

Report #8:
**An Inside Perspective from Adolescents and Adults
with an Autism Spectrum Disorder**

Table of Contents

	Page
<u>Section I: Introduction</u>	1
 <u>Section II: Reflections about an Autism Spectrum Disorder</u>	
Question #1: What do you feel people should know about what it is like to have an autism spectrum disorder?	2 - 6
Question #2: What advice do you have for parents of a child with an autism spectrum disorder?	7 - 10
Question #3: What advice do you have for other people your age with an autism spectrum disorder?	11 - 13
<u>Section III: Summary</u>	14

Section I: Introduction

Since 1999, we have been fortunate to witness the lives of many unique families and individuals touched by an autism spectrum disorder (ASD). We have explored the pains, joys, and continual growth these families have experienced, enabling us to make great strides in understanding the impact of ASD on the family. Specifically, we have learned about how raising a child with an autism diagnosis impacts the mother's health and well-being. Through these interactions it became apparent that we were missing an important voice, that of the individual with an autism spectrum disorder.

In recent years, it has become more and more evident that personal accounts of the experience of ASD have broadened our understanding of this diagnosis. A number of autobiographies have been published documenting the lives of people on the autism spectrum, and many internet websites are now available for the world to explore exactly what some people with an ASD feel, think, or desire. These personal accounts offer a wealth of knowledge about a world experienced by many but unknown to most of society.

In the latest phase of our research, we felt it was very important to talk to the individuals with an autism diagnosis. Over the past year and a half, we have met with 207 adolescents and adults. Of these 207 people, we were able to interview 95 of them, asking them to freely express their thoughts and feelings about their lives. These 95 individuals were verbally able and willing to participate in this part of the study. The remaining 112 individuals did not complete the interview portion of our visit. Some had limitations in their ability to express themselves verbally, while others preferred not to comment on our questions or became fatigued during the less structured part of the visit.

The responses from the 95 individuals have been grouped into categories which follow in this report. We fully recognize that each individual is unique and we greatly appreciate the opportunity to comment on the themes we found throughout the interviews. This booklet represents a collection of the thoughts, concerns, and wisdom expressed to us by the adolescents and adults. It is our hope that through these words we will better understand how it may feel to live with an autism spectrum disorder.

We sincerely thank the individuals who openly shared their personal experiences with us. We are also very grateful to the families who have freely given their time, as well as welcomed us into their homes. This is a process of learning and exploring, and we look forward to continuing this journey together.

Section II: Reflections about an Autism Spectrum Disorder

The three questions we focused on for this report were:

- What do you feel people should know about what it is like to have an autism spectrum disorder?
- What advice do you have for parents of a child with an autism spectrum disorder?
- What advice do you have for other people with an autism spectrum disorder?

In reviewing the responses to each question, we found several frequently discussed themes. Our goal was to discover similar and diverse responses and in doing so to gain knowledge about how society might better understand individuals with an ASD.

Question #1: What do you feel people should know about what it is like to have an autism spectrum disorder?

➤ *The most frequent response involved a discussion about the **challenges of having autism**. When asked this question, **46.3%** of the individuals made comments about the difficulties they face because of their autism diagnosis. Examples of such responses include:*

"Well, it's a mixed blessing and a curse depending on how you view it. It's a curse...because when I'm interacting with people [it's] very difficult [to come] up with words in my head to speak."

"It feels like you're on another planet."

"Things feel harder. I have a lower self-esteem."

"...it's a huge pain...you don't understand everything that people talk about. You don't feel the same emotions they do. You are hypersensitive to things they wouldn't even notice. And then there are times that your head just stops working."

"It's hard to be autistic when you're alone, or feel sad or feel good."

"...it isn't easy having Autism Spectrum Disorder and [other people] should stop picking on people who do."

"It's really hard to be in a class setting when you have to interact with someone for a long term project or just be friends because say I might recognize the person in the classroom but let's say outside the classroom they're a whole other person."

"...expect [for them] to alienate people through tactlessness or not knowing how to handle emotions, especially when [they] think someone looks pretty."

"I have a lot of anxiety."

"Basically the main emotion is loneliness, wanting to fit in, but knowing you're so different that even if you do fit in somehow, you are an outcast for life."

"...it's even worse [if you are high-functioning] because you're more normal than not, so you know that you should be acting a certain way, but you still act another and it's almost like you're aware of your actions, but you can't do anything about it and if you can, it doesn't feel comfortable the right [way]."

"...sometimes it's hard to make friends."

"...you talk strangely, and don't remember something. And it's hard to understand."

"Have trouble communicating with other people, introducing yourself."

"It's challenging for me. Just trying to go through life like a normal, typical teenager...you think of so many little details and little things and you think about them all day. It's so hard for me to focus on some classes."

"They should know that it impairs the social skills."

"It's tough. You don't always think like everybody else....it's harder for me to process stuff. I don't always respond right away."



➤ *31.3% discussed **problems with how society treats individuals with autism and how they in turn respond to society.** Some individuals spoke about the need for society to be sensitive and the importance of promoting social understanding. Others commented on difficulties with establishing trust due to negative reactions from others.*

"People should know what it's like to have autism."

"It's hard for me to trust people's intentions."

"I think people should understand autism and...know what it feels like."

"I am a national, you know, I speak out on it...I go and speak for other people with autism."

"I just want people not to take advantage of us."

"...the big thing is that there isn't one set of solutions, I guess I always feel like people assume it's like a mathematical formula, you just do this and that and then the person's automatically cured."

"People should be more understanding... I think others have misconceptions. It's hard for other people because I'm so close to normal [that] others don't see a problem. [That] can make it difficult."

"It's difficult because when you have a physical disorder such as I don't know, being in a wheelchair or being blind, people are more like, 'Oh, I understand,' but when you have a mental disability that isn't automatically apparent on the outside, people just think you're weird."

"...you're viewed as different because you don't [do] things the way people should do them."

"...people don't even give you the chance to get to know you."

"...other people that are not autistic, [need] to be more sensitive because it is really frustrating."



➤ *Others (24.1%) commented on how they **consider their life to be very similar to those who do not have an autism diagnosis**. These individuals tended to focus on their individuality and viewed the challenges they faced as a part of everyday life.*

"I think it's important to know that every autistic person's an individual person, not just a collection of symptoms...it's just like everybody else, different personalities, different sizes, different shapes."

"I don't seem as autistic as others. I seem otherwise normal."

"Actually people don't mind or at least people that I know. Actually, I don't seem to notice a difference."

"That all forms of autism are different and that doesn't make us outsiders of people. That makes us unique."

"...I really don't think about it that much. I just think I act [like] myself [and] I'm just like everyone else."

"...there's all different types of autism."

"I think I am a normal person."

"It's not really that big of deal, doesn't really make a difference."



➤ *We found that **16.7%**, of the people with an ASD reported on **specific advantages and exceptional characteristics or experiences** related to having autism. Individuals who answered in this manner typically explained a certain "above average" characteristic like memory or hearing. Such comments include:*

"I can hear things and I can see things you know very good, and I can smell very good and taste things...differently from other people."

"I do feel like I have a stronger imagination."

"... [autism] can get you into the front of the lines at Six Flags."

"I am very good at remembering things. My mind can soak up so many things, like movie trivia, things like that. It's amazing what I can pull out of my mind after a few years, so much trivia and knowledge."

"...[with autism] you're extremely intelligent, so you either don't understand anything that they're talking about or you think they're talking like babies 'cause you understand so much more on the subject than they do."

"...expect to be knowledgeable in a few fields. Expect to be knowledgeable."

"...I tend to remember a lot of facts...that's probably not something the normal person would do as easily."

Question #2: What advice do you have for parents with a child with an autism spectrum disorder?

➤ *When asked this question, sons and daughters addressed **proactive measures** that parents could take to overcome challenges. **40.7%** commented on specific actions that may be helpful in raising a child with an ASD.*

"...don't be discouraged. If your child has a disability and [is] not able to walk, don't just give up."

"...work with them [on their challenges] and don't get frustrated."

"...talk to the psychologists about what problems they have with their kids and go to places and see how the child reacts...then go talk [to] a social worker about what bothers them and have some therapy with them...do whatever helps the kid with autism."

"...get them diagnosed right away and help them...get through their battles in school or anything else that they may struggle in."

"...try to get them help."

"Get early intervention."

"Try to get a job for them."

"Be creative."

"Just help when they need your help."

"Don't give up or lose faith 'cause things will get better."

"Go to all your kid's meetings. Go to parent conference day...and do something about it, because I mean, if your kid is getting picked on his grades will drop, his self-esteem will drop, everything will drop."

"..they should assist the child in finding resources like if there's any groups or therapists or professionals who can help aid the family in dealing with the issues the child will be facing."

"...do more things to get more interested in groups, like...social events, like school or whatever and even some things to do at home...like music, books, games, and um, speech and language therapy, stuff like that, you know."



➤ *35.2% of the sons and daughters commented on **understanding the challenges your child is facing, as well as his or her abilities.** Many felt it was important for parents to have realistic expectations, but to not underestimate their child.*

"...we like repetition, doing one thing over and over and over and over until you drive everyone else nozzle-nuts! But we like it...get used to it."

"...understand the child's situation."

"...get as educated as you can about the ill... I don't want to say illness, but the condition 'cause I think it's too easy to just assume your child isn't motivated or isn't trying their hardest."

"Go into their world, not make them come into your world. Your world will come later when they're more adjusted, forcing them to come into your world will only upset them when they're young."

"It's not laziness necessarily; it's more like distractibility."

"... [parents] should accept the fact [that their child] is disabled and they should do everything they can to help without jeopardizing the individual. Be aware of their behavior and what they might be capable of."

"...understand more about the kid."

"...don't expect them to automatically understand feelings. Don't expect them to automatically understand your view point."

"...notice their limitations, their strengths and weakness."



➤ *Some individuals also recognized the importance of parents not only understanding their child, but also **emotionally supporting** them. **27.8%** commented on the need for patience, acceptance, and sensitivity when raising a child with an autism spectrum disorder.*

"...be patient with them, try not to be too hard on them."

"Be nice. Don't be mean to him. Treat him nice. Let him know your child's special."

"Parents should care even more than with a normal child."

"Be patient with us..."

"Be supportive..."

"Be there for them. Support them 100%."

"...bear with them because oh, it's tough for us."

"They need mental support just like emotional support, just like everybody else does."

"Patience, as much patience as you can muster and when you're out of patience, get more....autism requires so much patience and trying to understand them. Just let them be who they are."

"...just always be there [for] 'em."



➤ *A few (**3.7%**) made comments suggesting that the parents should **hide their child from society**. These individuals felt that some of the challenges faced in autism were too difficult to expose to others.*

"Sorry, but stay inside. Go to a hospital."

"Make a bomb shelter in your basement, because until someone with autism knows how to control it you're going to need it."



➤ *A few (3.7%) also advised parents to be **cautious in accepting advice from others**. These sons and daughters warned about unverified sources of information, and encouraged parents to trust their own instincts.*

"...don't go blindly accepting everything the so called 'experts' have to say. Take what they say with a grain of salt."

"...keep sight of your instincts, don't just take any doctor's advice as gospel because they're a doctor."

Question #3: What advice do you have for other people your age with an autism spectrum disorder?

➤ *As with the previous question, 55.6% of the people with an ASD commented on **specific proactive strategies to overcome the challenges associated with autism**. Many individuals spoke positively about the different measures they take to help them address certain difficulties in their lives.*

"...challenge yourself. Whenever you feel like frowning, just do it with your eye brows, just keep practicing. It's just funny eventually it just becomes automatic."

"...keep trucking. Don't lose hope."

"If you feel emotionally excited, calm down!"

"Get obsessed with birds...if you must get obsessed with anything that is."

"Find a nice hobby like knitting, it's calming."

"...try not to overreact when things bother [you]."

"Understand about autism."

"If you're going to work really hard - do not fail, do not give up...It may take some time, Rome wasn't built in a day."

"...probably the best thing would be to let people know about the disorder if there's going to be a long-term relationship."

"Just stay strong, hopefully things will get better."

"...it's a difficult road, but you definitely need to seek out services ...I mean you really need to go the extra mile and find people that can offer support."

"Communicate whatever way you know how...communication is the key to understanding autism."

"Don't let it stop you from doing what you want."

"If you have a goal, pursue it."

"Try to make friends with people who accept you for who you are and aren't judgmental."



➤ *22.2% encouraged **self-awareness and self-acceptance**. These individuals remarked on the importance of recognizing one's strengths and weaknesses, and advocated individuality.*

"...try and do your best at what you're good at doing, you know."

"You should present your ideas. The direction you may want to go in might be different but that's okay to share them."

"...pick and choose your battles; you know what you can do and what you can't do."

"...be yourself."

"...just remember, you're your own person, you're not just clutched in symptoms in a note pad, and ah, try to be as confident in yourself as you can."

"Don't listen to everyone else, 'cause a lot of them aren't as smart."

"To not be disappointed that you have it."

"Don't be ashamed."



➤ *When answering this question, **16.7%** spoke about how **they consider their lives to be similar to those who do not have an ASD**. These individuals encouraged their peers to accept autism as a part of life and to realize their unique qualities.*

"...just go through life normally and not to be ashamed of this, you know."

"...it's not so bad having autism...I mean, everybody has autism."

"...don't give up...We all have things we don't want to do, but it's better to get them out of the way."

"...it's not our fault we're born with it. We have to learn to live with it."

"It doesn't really mean that much about a person's life...Not as limiting as others might consider it or I've considered it."

"...just go through life normally. It's like if someone had a physical disability...they'd have to live with it. You've gotta' make changes to it and you know it's gonna be hard, just battle it out."

"...all people can be the same."



➤ **13.0%** of individuals ***promoted caution in interactions with others.***
Individuals who answered in such a way spoke about their inhibitions due to society's lack of understanding about autism, and felt as though they could not trust others.

"Just be careful who you trust, and just make sure that person knows you."

(speaking of interacting with the opposite sex) "...be a little more hesitant."

"Sometimes they talk about [how] the family suffers from this person's autism. The doctors, some doctors do, I'm not saying all doctors do that, I just hear it said, the family suffers from this person's disorder, it almost seems to imply that that person's a burden on the family."

"...animals understand you better than people...they don't argue when you have a very bad day."

"Don't tell people about being upset."

"Don't let [others] make you feel like you're as worthless as they seem to think you are."

"If you're worried about saying something that is the wrong thing, don't say anything."

Section III: Summary

Each individual who participated in these interviews offered a unique perspective on how an autism diagnosis affects their life. It was also evident that many individuals share similar thoughts and experiences. When asked what they would like to tell others about having an autism spectrum disorder, almost half of the participants spoke openly about specific difficulties they face on a daily basis. Although there are many studies describing the variety of difficulties associated with an ASD, it is enlightening to hear how those challenges affect a person's life through his or her own words. About one-third of the responses also detailed the complications that arise when interacting with society. Many of these individuals emphasized the need for social sensitivity and awareness. Some also included stories of societal misconceptions, or negative experiences due to lack of understanding. It is our hope that through studies such as this, social awareness will be enhanced and misconceptions will be dispelled.

A proactive approach was recommended to the parents of a child with an autism diagnosis. These individuals recognized the important role parents play in the life of a child with an ASD, and they encouraged parents to advocate for their child. Many of the sons and daughters also spoke about the importance of not only of understanding who their child is and how ASD affects them, but also how critical it is to be emotionally supportive. One of the most frequently mentioned desired parental characteristics was patience. The individuals in our study acknowledged that their behavior may be different or seem difficult, but they asked for understanding and tolerance. Such characteristics may be challenging at times, but as attested to by these sons and daughters, patience is beneficial for everyone involved.

The majority of individuals also felt that the best advice they could offer to someone else with an ASD is to be proactive. Many commented on specific actions they would take in an effort to overcome their challenges. Almost one-fourth of the individuals also promoted self-awareness and self-acceptance. This type of encouragement is important for the mental health and emotional growth of any individual with a disability. It creates the sense of empowerment necessary to overcome the challenges and obstacles of life.

One of the goals of this study was to help broaden the understanding of what an autism spectrum disorder is and how it affects the daily experiences of a person living with the diagnosis. Through these interviews we have derived many new insights. These themes may open the door to further research, and such exploration will hopefully lead to a better understanding of the world of autism.