I think they care about each other and that really helps her quality of life.

The most important aspect for his quality of life are the people that he knows and sees regularly, which would be the people he works with, the people at his church, and a couple of friends that help him out on a regular basis.

SERVICE SYSTEM

She has a good team with the different case managers. Her caregivers are very good and very qualified.

His day services are very important. He enjoys that. It's important to him to be around people other than us.

Financial support from service programs such as SSDI . . . The service broker that he has. Without her assistance, things would be unmanageable. All the paperwork, all that stuff. . . Without her help, I would be totally stressed out and so would Steve. We'd probably get it all wrong.

Good day programming so that he isn't idle during the daytime. The day programming has specific goals for working with him.

Having work and daytime activities. I think he wishes things were a little bit different in his life, but on the other hand I don't think he is realistic about what those situations could possibly entail. I don't think he realizes that he's in a pretty good situation as far as work.

Where she lives and the staff who take care of her. She has a steady day service that she can go to. Everything is steady for her and that's what she needs---a routine, a schedule. I think we got it in place right now.

Section V: Summary and Conclusions

This report has highlighted our preliminary findings about quality of life during adulthood for individuals with ASD. We shared with you new information about mothers' satisfaction with their son or daughter's quality of life in several domains. We also provided quotes from mothers about their son or daughter's quality of life and what factors contribute to a high quality of life. In summary, this report has shared the following information:

- ❖ In many areas, mothers were satisfied with their son or daughter's quality of life. Almost 70% of mothers were "very satisfied" with their adult child's living arrangement. The majority of mothers were also "very satisfied" with their son or daughter's quality of life in terms of family relationships and Federal support.
- ❖ There were some domains of quality of life where mothers expressed dissatisfaction. For instance, 37% of mothers were "not at all satisfied" with their son or daughter's quality of life in terms of friendships. Further, over 20% of mothers were "not at all satisfied" with their son or daughter's quality of life in terms of communication.
- ❖ Mothers of adult children who were living at home and mothers of adults who were no longer living at home reported mainly similar levels of satisfaction with their son or daughter's quality of life.
- ❖ Mothers gave thoughtful responses to the following question: "What contributes to the quality of life for your son or daughter with ASD?" Responses clustered into four key factors: the adult with ASD (20%), the family (35%), the service system (33%), and community support (12%).

Looking ahead, we are excited to continue to investigate the factors that promote a high quality of life for all individuals with ASD. By gaining a better understanding of quality of life during adulthood, we aim to inform policies, interventions, and services for individuals with ASD and their families across the life course.

Thank you again for your partnership in this work.