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Adolescents and Adults with Autism
A Study of Family Caregiving

**Report #1:
A Book of Quotes: Shared Experiences from
Families of Adolescents and Adults with Autism**

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Dear Family Members,

Over the last year and a half we have conducted interviews with more than 400 families who have a son or daughter with autism. Our study on the challenges and rewards families experience in having a child with autism is the largest federally funded project ever conducted on this issue. We have interviewed families whose child is as young as 10 years old and families whose son or daughter with autism is now in his or her 40s. Some live with their parents while others live away from home.

One goal of our research is to understand better how the condition or manifestation of autism changes over time, the kinds of services that are received and/or needed, the impacts on mothers, fathers, and siblings of having this “difference in the family,” and the ways in which families accommodate or handle their unique and common experiences.

In this booklet, we have assembled many of the thoughts and feelings parents shared with us during our first interview. There is an extraordinary amount of wisdom, energy, struggle, and triumph expressed in these diverse comments. Some of the comments may surprise you, others will ring true to your own lives, and some may help you see both similarities and differences between your family and other families who have walked familiar paths.

We are extremely grateful to you for your willingness to give so much time to our project, to welcome our interviewers into your homes, and for helping us teach others about the unique experiences of families caring for a child with autism. We look forward to continuing to learn together.

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Please note that **comments made by fathers are in boldface type.** Mothers' comments are in regular type.

Living, Loving & Learning

...She keeps us focused on what's important in life - compassion and love - and helps us become stronger as a family.

...Because of autism, I am able to see how society is set up for “normal, average.” It is not set up for someone with a disability or for parents of a child with a disability.

...I've learned not to take anything for granted. I am not judgmental about other people. I am more sensitive for other disabled people. I am learning better to take one day at a time.

...I've learned about loving a child who does not fit in, about dealing with consistent frustration, of living with terror. I've learned about suffering.

...You can't totally control you child or her behavior. The right medicines do help. Love and, possibly, understanding work best along with creating an environment she's comfortable in. Forget yesterday and today; tomorrow is a new day; try and do better.

...I have learned to value the positive in life, as well as to view “problems” as challenges to grow. I've seen that the best way is to deal with life as it unfolds and accept what is real rather than what might have been or what one might wish had been, to put energy into positive solutions and feelings whenever possible.

...My son has given me invaluable strength and confidence. Observing the obstacles that he has overcome; the ridicule he has dealt with from his peers, the challenges he has accepted and the levels of independence he has obtained are remarkable — I have learned that almost anything is possible.

...I have learned that there is a God and to never take anything for granted. This has brought me closer to my wife, daughter, and God. I am thankful for my family and all the things I have, especially my wife, daughter, and son.

...First of all, he is our son and we love him dearly. He has taught our whole family much more than we can ever teach him. Everything that he learns just makes us smile.

...I think the thing I learned the most is to take things a day at a time. Progress is much slower than with other kids but it does happen with patience and persistence.

...I have learned to find joy and excitement in small things. A small step for my son is really exciting to all others that love him. I have learned to enjoy life more, and to be more aware of other people's feelings.

...The power to love. There are times you can get so frustrated you could just strangle him, but you always realize how important that hug is.

...That even the simple achievements in life are most wonderful. A smile from her melts my heart. The first time she said "mom" made me cry.

...Be tolerant. Don't always expect things will happen the way you want. Be sympathetic. Those who can't lead a normal life are not to blame for their problems. Trust in God. Things in life may seem to be out of control, but trust in God can bring us peace.

...I've learned to take things a day at a time, to enjoy the good things in life. I've learned to be more flexible and tolerant.

...I've learned how resilient a kid can be. I've learned that sometimes it's a joy and sometimes it's the pits. I've also learned that it can be a challenge raising a child with exceptional needs, and that the challenge doesn't end magically when your child becomes an adult.

...I have learned to deal with this and other common problems in conjunction with my wife. We feel closer as the result of having an autistic child.

...I've learned that he was a gift of God and taking care of him for nineteen years has made me a better person.

...I have learned to accept him as he is as an adult. I have learned that every human being has an inner dignity.

Special Things About Our Child

...She is part of our family. We all give and take with each other. Her insight is unique and challenging . We're richer for her being here.

...He's a great kid. He's helpful and fun.

...He is fun, laughs, is enjoyable, loves to travel, watching sports, library, wrestling, party once a month, we enjoy him.

...I like his sense of humor and his depth of interest in subjects that interest him.

...He's friendly and cooperative, easy-going.

...She keeps me young and my outlook good.

...He keeps us laughing. He just gives everyone a different perspective. It makes you see the world through other eyes. He has a sense of humor - he's funny. He gives us better patience and appreciation for other people's shortcomings.

...He is the most loving, caring and contented person I know. His heart is full of innocent love. He is so giving to others.

...He has some unique perspectives about the way the world works - is constantly asking questions. He has a unique sense of humor that we don't always see - but that others do.

...He is very happy, friendly, smiling, nice to be around.

...She is a very important part of our family. She and her sister are very close. We enjoy her sense of humor and the everyday joys of being her parent. She is quite creative and is very good company.

...He's happy, compliant, not aggressive. The worst he'll do is ignore you. He has a sense of humor and enjoys company.

...He's very good with computers and he picks up this photo manipulation really fast. He's a very good driver. He sees things before other drivers do and reacts to situations very well. He likes working in the yard and has a good sense of artistic balance. Now he's in a club with other people who share the same interests (trains).

...He's very helpful around the kitchen. He likes to cook with supervision at the group home.

...Everything is positive. His brothers interact with him all the time. He helps with household chores. His personality is very important to our family structure. He also stimulates interesting conversations daily.

...I think, somehow, there will be a career; she has an incredible way of working with animals. She is an "incredible servant." She's focused in on doing for others. She shows her love by being helpful and selfless in her relations with people. She has great value.

...She lightens my day, I enjoy her company. I love when she laughs. She's my little angel. She always will be.

The Hard Times

...It is difficult to get him to see any doctor other than his pediatrician. He had a very bad experience with a psychiatrist that exaggerated this problem. We have difficulty getting him to see a dentist. It's been two years. He bolted out of an eye appointment and hid in the parking lot.

...Demands huge blocks of time. It's extremely frustrating because of the lack of progress, both socially and academically.

...He is very belligerent, he's uncooperative. He's either really good or really bad.

...It is necessary to spend more time with him which takes time away from my other son. Often there is tension in the day-to-day running of the home.

...Can be really aggressive, scratches, hits, kicks, screams and bangs head.

..It's hard to have a social life. We cannot plan ahead about any outings since we do not know how my son will be then.

...The hardest thing is watching her struggle in a society that does not accept her. It's also hard to know that she is very lonely and not know how to help her make friends.

...The MESS. The noise. She still can't wash her own hair. I worry all the time.

...When he wants something and we don't understand what he wants - puts face up to yours and makes a noise - gets really frustrated, makes noise louder and louder.

...He's a tremendous drain on our energy - requires/demands our attention and is not self-reliant. I feel like our lives are not normal - very little down time - puts limits on our socializing.

...In a new environment he gets frightened, starts crying to go home, won't hit anybody, just upset.

...He will slap, hit, pull hair, bite, and moan. The hitting is the worst; he will walk up and hit a stranger.

Thoughts About Having Our Son or Daughter Live At Home

...He is safe and is taken care of. He is less likely to get into trouble in the complex society. He can help to do some small things. He can keep us company.

...Enjoy being with him (usually). Don't have to worry about the quality of his care.

...He is a joy to be around most of the time. His innocence draws me to him. He generally is very happy to see me. His needs are simple and he's easy to please.

...I know how she is being taken care of and treated.

...I know that he will get the love and affection every young boy needs.

...It's easier to assist him with schooling, life, skills. He's a very interesting person — he doesn't require much supervision. He does his chores without reminding him a lot. We can stay together as a family.

...Doesn't sleep well. Always have to be on guard 24 hours a day as to what she is into. Cleaning messes constantly.

...She is very time demanding, we don't let her do much on her own since she doesn't have any sense of danger.

...He's pleasant, helpful when asked, much calmer than he was as a young child. In a way, we're "making up for lost time." Social interactions continue to improve.

...We can never leave her alone. We never do anything as a whole family, i.e., church, restaurants, etc.

...Requires constant oversight. Makes sexual intimacy with my wife problematic. Destructive behavior makes house a shambles.

...Since puberty he has done some negative changing and this is very stressful. I probably won't ever be able to work outside of our home.

...We do love our son and care about his welfare. We can and do enjoy spending time with him. He is unique. He is in a caring, loving environment where all of his needs are trying to be met.

...He is my best friend, and he is a lot of company in his own way.

...I never have to worry about his living conditions or if he is getting into trouble. I would go crazy with worry if I didn't know where he was. Whenever he needs me, I'm right here.

...Companionship: it's like having a friend other than a spouse to live with. Security knowing she's safe and being well taken care of. Closeness of family, being a family.

...We love him, as any family member who is loved, our lives would seem incomplete without him here. He brings joy, innocence and uniqueness to our lives.

...He would be missed a great deal if we had to go more than a day or two without seeing him.

...I know what care he is getting, that he is safe, not being physically or sexually abused and is being taught the values we want. The family has learned much from being with him.

...Very stressful because you have to be on the top of your game dealing with his autistic tendencies.

...He is still in high school so living at home is the "normal" thing to do at this point in time. It is hard to say how I would answer this same question in 5 years if our living arrangement is the same.

...Even at 16, there's constant care involved.

...We are older parents and we feel so fortunate to have him. He is truly a blessing to us and the time could come soon enough for one or the other and we would have to give him up.

...Stress and hard work.

...Violent language and behavior. Poor example for younger sister. Marital stress. Financial difficulties.

...He is all-consuming of our time, energy, patience. It can be emotionally and physically draining to be constantly vigilant of his emotional arousal levels. I cannot work outside the home. It is a full-time job caring for our son's needs.

...We have difficulties with behaviors - they can be highly stressful. The household is often very tense. We tend to be confined by the rigidity and fragility of our son.

...Because of her disability there is a constant stress in our family. She is very obsessive-compulsive. Everything must be just right; if not, she can make us miserable. It's like walking on egg shells at times.

...I have no time for myself. My husband and I don't have much time for ourselves.

...At least one parent is always "on duty" when he is home. It can get exhausting. It's hard to get routine chores done or get enough personal time.

...At 18, she has emotional desires to separate and leave home, but not the social and adaptive ability to do so. We worry about transition to living away.

Thoughts About Having Our Son or Daughter Live Away From Home

...My husband and I finally have time for ourselves. The home atmosphere is much less stressful. We have him with us each weekend and by not having to deal with the daily stress, we have a lot of fun with him on the weekends. He has grown and changed because of his independence from us. It's been great for us and great for him. My mental health is vastly improved since he moved.

...It is comforting to know that he is able to take care of himself, albeit with some support. I'm glad he is getting "real life" experiences. In fact, he has seen the value of some things I've been trying to teach him for years, like cleaning his room or picking up after himself. I'm glad to see him rise to the challenge of handling money, paying rent, etc. I've seen him mature some in the 8 months since he's been on his own. It helps me a lot to know he can live on his own. Home has become less tense. He was starting to challenge his school routines and his responsibilities at home in the last year or so. I can tell our relationship has improved since this tension is not present anymore.

...He has an excellent staff that keep him safe. He has companionship (he is VERY happy in his group home!). He is learning so many things! He has excellent physical and mental doctors. He has made several friends and goes out in the community often (daily). Our home has much less tension. We are able to live a somewhat "normal" life.

...Because he does not verbalize, he cannot always get his needs met. I think it is very difficult for people who do not understand autism to care for and support someone who has autism. I feel bad about the lack of communication and at times the lack of skills of employees. Also, this "house" has not become a home yet.

...She is less dependent on us and has a greater chance for an independent life.

...She continues to learn more life skills. By my letting go she has blossomed in many areas. She has a very good feeling about herself and I hope she will continue to become more independent.

...I love doing things with him. I feel bad because he's more isolated and has less social life. I worry that he'll be harmed emotionally by people who don't care about him the way we do.

...Having to deal with the continual shortage and turnover of staff. Worrying about the quality of care he receives. (Abuse). Having to deal with the "adult system."

...I must still be "on call" for the next disaster, the staff is not pro-active. I visit her and find her life could be better if staff were better trained/better skilled. What will happen to her when I can no longer advocate for her? She lacks the initiative to correct/complain about quality of life issues, i.e., healthy food, safety, cleanliness.

...I wonder about his diet and his health. He doesn't eat the most nutritious foods, though lately he's taken an interest in actually cooking rather than heating up a frozen dinner of some sort. I am concerned about him socially. His best friend lives in the same apartment building, so that's a big help, but he does not work yet, so he spends a lot of time in his apartment on his own. I also am concerned that he might be taken advantage of.

...I miss him, especially his smiles and hugs.

...He is a long way from home. Very hard on us. The group home he is in is terrible. The only reason he is there is because there are no options. Would love to have him closer to home. There is no communication between the group home and ourselves.

...I can relax somewhat. I can spend time with my wife.

...She is learning new skills. Since she tends to withdraw, it is good for her to belong to a group of friends. She will be better prepared when the final separation from me comes about. The social life provided is wonderful. She is becoming more and more independent.

...He is becoming more independent and responsible about taking good care of himself. He has developed a new personality away from home which makes me very proud of him.

...His relationships with both parents, especially Dad, have improved. He has grown tremendously, socially and in living skills. It's good to be out of the power struggles and behaviorally he is much more appropriate. He rarely loses his temper or becomes aggressive. He is much happier now.

...He's learned he can live on his own with limited help. It's a great plus not to have to live with emotional and behavioral bursts daily. Also, my life doesn't have to revolve around what he'll accept in our home.

...I've always felt that if my son lived at home with us, we'd be prisoners in our own home. It gives us freedom to enjoy our lifestyle. I also feel it's better for him because he's in a more structured environment, which he needs.

...He is an adult and is happy living in his own home.

...I don't have the opportunity to observe the progress that he continues to make and I also miss his companionship.

...He can get more individualized attention. The environment allows more freedom from timelines and is flexible. We hope this is giving him more independence. If his Dad and I should die or become incapacitated, he is adjusted to a different environment and well cared for.

...He doesn't have the protection of my home and I miss him very much. The staff has changed several times which doesn't give the stability that is needed. They also lack knowledge about certain domestic problems.

...He's a little lonelier.

...Feeling guilty like we gave up but realistically knowing we did all we could.

...I worry about him, feel guilty, uncomfortable about the peers he is with, frustrated with his program and sometimes staff members.

...The separation — the worry — the love we need to give him that no one else can nor does. The feeling that we abandoned him. Not being able to take care of all his needs forever. The guilt of saying goodbye and leaving him behind. The stolen moments with our precious boy...

On How Parents Have Changed

...My faith in God has grown deeply. My sons are precious gifts from God and I thank God everyday for them. I have learned patience from my autistic son. I have learned to take delight in the little things in life. I have learned the true meaning of trust and love from my son. I have learned never to underestimate the things my son can do, for the sky is the limit!

...I have had to learn to become patient. I have had to restructure my thinking on discipline. Use of positive reinforcement. I have had to give up my pride and accept my child for what she is and not what I want her to be.

...I have learned that we're all individuals and no matter how disabled, life has value. Through my daughter God has given me a strength that I would have never thought I could possess.

...I don't think I'm any different at all.

...My husband and I and both of our older sons became much more thoughtful and understanding persons as a result of knowing and living with him.

...My two autistic children have taught me how to be patient and understanding and considerate of other children or people who have disabilities.

...It has helped me to become a stronger person and appreciate things that other people might take for granted.

...I am probably my son's best friend. My other sons have many friends and use me more in the traditional father role. I also grew up playing sports and have had to adjust to my son's lack of interest in sports. That has been very positive for me.

...I've been humbled, encouraged and discouraged. I look at life entirely different and I love her. She brings out my goodness and helps me to see my faults everyday! Thank you!

...It has made our family stronger and closer than any other family I know. We have had to overcome things that others can't comprehend.

...I was forced to draw upon a strength bigger than my own that is in God. If I had focused on myself, I would have been a much “smaller” person than I am now, because my daughter drew me out and beyond the limits of my own strength. Her unique viewpoint and outlook has broadened my own.

...I have learned to be a lot more patient. I learned how to explain things in simpler terms.

...People with disabilities are people first. I used to think that my son was “broken.” I now know he is just different. And a real special and interesting different person to boot.

...First, I have been more involved with immediate family. Second, I have diverted myself from some career opportunities. Finally, I have been closer to my wife than I otherwise might have been. We have suffered the grief, etc., together.

...I never thought I would have a child who could not read. My son has taught me a humbleness and to have compassion for those less fortunate than myself. My son deals so well with his disability; he inspires me to be a better person.

...I've coached soccer and baseball teams that my typical son was on as well as Special Olympics basketball and soccer. I would never have thought I had the skills to coach disabled kids but this experience has been richer for me than the “typical coaching.” Getting as much involved in school work, recreation, cooking, music, etc. as I have has been different and difficult. I simply spend more time with my son.

...I've tried things and done things I never would have without him — such as running for School Board (5X) and serving for 15 years. Having him has been a challenge and a chance to grow in many unexpected ways.

Impacts on Social and Family Life

...Not at all socially isolated. We socialize with friends and family who are aware of and understand her problems - most enjoy her.

...Self-reliance is essential. In caring for him, family, friends and institutions have frequently let us down. We're on our own with him. The great fear is: what happens when we're gone?

...Estranged from husband's side of family, not easy finding sitters/money to go out often - used to work different shifts, so hard to coordinate time together. We are careful about situations we put him in - friends, kids, families without disabilities

...We have had no real impediments to social activity because of his behavior. Sometimes we have to withdraw from activities, but that is the exception, as some of it is because of my own reaction to the behavior more than the behavior itself.

...We are ignored by neighbors. We have two friends.

...It's difficult to socialize with neighbors or friends.

...Siblings don't feel they can invite friends over.

...The negative side includes how his behaviors have caused us as a family to be socially isolated. We tend not to go out as a family (or even as a couple) because of this.

...His antisocial behaviors have alienated some neighbors. It is difficult for our family, especially our other two sons because he doesn't like them to have friends over. He becomes very negative about certain people.

...We feel isolated because others cannot understand the problems of a home with an autistic son.

...Sometimes the other children [siblings] have to make sacrifices that I know they really don't want to, but do.

...When he was a small child he had many tantrums which curtailed our social contacts, but that is no longer the case.

...We can't go on family trips or visits without a great deal of stress or tension being involved so we tend to avoid doing it.

...People don't want to associate with you. Most people act like her condition is contagious.

...We're active in community — have close contacts with neighbors and church.

...His "weirdness" has become "normal" to people in this community. Outside, no.

...Our family is very socially active. However, it is true that there are some large family gatherings which are just too stimulating for my son, leaving us a little isolated.

...We do not let ourselves be socially isolated - we go, and are there.

...Relatives do not want to visit with us when our son is at home. Only a few select friends of ours feel comfortable with him.

...It's very difficult to participate in activities without wondering and looking out for him.

...We (I) have been criticized for the shyness and skills deficits. "Over-protective mother." I avoid people who are openly critical. Some are relatives so that is hard.

...Most of our friends accept her as an individual. A few people are concerned about setting her off.

Reflections on a Life

...The main point would be not to take anything (the simple things) for granted.

...I have learned that there are many unique and different ways to approach the same life experiences, that sometimes it is vital to “walk in the other person’s shoes” and to try to understand how they look at and experience life. That autism can be a really great thing! That I had strengths that I never knew I had. I never take things for granted. If you want something, you have to create it and not wait for someone else to create it for you.

...A child with autism can be a handful, but the growth and the things he has done I would never trade for a normal (I hate this word) child. Even though the problems could rise as he gets older, I think he likes what he has in life and the way we have raised him. I think we have helped him in this regard. I love him with all my heart and will continue to fight for him everyday.

...I have learned that life goes on and you have to make the best of it. Nothing in life is easy; you have to fight for what you want; it’s not easy but still you try and try and keep on trying.

...A Father’s Observations: An Evolution of Emotion

Phase One: Oblivion — “Thank goodness, our newborn son is perfectly normal. See, all the fingers and toes and he’s cute as can be.”

Phase Two: Concern — “Maybe Mary’s right, he should be talking by now.”

Phase Three: Investigation — “This can’t be serious, we can find out what’s wrong and fix it.”

Phase Four: Denial — “It can’t be autism. It has to be another misdiagnosis.”

Phase Five: Realization — “This is serious and there’s no way to fix it.”

Phase Six: Mourning — “The son we thought we had is gone.”

Phase Seven: Acceptance — “These are the cards we’ve been dealt, we have to do our best.”

Phase Eight: Advocacy — “We are going to have to work day and night to make people understand, accept, accommodate, and respect him.”

Phase Nine: Admiration — “This son of mine has to cope with things I can’t even comprehend. He works incredibly hard to fit into a world we take for granted. His every success a victory, his accomplishments inspiring. I respect and admire him more than anyone I have ever known.”

...Never give up. It takes a huge amount of physical, emotional and spiritual energy to survive. Everything is possible for your child. (Not always on my time schedule.) If a door closes, look for a window to open. Every child has a right to be able to reach his potential. To keep me sane I had to know that God wouldn’t give me more than I could handle.

...I’ve learned that living with a kid with a disability can be a blessing and a privilege - and that you can be as proud of him as if he were a Phi Beta Kappa. I’ve learned that living with a kid with behavior problems can be hard without being unbearable, and looking back I wouldn’t change a minute.

...He is a true blessing to us! He is so honest, sincere, and innocent that he is just a joy to be around. He has a wonderful sense of humor and makes us laugh. His laughter and smile are very contagious. He gives us a new perspective and life. I can’t imagine life without him.

...Life is not fair. People are usually not willing to take the time to understand others’ problems. The above two thoughts sound too bleak... there are some good people out there.

...What a long strange trip it has been. The only person I can rely upon for help/support is myself.

...It was life changing. It drove me to the Lord. It humbled me, I'm still learning. I was unprepared for the challenges that I faced, but am now thankful for what I've learned, to depend on God; to appreciate uniqueness, the specialness of everything... We take language, etc. for granted so much, as well as social relations. I learned how important the words "I love you" are and the simplicity of a genuine smile/touch. I learned to let go, let a child be different and for it to be OK.

...I've had an opportunity to love and care for one of God's Angels. The road has and will not be always easy, but this kind of love comes from "Above" — And, I'm sure that is where my questions of "why us" will be answered. Until then I will do my best to educate society and help others along this journey!

...I learned a lot about myself, much more than I would have, had he not been autistic. This was very hard, but also very good for me. I learned first hand the power of human spirit. I suspect he experienced a lot more from his peers than I'd ever care to know about, but it did not get him down very much. I learned that our minds can be wonderfully diverse and those that think or view the world differently can teach the rest of us a few things. I learned to be more accepting of those who have handicaps.

...I've learned that a child with autism is a lifelong responsibility - and that I must accept what happens in life that I cannot change. Also that there are very good people willing to help with this problem and to count the blessings that come your way and the good times too. It has been very satisfying to see the help our son has gotten and the miraculous results and improvements in him. He has come a long, long way in his life.

...Never give up.