

Acceptance

If It Doesn't Mean Giving Up: What Does It Mean?

I thought I could never accept my baby's autism. After 29 years there are times when I still wonder who my son might have been. Yet it seems like only yesterday when I held Tariq for the first time. My heart pounded with excitement as I held his soft body next to my heart and our eyes met. I had visions of playing baseball and building model airplanes together.

Everything changed when the "autism bomb" hit and he began endless repetitive activities. He stopped sharing his joy of playing and stopped talking. A few years later he was diagnosed with autism and mental retardation. The impact sent family life veering sharply from the course we were on. That I would lose my perfect baby was beyond anything I could fathom. How could it be that he would grow to adulthood and not read or write or speak? I can remember believing that I would never smile or laugh again.

Parents need support and good services to come to terms with what is possible and what is not for their child. I could not have ever found peace without support. My wife Cindy, Tariq's stepmom, weathered the storms of his autism with me and never wavered in her love. She knew autism from working in the field and helped me grasp the diagnosis I was trying desperately to deny. It took me two years before I could utter the word "autism."

I learned deeply through my experience, what Kahlil Gibran meant in *The Prophet* when he wrote that joy and sorrow are inextricably woven together, for sorrow


opens our hearts to the experience of joy in everyday life. Accepting that his condition would be enduring was imponderable. Nonetheless I learned the developmental approach of celebrating what he *could do*. This made a huge difference for our relationship. He became a happy child, and I learned to enjoy him and accept him as he was. When I played with him in the ways I thought were weird, he laughed

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and responded and was happy. When I constantly pushed him to look, to feel, to do the things that seem 'typical,' he was frustrated and cranky. The autism I hated with a vengeance refused to go away.

On the path to acceptance, I have learned many things that have helped me. My son taught me the meaning of unconditional love—to honor his sacred right to be loved for who he is, not what he has achieved lately, how he looks or how much money he will earn. I learned the lesson that hard work isn't everything. That grief comes and goes. That anxiety and sadness come and go. That it takes time to heal a broken heart. That

happiness and meaning can abound with acceptance. We don't have to push away our painful thoughts and uncomfortable feelings. I learned that acceptance does not mean giving up but rather learning to live with our mental and physical challenges. I still try to get Tariq to look at me, to sit with me, to communicate with me. And simultaneously, I offer to do the activities I know he will enjoy and offer the food he loves and the freedom for him to be himself. I don't have control over the autism, but I do have a lot to offer in our relationship with my child who is living with this condition.

I have come to know that Tariq's life does make a difference in the world. He is still my little boy. He still puts his head on my shoulder, and I have never stopped wanting to hear the sound of his voice. Yet I love him no less because of that and perhaps more in ways I could have never imagined. He has brought many kind people into my life and helped me to understand myself and others. He made me a better father and a better man. His greatest gift to me is a glimpse into the human heart where it is not who you know or what you know or what you have—but who you are. My son has only ever spoken aloud to me once in a while—in my dreams; but this is how his autism has spoken to me every day. 



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A Diagnosis of Autism is not a Prognosis of Divorce

Myths and Realities of Maintaining a Marriage as Parents of a Child with Autism

ROBERT NASEEF, PH.D. AND BRIAN FREEDMAN, PH.D.

For years, an 80% divorce rate among parents of children with autism spectrum disorders (ASD) has been widely reported in mainstream media and generally accepted by the community. Oprah, Dr. Phil, Jenny McCarthy as well as major autism organizations reported this. It became an "urban legend" with no source or data to back it up. Even the popular television show "Parenthood", which generally depicts Asperger's accurately, had an episode in 2010 called "Date Night" in which an 80% divorce rate was reported as fact. This article will attempt to set the record straight using available research and also provide insights and coping strategies from clinical experience supporting families.

The assumption that autism causes failing marriages seemed believable. Stress from dealing with related behavioral and medical issues, and finding high-quality services can increase tensions between partners. The divorce rate myth certainly called attention to autism and parental stress, but it did not reflect the reality on the ground where families were also courageously coping with challenges while passionately loving their child and trying to stay together.

In June 2011, the Autism Society posted a blog written by Liz McGarry, an intern at Alternative Choices, summarizing a research study conducted at Kennedy Krieger Institute on the topic of marriage and children with autism. Several hundred people posted comments about the blog on the Autism Society's Facebook page:

"My parents are still married and we all love my brother to death."

"I think having an autistic son made our marriage stronger because we both love him and know we need to work together to make the best life for him."

"After our daughter's diagnosis, the first question everyone asked was if the father was still in the picture? If I were the father of an autistic child, I would be very offended."

Indeed the myth not only painted the picture of skyrocketing divorce rates but also masses of deadbeat, irresponsible fathers.

Research on Parenting

When considering the experiences among parents of children with ASD, it is critical to examine the research previously conducted on the topic. The field of ASD in general has become much more astute in examining ideas regarding characteristics of, and treatments for, ASD through an "evidence-based" lens (making judgments and drawing conclusions based upon high-quality research). So, it seems interesting that the ASD community has not used the same criteria for drawing conclusions about the experience of parents, particularly in terms of relationships among couples. That said, when utilizing research to draw conclusions, it is important to keep in mind that each scientific study has its own set of strengths and weaknesses. Some studies are designed better than others and some studies draw conclusions erroneously. In addition, no research study should be considered to contain the ultimate truth on a particular topic, since each family has their own unique experience raising a child with ASD. However, when taken together, these studies can begin to tell a story which brings us closer to understanding the situation for many parents of children with ASD.

Parenting Is a Stressful Experience

In the case of understanding the experience of raising a child (or children) with ASD, the results of research tell a complex story. By and large, parents of children with ASD tend to experience significant stress related to parenting. This has been shown in many studies over the past thirty years with a variety of samples, among various age groups, a range of socioeconomic statuses, and even across different countries. In fact, research has also indicated that parents

of children with ASD typically exhibit more stress than parents of children with other disabilities. The potential reasons for experiencing this stress tend to vary. Most studies suggest that parenting a child with ASD is often significantly stressful regardless of where your child falls on the autism spectrum. Some studies do suggest that more challenging behaviors can become particularly stressful for parents.

Overall, there is far more research on maternal stress and the findings that show differences between the stress experienced by mothers and fathers tend to be mixed. However, even in those studies which show that mothers have more stress than fathers, fathers still often exhibit significant levels of stress. Despite the significant stress that both mothers and fathers seem to face, scientists are also learning how to help parents decrease their stress by examining how parents "frame" their parenting experience.

Staying Positive in the Face of Stress

The examination of a person's positive and negative thought patterns, and its impact on emotions and behaviors, is a concept commonly used in general treatment of depression and anxiety (via "Cognitive Behavior Therapy"). Scientists are now applying these concepts to parents of children with ASD. Changing your thought process though, especially in the face of true physical and emotional stress, can be incredibly challenging. Furthermore, the experience of their spouse also can play a role in a parent's well-being.

Research has examined the significance of positive experiences on parents of children with ASD, as well as its relation with parenting stress. For example, Kayfetz, Gragg, and Orr (2010) examined stress among parents of children with ASD as well as the positive experiences parents associated with their child. They found that although these parents experienced significant stress, this stress level was significantly lower when parents also identified positive experiences associated with raising their child with ASD.

This study was consistent with previous studies which indicated that life satisfaction of parents of children with ASD was determined more by their personal rating of the difficulty of parenting tasks as opposed to an objective rating by an outside person. All of this suggests that parents' capacity for maintaining a positive perspective may impact their parenting stress.

Another interesting finding in this study was that mother's parenting stress and overall mental health were related to fathers' positive experiences related to their child, but not vice versa. This does not mean that one causes the other. What it might suggest is that for some families, when a mother feels particularly stressed it can impact the father's ability to perceive positive qualities of the parenting experience or that a father's perspective (positive or negative) may have a direct impact on the mother's stress and mental health. Regardless of the causal

direction, it is clear that parents' experiences are closely tied to one another. Therefore, it can only be assumed that their relationship with each other would be impacted.

Research on Couples and Relationships

The research on marital and couple relationships among parents of children with ASD has not been widely conducted. This may be the case for a couple of reasons. First, the focus of most funding streams, which provide researchers with the time and resources to conduct their research, is usually more focused on child well-being. Often times, it is assumed that the child's well-being controls the family and parent stress level (i.e., if a child is doing well, then the family is less stressed). However, research is starting to point to the importance of parent and family well-being and its direct implications for the child's well-being. The second possible reason that less research is conducted on parents and families is because parents themselves may not view this type of research as a priority. Most parents may not have any available time to participate in the research, given the needs of their child, and furthermore may dismiss the importance of such research as not being as important as work being done to more directly help their child to improve.

The research on couples suggests that many parents of children with ASD have significant challenges in their marital relationships. Marital satisfaction tends to be lower for parents of children with ASD than other couples. This is thought to occur because parents have little to no time available to maintain their relationship and often have to work especially hard to connect with one another in areas unrelated to their child. This becomes exacerbated by parents also feeling physically and emotionally overwhelmed, as well as isolated from their communities and support systems, which may offer limited resources and support for parenting a child with ASD.

Hartley et al. (2011) found that the marital relationships among parents of adolescents and adults with ASD are related to stress. As marital relationships improve, parenting stress and burden tends to decrease. It is important to note that it still cannot be determined if one causes the other. However, this important relation was found after controlling for other child-specific characteristics like symptoms of ASD and intellectual disability, suggesting the direct relationship between marital satisfaction and parenting stress.

Debunking the Divorce Rate Myth

The research on marriages actually suggests that families are making decisions to stay together more often than the ASD community and mainstream media had previously considered. Despite the urban legend of the dramatically high divorce rate, recent research has examined these statistics and is not finding the same results. Freedman et al. (2011) examined the

rates at which children with ASD continued to live with their biological parents. They found that a similar percentage of families (approximately 64%) remained intact in comparison with families who did not have a child with ASD. The remaining 36% of families consisted of single and divorced parents, as well as children living with grandparents or adopted parents. Unfortunately, this study could not identify an actual divorce rate, due to the way in which the questionnaire was originally designed. However, it's clear that the divorce rate was far below the 80% usually reported by the media.

Hartley et al. (2010) similarly did not find dramatic rates of divorce among parents of ASD. However, they did find that parents of children with ASD did divorce at a rate (23.5%) that was higher than the rate for families of typically-developing children (13.8%). Although all families in the study had a similar risk for divorce until their child was 8 years old, families of children with ASD had a higher risk than the comparison group during adolescence and young adulthood. Unfortunately, there remains little research regarding marriage and divorce rates among parents of children with ASD. The differences in the results between these two well-conducted studies suggest the importance of elaborating on this research in order to understand the rates at which parents are staying together, risks for breaking up, and the reasons which drive these decisions.

These findings, taken together, begin to tell a story about many families of children with ASD, in which both parents often seem stressed and their parenting stress and overall well-being seem to have deep impacts on one another. Furthermore, parents of children with ASD do experience real difficulties in their marriage, although many choose to remain together. With this, we offer suggestions for couples in order to support them in maintaining a healthy relationship.

Intimate Partnership as a Developmental Process

"When a baby arrives, everything changes. Parents must adapt to the 24/7 care of a new, vulnerable infant – an enormous task. Not surprisingly, 40% to 70% of couples experience stress, profound conflict and drops in marital satisfaction during this time, all of which affect their baby's care." (www.gottman.com) Most of our experience is with heterosexual married couples, but we are also familiar with unmarried, remarried, adoptive, and same sex couples. What follows are general observations applicable to relationships within the uniqueness of each family. Some of these have been substantiated by research while others have yet to be scientifically investigated. However, we offer them in the absence of a large scientific literature to draw from.

Children with autism are fundamentally just children, and couples raising them are just couples. Any child changes the couple. While the birth of a child brings astounding joy, the partnership takes a big loss in terms of sleep, sex, and privacy. A man may feel shut out by what psychiatrist Donald Winnicott

called "primary maternal preoccupation"—a consuming attachment to one's baby, which he saw as a normal condition from which most mothers recover. A father may be sad and feeling deprived of the exclusive connection the couple once had. A mother may be exhausted from lack of sleep and anxious about her baby's health and development.

Judith Viorst describes children as an antiaphrodisiac since both partners may be so stressed and exhausted that sex loses its appeal. Even parents of typical children describe "marriage on the backburner." For parents of a child with ASD, these experiences can be more intense and last indefinitely.

Does it get easier? That's a difficult question to answer. Do you change? You change profoundly. If you learn to navigate your most difficult thoughts and feelings, you get better at handling things. You can have a deeper relationship with your partner and your children. Raising a child with ASD is a journey in which we can become wiser, more compassionate and more loving.

What Men and Women Want

It is important for partners to talk about what they want from each other. How can women be expected to understand what men don't say? It's easy to talk about work and sports, but raising a child with ASD gets hard.

Here's a sample of what men say would help them:

- Understand we are trying to help, and get frustrated when we can't make things better.
- More time as a couple, without the children, and a little more sex.
- Less emotion, so we can discuss problems and find solutions when possible.
- Feeling less like an assistant and more of a competent parent.
- Tell us what we are doing right so that we can feel more secure in the relationship.

Here are some of the things that women tell us they want:

- To be appreciated for all we do.
- To attend meetings as a couple instead of alone.
- Time alone without the children to relax.
- Time together as a couple not just limited to sex.
- To talk about feelings without men getting defensive.

Wanting to solve problems and wanting to be useful to one's family is positive. But difficulty listening first often sabotages those instincts. When a man learns to listen to his partner, he can become a better man and a better father. Often fathers don't realize that feeling heard may be all someone needs.

Women might set the stage by saying, "I just need you to listen; I don't need you to do anything." This often relieves the knee-jerk response of trying to come up with a way to "fix" the problem. In other instances you might say, "First just listen, and then there is something I want you to do."

More involved problems are beyond self-help strategies

and can best be untangled by consulting a professional skilled in counseling couples who is sensitive to the issues around having a child with autism. While this article discusses general difficulties encountered by parents of children with ASD, we are just scratching the surface. It is crucial to remember that every relationship is unique. Raising a child with ASD may require more relationship maintenance for couples living with those stresses and strains. If your partner is too discouraged, then take the first steps on your own. Sometimes a change in only one of you can change the chemistry of the situation for the better.

Romance and Intimacy

The strain of living with autism can lead to couples who rarely go out together with any regularity, but those demands make it even more necessary to find time together for the marriage. It is a reality that babysitters who can handle a child on the spectrum are hard to come by. Focus on how you can steal some time for yourselves as a couple. Here are some of the things that people tell us have worked for them:

- ▶ Socialize with friends even with the kids around.
- ▶ Stay up after the kids are sleeping and doing something together.
- ▶ Take a break from talking about autism.
- ▶ Take turns listening to each other even if we don't really understand or fully agree.
- ▶ Go for a walk together even if it's just for 10 minutes

While marriage is often on the back burner for parents of young children, when there is a child with ASD the marriage may often not even be on the radar. While there are many self-help books about relationships, there is only one we are aware of which focuses exclusively on the complexities of relationships for couples raising children with special needs. In *Married with Special-needs Children*, authors Marshak and Prezant observe that many people insist they will work on their marriage when things get easier. However, the stress is endless. According to the authors, being consumed with the child is not really good for anyone including the child.

Hope for relationships can spring from the crises that couples experience. "Normal" crises like childbirth, moving, financial problems, and trials in parenting can all strain relationships. Many have observed ordinary trouble differs only in degree from the strain caused by autism. While having a child with ASD is a quantum leap from everyday problems, it nevertheless prepares us to learn and grow in ways we might have never imagined. By working hard to maintain their relationship, partners can preserve the love they have for each other.

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Involved Fathers Get Results

BY ROBERT NASEEF, PH.D.

Male role models are important for children, and boys and girls growing up on the autism spectrum are no exception. Fathers are more involved than ever, and research backs up their impact on children. However, when a child has autism there are often steep challenges for the typical male parent. Let's take a look at the potential for growth and how to overcome the barriers that autism may present.

RESEARCH FINDINGS ABOUT FATHER INVOLVEMENT

- A nationally representative survey of over 10,000 men found that most American fathers report being heavily involved in hands-on parenting. Ninety percent of these fathers said that they bathed, diapered, helped with toileting or dressing, ate meals together, and talked about their day with their family on a daily basis. Even more frequently, played with their children. This type of father involvement has been shown to result in better academic success, fewer behavior problems, and healthier eating habits.

- Forbes writer, Susan Adams, recently reported that men who spend more time with their children are likely to have a greater sense of satisfaction at work and less desire to change jobs. They are also less likely to experience conflicts at home, according to Beth K. Humberd, Assistant Professor of Management at the University of Massachusetts, and one of the study's co-authors.

- Studies of father-child interactions with typically developing children indicate that fathers offer different language models than mothers, which make important contributions to children's language development. Fathers tend to use a more complex language model than mothers, and this likely applies to interactions with children with ASD as well.

- New research from the University of Illinois also suggests that fathers who read to their infants, and take active roles in caregiving activities, promote healthy development in their children and boost mothers' mental health as well.

- Through play, both mothers and fathers help their children develop language. A father's play is typically more active and rough-and-tumble. As their child's primary play partner, fathers have a distinctive role in supporting their development through play. Research has demonstrated that interventions can improve both play and language outcomes for children with ASD.

IT'S NOT EASY TO DO IN PRACTICE

When you love someone you want to be with them, but children with autism can be hard to be with. Most typical children are engaged every waking hour, but it's not easy to engage with a child on the spectrum. They often prefer to do the same things over and over again. Parents can easily become exhausted or frustrated—not to mention feel rejected and sad.

Even though there's a huge potential for fathers to contribute positively to the development of children on the spectrum, many fathers feel powerless to engage in play with a child who has more repetitive and less varied play. Most fathers have a difficult time talking about their feelings, especially when there is a problem that they are unable to fix. 80% of children diagnosed with ASD are boys, which can be especially difficult for fathers who expected a different kind of son.

WHAT FATHERS CAN DO?

First, acknowledge the spectrum of painful feelings, including sadness, hurt, frustration, anger, embarrassment, and rejection. Share your experience with your partner, family members, and friends who want to support you. Like the weather, your unpleasant feelings will come and go periodically. Accepting this experience opens the door to hope, building a connection, and celebrating every little step of developmental progress.

Second, spend some time each day joining your child on the floor, at the table, in front of the screen, or outdoors watching and following your child's lead, having fun, and building connections. Your child with autism is still a child and needs more than therapy. It may not be what you imagined, but it can still be wonderful regardless of the severity of the challenges. As fathers, you cannot control the outcome for any child, but you do make a difference, and you can have a rewarding relationship regardless of who they are.

Third, focusing too heavily on behavior, and trying to change the person that they are can suck the joy out of your relationship with your son or daughter. This may seem impossible, considering your child's behavioral issues, but this does not mean denying real problems. It just means paying attention and cultivating the moments you might overlook or ignore when problems are absent; such as when the kids run to you when you get home at the end of the day.

Fourth, attend as many meetings as possible with your child's school and other service providers. Don't hide behind your work. Being an active partner in the parent-professional affiliation is an opportunity for fathers to deepen their understanding of their child's strengths and challenges and use their problem solving skills to promote greater success. Many couples report better results in collaboration with professionals when fathers are involved, and in turn, mothers report less stress and more happiness.

The science is in: wherever a child starts on the autism spectrum, with parent involvement and good services, progress is possible; and father involvement certainly makes a difference.

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SIBLINGS OF CHILDREN WITH AUTISM: HONORING THEIR PERSPECTIVE

by Robert Naseef, Ph.D.

We are siblings all our lives. The bond with our brothers and sisters is the longest we will ever have, and that experience impacts development through the life cycle. A child with a disability alters the hopes and dreams of parents and affects the lives of the other children in the family. The issues faced by siblings of children with autism are another challenge to parents. This article will discuss the significance of the sibling bond and the repercussions of autism on that bond. To understand what our children need, it helps to begin looking at ourselves as siblings.

It is relatively easy to talk about the love and loyalty that bonds a family together. The darker, more difficult side—like the rivalry amongst brothers and sisters—is easy to ignore. It is uncomfortable to think about. Overemphasizing sibling rivalry tends to accentuate the negative, but ignoring it denies a big part of the reality that bonds siblings together. Striking a balance is an ongoing struggle.

In *The Sibling Bond*, Stephen Bank and Michael Kahn discuss the positive aspects of aggression and rivalry. Two brothers wrestling, for example, can represent contact, warmth, and presence. In a fight, a child is alive and real and noticed. In these power struggles and interactions, siblings can learn how to resolve conflicts. On the other hand, for parents, the fantasy of a close, cozy set of siblings is the image of a perfect family. Squabbles among brothers and sisters crush that dream. The dilemma is when to let children work out their differences and when to intervene. Too much intervention can prevent children from learning for themselves how to resolve conflict.

The key is to be able to express negative feelings, such as jealousy or anger, without doing damage. The goal is for children to work out their own solutions whenever possible. It takes patience and wisdom on the part of parents to give up an element of control and facilitate this process for children. Sometimes it just means waiting a moment or two. *Siblings Without Rivalry* by Adele Faber and Elaine Mazlich shows how to promote cooperation while being fair to both children in a squabble.

Birth order has a lot to do with sibling relationships. It helps for parents to look at themselves within their family of origin—for lessons about the family they are procreating. Whether you were the oldest, the middle, the youngest, or an only child leaves a lifelong imprint on your personal history.

The oldest, for example, generally helps to take care of the younger ones. It is common for those born in this

position to feel very responsible at a young age. They are expected to be more advanced physically, socially, and mentally than the younger ones. There is pressure to "set a good example", but that also develops valuable traits, such as leadership ability and responsibility.

Those born in the middle positions tend to have a hazy role and get pressure from all sides. They have no unique place, but the experience tends to produce people who are friendly, diplomatic, and good negotiators. They are generally blessed with a moderate amount of responsibility and connect strongly with older siblings and are very protective of younger brothers and sisters.

The youngest, like the oldest, has a unique position and is never displaced. This child usually feels chosen for special protection by older siblings as well as parents. On the other hand, the youngest is often regarded as spoiled or as the favorite. While the oldest is expected to help in parenting, the youngest is often expected to care for parents as they age and become frail.

An only child may have a combination of all of the traits of the oldest, middle, and youngest positions. In addition, only children tend to identify with their parents more and therefore relate well to authority figures. On the other hand, they usually long for siblings in order to have peers within the family.

In *Mixed Feelings: Love, Hate, Rivalry, and Reconciliation Among Brothers and Sisters*, Francine Klagsburn explores the unique perspective of each position within the birth order. While these generalizations about birth order don't always hold up, the concepts are useful in understanding ourselves and others. She also discusses the impact of disability. In every case, the sibling bonds of parents leave special imprints that affect the way they parent their children.

Frequently, when I work with parents in groups or as couples, I ask them to reverse roles and imagine what it would be like for them to have a sibling with a disability. What would the problems be? What would they want from their parents? Several key issues are consistently identified:

- more is expected of the normal child and parents don't always notice their struggles and accomplishments.
- a fair amount of attention is wanted by siblings who see their parents spending more time with the "special needs" child.

- the child with the disability does not have to compete for the parents' attention. That child always "wins".
- time alone and time with friends without responsibilities would be important for siblings who feel like junior parents.
- freedom to express their negative as well as positive feelings about their experiences.
- as normal a family life as possible.
- time alone with their parents is rare but welcome.
- information about autism so that they can understand and explain to others.

Parents are always able to identify the main issues that siblings themselves often mention as reported in the professional literature. Why then does it seem so hard to do? Why do parents agonize over whether they are doing the right thing? Simply put, it's hard when you're "stressed out". In the words of a woman I met recently, "So much of the time I'm out of breath chasing the special one—watching out for what might happen next. I find myself calling my other daughter for help when my husband isn't home. It's hard for me to hear my daughter's concerns. I feel like a broken record. I'm so wound up..."

It is very, very hard, and there's no other way of looking at it that makes sense. Sometimes parents do "run out of gas". Talking about these things is one way that parents can find the good side, take care of themselves, and replenish their energy. Parents can take better care of their children by taking care of themselves. This sounds simple, but there's another twist—something else to take into account.

Disability can disrupt some normal occurrences in the family life of brothers and sisters. Recently, I met a man who was very concerned about his three year old daughter. She kept calling her older sister who is six and has autism the "baby". It seemed weird and eerie to this father. Indeed it is unsettling to hear your three year old calling your six year old the baby of the family. On the other hand, it is reminiscent of the saying "what wisdom comes from the mouth of babes". In this case, the younger child functioned at a much higher level than her older sister, and her way of looking at things was in accordance her reality. She needed to be understood and her perspective needed to be validated.

Disability had reversed the natural order. Even though the father explained the disability, the little girl continued calling her older sister the baby. That will eventually stop when the younger child develops the intellectual capacity to understand the abstract concepts involved. It will also at times be uncomfortable for her, because this younger child feels like she is the oldest. What is historically false

is actually true in terms of the roles that the children play in the family. When parents are sensitive to this, they can help their children to understand. The younger "normal" child loses both a "normal" playmate and a role model—not an easy thing to understand.

When parents have the "normal" or "typical" child second, they are quite naturally thrilled with the healthy child's development. It is, however, a two-edged sword. Every achievement can remind parents of the limits of their special child. Without warning, the inner confusion and turmoil of chronic grief can be reignited. Physical resemblance is another tricky area. When the normal sibling looks like the sibling with the disability there may be more embarrassment and the fear that something is secretly wrong—even something that may be transmitted to their children.

But isn't it the parents' task, disability or not, to carry the brunt of the worries and the responsibility? Parents lead the way as hard as it might be. When there is a disability in the family, the trail of life can be steeper and more treacherous. More than ever the children look to their parents for direction in how to handle the practical obstacles and their mixed emotions.

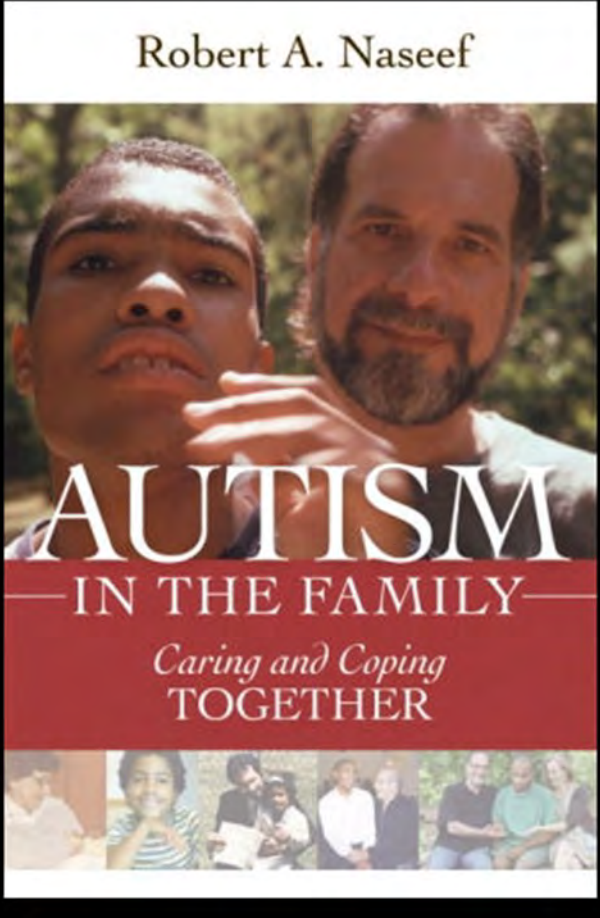
What sustains parents as well as siblings is a special kind of sensitivity and pride that develops. Every family member knows how much effort it takes for the child with autism to learn the things that so many people take for granted—like getting dressed or communication skills. Siblings can take pride in their parents for how they handled the challenges and for making each child feel truly special. Each family member can find pride in their own accomplishments and gratitude for their physical and mental health.

Rivalry and reconciliation, grief and joy, embarrassment and pride. These are themes of family life. We are really all in this together—parents, children with disabilities, and their special siblings.

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EDITOR'S NOTE: Robert Naseef is a psychologist in independent practice in Philadelphia specializing in disability issues. He is the father of four. His oldest, a son, is fourteen and has autism.

	<p>“Autism in the Family, Getting the Big Picture: Insights, Experience, Intervention, Research” is based upon this 2013 book from Brookes Publishing who produced this interview. The work received advance praise from autism experts, parents, and people with autism such as Temple Grandin and Stephen Shore. The writing integrates clinical, research, and personal perspectives and focuses on helping families navigate the emotional landscape and the controversial issues of raising a child with autism through the lifespan. The book includes insights into the needs, emotions, and parenting experiences of fathers. Topics include:</p> <ul style="list-style-type: none"> • navigating the journey to acceptance • guiding children’s behavior and development at every stage • maintaining a supportive marriage • understanding the needs of siblings • collaborating effectively with professionals • specific issues like meltdowns, food sensitivities, sleeping, and toileting • managing stress • building a circle of support with family and friends
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1. You are in the distinctive position of being both the father of a-now adult-son with autism and a psychologist who specializes in working with families with a child on the spectrum or other special needs. Which of these came first, and what influence did one have on the other?

When my son was born, I was teaching reading in a literacy program for teens who had dropped out of high school in Philadelphia. The goal of the program was to help inner-city youths become employable and obtain their high school equivalency diploma. By the time my son was diagnosed with autism in the mid-1980s, I was the director of a federally funded special services program for disadvantaged students as well as those with disabilities at a two-year college.

Having seen so many of my students make significant progress, I passionately believed that the same was possible for my son. Yet early intervention and speech therapy was having little impact. From this experience, I was inspired to return to graduate school and become a psychologist focusing on the family issues of children with autism and other special needs. My research focused on how families of children with special needs developed coping skills. Make no mistake about it; I was doing this to help myself as well as others.

Tariq's autism drove me to learn and do more which helped me and helped me to help others. That dynamic relationship has grown and developed from his first red flags of autism to the present. Tariq's 33rd birthday 11/29/2012 was coincidentally the release of this new book.

2. Twelve years ago, you wrote *Special Children, Challenged Parents* to talk about the experience of having a child with autism. Now you and your son are 12 years older-how does the perspective of this earlier book differ from the perspective of your new book?

I actually began writing the first edition of *Special Children, Challenged Parents* in 1988. I loved reading as a young child, but I never dreamed I would write a book—not until years after my son was diagnosed with autism. Then I had a story that I had to tell. It was a privilege and honor that it was published in 1996. People read my words and told me of the comfort and hope they found there, and so I kept writing. In 2001, Brookes published a revised edition as Tariq was entering adulthood. The central theme of my life and work from Tariq's diagnosis until now has been the journey to acceptance.

This new book, *Autism in the Family*, focuses more narrowly and deeply on the challenges that the autism spectrum poses for family life. Over the last decade, I have traveled around the country and spoke to thousands of people struggling to accept autism and do the best job possible for their families. Seasoned by 24 years of professional practice as a psychologist and integrating advances in research and treatment, I have attempted in this book to help families navigate the emotional landscape and the practical roadmap through the lifespan—from early childhood through the school years and adolescence and on to adulthood.

3. It's hard to think of almost anything more heartbreaking than to see a glimpse of the spark within a child and then see it be shuttered-as happened with Tariq and other children with a regressive form of autism. What, if anything, can professionals say to a family for whom this experience is fresh?

It takes time to mend a broken heart. It is so vitally important for professionals to just be there and listen to what it's like for mothers and fathers. It helps to ask what it's like for them. It is usually encouraging to observe even the smallest steps of developmental progress. Most of all, professionals can help parents to be present in the moment with their child and find what they can enjoy together. In these moments of connection and attunement, the heart finds strength and rejuvenation.

The emotions of a broken heart are rarely far from the surface and not just for the families of those who are more severely impacted by autism. Generally speaking, children diagnosed with autism seemed normal for the first year or more. At times I think it may be even harder for the

parents of children with milder symptoms because it often seems that just working harder might make everything “normal” again. My perspective is that mothers, fathers, siblings, and children on the autism spectrum are doing the best they can under the circumstances. When professionals note and comment on the resilience of families, those families feel supported and encouraged.

4. A central theme of your book seems to be the process of coming to accept your life as it is, not as you wish it could be. As a professional, what would you recommend to parents to help them reach that point within themselves?

First, I try to help people look at their grief. It doesn't help to pretend to be positive when underneath you may be lonely, afraid, or sad. I learned we don't have to lie to ourselves. You can grieve. You can complain. You can mourn. This helps you to go on, make the best of the situation, and enjoy life. Our life force is resilient, but the desire for the healthy child or a typical family life may endure, and it may be hard to let go of that longing.

Second, I try to help people accept themselves. A perfectly lovely child or adult on the spectrum can be very hard to be with because of behavioral, social, or communication issues. When you love somebody, you love to be with them. When you don't feel that, the guilt can be unbearable. You cannot accept yourself or any experience without seeing it clearly in a tender way with compassion. What Tariq has taught me besides accepting him is to accept myself.

Finally, accepting our pain and ourselves leads to accepting and enjoying our child and our family. That awareness is the gateway to love and wholeness. Ultimately children with autism are not just puzzles to be solved. That deep connection that a parent feels with a newborn, or a child's first steps, or first words can be felt at any moment when we are truly aware and attuned to our child. Yearning for what we don't have blocks knowing and loving the child we do have. Seeing our child for who she is and giving what she needs from us to whatever extent that is possible. As best as I can understand it, this is the path of acceptance for families.

5. As a father, what's the one thing you think professionals don't "get" when it comes to supporting families of a child with ASD?

I think professionals don't “get” how hard it is to have a child with the behavioral challenges of ASD. It often seems from the outside to look like the child with ASD is the boss or king of the family. Families often live holding their breath until the next meltdown. The household is often held hostage. Some families feel incarcerated in their own homes.

The over-emphasis on lessening the behavioral symptoms of autism makes it difficult at times to implement positive behavioral strategies which incorporate an acceptance of a child's developmental level and skills. Fathers traditionally feel responsible for discipline in the home.

Professionals do not see or hear nearly as much from fathers as they do from mothers. So it is actually very understandable that the role of fathers is under appreciated. In general, men have a difficult time talking about the things they cannot change or fix. I discussed at some length what I called the “secret life of men” as it pertains to raising a child with ASD; admitting tender feelings has been taboo for boys and men. This can be a secret even from the men themselves.

6. In the book, you mention "shedding the shame" at various points. You also mention your suspicion that challenges in children radiate inwardly to parents' own sense of being flawed. Do you think that shame is imposed mostly internally or more externally, from the community? If the latter, can you think of a change you'd like to see that could alleviate that shame in the first place?

Both apply and it's hard to separate which comes first. There may be a sense of failure for bringing a child with the challenges of autism into the world along with shame and guilt for feeling disappointed in your child. Given the genetic linkages, thoughts about parents' own quirks are natural. Shame results in wanting to hide and not be seen. Sometimes parents avoid families with typically developing children because of the practical difficulties of socializing together plus the embarrassment often triggered by their child's differences. These feelings can be the most intense in public when people seem to stare at a child who is different from the norm. When people stare, the parent feels different. It is easier for many to feel angry and embittered.

For mothers as well as fathers, accepting and embracing their painful feelings opens the door to shedding shame and embracing acceptance. The opposite of shame is pride. As awareness of autism grows, parents receive more compassion and support in their communities. Pride can come from celebrating a child's successes, finding what's right with parent and child, and enjoying time together are antidotes to shame.

7. What about policy changes you'd like to see? (You mention the group of individuals diagnosed in the early 90s who have now reached adulthood ... You mention the group of people whose symptoms are not severe enough to receive adult day services but are too severe to enable them to function independently ...)

As 2012 winds down, there has been a national conversation about a fiscal cliff for the federal government and the country. For parents of children with ASD and other special needs, there is a cliff at age 21 when services are no longer guaranteed except for those diagnosed with intellectual disability. From the moment of diagnosis onward, parents understandably worry about adulthood for their children. If a child cannot become independent by adulthood how will they live and how will they be supported?

It has been said that there is strength in numbers, and for a humane society as well as for the autism community it is essential that we use our strength to secure a meaningful future for our families as well as our children with autism. While the social and emotional development of young people with ASD may be delayed, there is strong scientific evidence that it continues in adulthood. Racism and poverty compound the challenges for families. With adequate support, it is reasonable to expect continued slow steady progress just as with typically developing adults. The policy change which we need desperately is to extend support and training for individuals with disabilities through adulthood.

8. Parents of adult children with autism have exhausted themselves trying to do what is best for their families. They've tried treatments. They've read books. They've talked with specialists. What can anyone tell them or provide them at this point that can give them genuine relief or support?

This exhaustion is typical for parents from the early years onward. Trying to cure autism or even eliminate its most troubling symptoms can feel like drowning in quicksand. Accepting a child with autism involves working to change what can be changed, celebrating each step of progress, and embracing the child in the here and now. It is a delicate balance which is constantly evolving and requires dedicated parents with good supports and services.

Parents of adult children with autism like those you mention have done a good job. They worked hard and come a long way with the love and courage. What they need more than anything is the peace of mind that their vulnerable adult children will be adequately cared for when they can no longer do so themselves. This is a public health challenge and a moral imperative for society.

9. One of the most poignant moments in your book comes when you talked about the election of a mixed-race president and not being able to talk about the historical significance and relate it to your own son-a grief any parent can understand. What can a parent of a child with autism do with all the If onlies and the unanswerable questions?

Thoughts like these are human and natural. Many parents have told me that they try not to wonder what might have been but trying to block these thoughts can cause more pain.

When Tariq was born, it seemed inconceivable that there would be an African-American president in our lifetime. Yet a fundamental truth is that everything changes and nothing remains exactly the same. This is also true with our troubling thoughts and intense feelings. Like the weather they can come and go. But just as after a storm, the sky clears and the sun does come out again.

This is an approach based upon mindfulness which does not mean eliminating painful thoughts and feelings. Too much focusing on what's wrong and too much trying to change someone with ASD blocks us from experiencing happiness and acceptance in our lives. This does not mean denying real problems. It just means paying attention to the moments we might overlook or ignore, such as our children running to us when we get home even as the house may be a mess. I counsel parents to pay attention to the experiences that bring pleasure in family life.

10. Your book focuses on your experience with Tariq; in it, you thank him for being a good son. What message would you like to give your daughters?

My daughters will be glad you asked this question, as am I. Tariq gets the book, but they get the final question. I am incredibly grateful to have them in my life. As I reflected within my writing, Tariq taught me among other things to look inside myself and find how to be a better man and father. My daughters on the other hand have taught me to listen and think even deeper. They boost my manhood in different and untold ways. Sometimes I bite my tongue when they tell me, "Just listen, Dad." My brain is instantly overloaded. What am I supposed to do? How can I solve the problem? What have I done wrong?

More often than not I don't have to do anything—I just have to get out of their way and be there while they find their own way. Watching them grow has filled me with pride and wonder. They are young women now with big hearts and strong keen minds. I have no doubt that their lives will make a difference; that they will make a difference. It is a distinct honor to be their father. More than anything they continue to teach me how to be human and what it means to be family. Recently they surprised me on my birthday by showing up from 2 different states to have dinner. This was one of the best days of my life so far. They show me a kind of love that is different than what Tariq can ever show me and it means the world to me.