

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, Kayfitz, 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.

References

Freedman, B., Kalb, L., Zablotzky, B., & Stuart, E. (2011). Relationship status among parents of children with autism spectrum disorders. *Journal of Autism and Developmental*

Disorders. e-Pub ahead of print.

Hartley, S., Barker, E., Seltzer, M., Floyd, F., Greenberg, J., Orsmond, G., et al. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder.

Journal of Family Psychology, 24, 449–457.

Hartley, S.L., Barker, E.T., Seltzer, M.M., Greenberg, J.S., Floyd, F.J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism spectrum disorders. *American Journal of Intellectual and Developmental Disabilities*, 116, 81-95.

Kayfetz, A. D., Gragg, M. N. and Robert Orr, R. (2010), Positive Experiences of Mothers and Fathers of Children with Autism. *Journal of Applied Research in Intellectual Disabilities*, 23, 337–343.

Resources

Gottman, J. M. (1999) *The seven principles for making marriage work*. New York: Random House.

Marshak, L.E., & Prezant, F. (2007). *Married with special needs children: A couples guide to keeping connected*. Bethesda, MD: Woodbine House.

Viorst, J. (2003). *Grown-up marriage: What we know, wish we had known, and still need to know about being married*. New York: Simon and Schuster.

ABOUT THE AUTHORS

Brian Freedman, Ph.D. is the Director of the Transition, Education and Employment Model (TEEM) Unit at the University of Delaware Center for Disabilities Studies. He has a background in clinical psychology and expertise in working with children, adolescents, and young adults with developmental disabilities and their families. At UD, Brian oversees model demonstration programs for adolescents and adults with disabilities, conducts research, and is an Assistant Professor in the School of Education.



Robert Naseef, Ph.D., is a psychologist and parent of an adult child with autism. At Alternative Choices in Philadelphia, he specializes in working with families of children and adults with autism and related conditions. His book, *Special Children, Challenged Parents: Raising a Child with Autism While Taking Care of Everyone's Needs*, Second Revised Edition, will be published this fall by Brookes Publishing.

