

How to stay married when Autism blows your budget

A couple's perspective

Our children



Support for Marriage

- Divorce – what the studies say
- Three Questions for TACA's Family Counselor
- TACA Moms Speak Out – Listen up Dads
- Top 10 ways to stay married (with Autism in the family)

The bad news

- Divorce
- What is the divorce rate for parents of ASD children?
- What does the media say?
- Are there any studies on Autism & divorce?

What does the media say?

Reputable (mainstream) sources

- **Oprah Winfrey Show** (9-18-07): The stress of raising an autistic child also takes a toll on many marriages. Autism Speaks, the nation's largest autism advocacy organization, reports that the divorce rate within the autism community is staggering. According to their research, **80 percent** of all marriages end.
- **Denver Post** – Autism's terrible toll (12/02/08): There is an **85 percent** divorce rate among parents of autistic children.
- **Fox News Houston** (4-14-10): Divorce has been called a common side effect of autism. **80 percent** of couples with autistic children get divorced, according to the National Autism Association (Note: this is not what NAA is saying)
- **Dan Burton**, Congressman – The Autism Epidemic and Its Possible Connection to Vaccines: The divorce rate in autism is said to be about **85%**.
- **John McCain**, in his 2008 statement on autism for the ASA's rally stated that "divorce rates of parents of children with autism are **well above the national averages**." (Autism Advocate, 3rd Edition, 2008, Vol 52, p. 58.)

Autism & Divorce

Parents of children with ASD experience **higher levels of anxiety** and other emotional problems and lower levels of family functioning than do parents of children without autism and/or parents of children with other disabilities (Desmond, Lin, & Seltzer, 2007; Baker, 2007)

Moms of children with autism had **higher levels of parenting-related stress** and psychological distress than mothers of children with developmental delay. Children's problem behavior was associated with increases in both parenting-related stress and distress in both groups, but this relationship was stronger in mothers of children with autism. The research also found no link between a child's decreased daily living skills and increased parental stress and psychological distress. (University of Washington Released, Wed 08-Jul-2009)

Numerous studies have asserted the prevalence of marital conflict among families of children with attention-deficit/hyperactivity disorder (ADHD), but **evidence is surprisingly less convincing regarding whether parents of youths with ADHD are more at risk for divorce** than are parents of children without ADHD. (Rate and predictors of divorce among parents of youths with ADHD. Wyboms BT, Pelham WE, Molina BS, Gnagy EM, Wilson TK, Greenhouse JB. J Consult Clin Psychol. 2008 Oct; 76(5):735-44.)

Autism & Divorce

- Definitive statistics on the divorce rate for couples with disabilities are not available but there is general consensus that it is somewhat higher than in families with typical children. (Married with Special Needs Children L.Marschak, PhD/F Professor, MEd)
- NAA is currently involved in an informal online poll. Their respondents reported a 38% divorce rate.

Autism & Divorce

- A study published last year (2008) in the Journal of Consulting and Clinical Psychology looked at the divorce rate of parents who had **children with and without ADHD**. By the time the kids were 8 years old the rate of divorce without ADHD is 12.6 percent. The figure was **22.7 percent for parents of kids with ADHD**. Couples with ADHD kids also tended to reach the point of divorce or separation faster. The study mentioned the importance of parents being "on the same page" and to take care of themselves as individuals. Quote from Andrea Chronis-Tuscano, a psychologist who directs the University of Maryland's ADHD Program: "One of our mantras is, 'If you don't take care of yourself, you can't do your best as a parent.'"

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- Divorce rate for parents of children with ASD = 30%
- "Among those parents with children who have Autism Spectrum Disorder and have been divorced, **only one third** say their divorce had anything to do with managing the special needs of their children" (34%)

Three studies - #2

- Adolescents and Adults With Autism (University of Wisconsin-Madison, Georgia State University & Boston University)
- 391 families participated
- 23.5% divorce rate (family with autism)
- 14% divorce rate (control group)

Three studies - #3

- Kennedy Krieger Institute in Baltimore
- "There really **were not** any significant differences in terms of family structure when you consider children with autism and those without. In fact what we found is that children with autism remained with both biological or adoptive parents 64% of the time, compared with children in families without autism, who remained (with both biological or adoptive parents) 65% of the time."
- Reversing that data gives us a 36% divorce rate for families with autism

Summary

- NAA informal poll = 38%
- University of Maryland ADHD study = 22.7%
- Easter Seals' *Living With Autism Study* = 30%
- Adolescents and Adults With Autism = 23.5%
- Kennedy Krieger = 36%
- Average = 30%

A study on divorce (without Autism)

- A study conducted by University of Chicago found that two thirds of unhappily married couples who didn't divorce reported happy marriages five years later
- Among those who rated their marriages as VERY unhappy, almost 8 out of 10 who avoided divorce were happily married five years later
- Study found no evidence that unhappily married adults who divorced were typically any happier than unhappily married people who stayed married
- Article on TACANOW.org with practical suggestions for providing for your child's financial, medical & educational support in the event of a divorce

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- Moms concerns: social development and the quality of their relationships. Dads concerns: will they lead productive lives and sports.
- Moms may be more protective of the child where dads tend to give them more rope.

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- Moms need to talk (to download) to their husbands. That is part of what makes them feel appreciated and validates their efforts. Dads need transition time. Dads can do a quick check-in.

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- **Being on the same team is crucial.** Discuss money - trigger point for arguments.

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- **"What piece of advice would she like me to pass along to TACA families?"**
- Enjoy your family & children. Get off the "autism machine". Meet your children where they are in their development. Build a relationship with your kids. A particular challenge for dads, as many are away from the home for much of the day.

**Married with Special Needs Children*

- *A child's disability does have a large impact, but it is not predetermined whether this will be detrimental, beneficial, or result in a mixture of effects.*
- *Overall, you can think of having a child with a disability as **amplifying** what occurs in a more typical family and marriage. Closeness may be stronger, divisions greater, anger intensified, sadness deeper, parenting decisions weightier, and happy times more exhilarating.*
- *There is no doubt that marriage is more complicated.*
- *Just as we learn to adapt our childrearing skills to meet the unique needs of a child with special needs, we generally need to do the same with our marriages. Both in childrearing and marriage, having children with disabilities requires that we develop even better skills than others may need to have.*
- *Mom's quote: "I once felt like we lived in a prison; however, my husband and I were a refuge for each other."*

TACA Moms Speak Out

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- Question: **“Can you please list one or two things (from a TACA Moms perspective) that you think Dads of children with autism should know or should do?”**

TACA Moms Speak Out

- 33% of those who responded stressed the importance of Mom and Dad being a “team”.
- 33% said that Dads needed to support the current interventions and recovery plan. A number mentioned the diet specifically.
- 23% said that Dads needed to become more involved in a general sense .
- **Three levels of involvement**

TACA Moms Speak Out

- 23% of those who responded mentioned how much it meant to them when their husbands acknowledged the work they are doing for their children. In a more general sense they wanted to be appreciated.
- 19% spoke of the financial burden of raising a child on the spectrum. Autism is expensive, no doubt. Parents need to have full disclosure with each other on what everything costs, how long a given expense is expected to last and what costs are coming up in future.

TACA Moms Speak Out

- 14% stated that women need to download.
- 14% mentioned sex in a diminished capacity.

TACA Moms Speak Out

- 14% of respondents wanted to offer encouragement to Dads. Hang in there. Don't give up.
- 14% are looking for Dads to arrange for them to have a break from autism.
- 9% mentioned specifically how helpful it is when Dads are involved in dealing with the school district (attendance at IEPs) and service providers. These Moms feel that providers are more responsive to men.
- 9% expressed how important it is for Dads to work on the relationship with their child.

TACA Dads (sort of) speak out

- Little feedback from Dads
- Moms going too fast
- Mom “My husband needs to talk to you”
- Mom: “he’s not supportive”
- “Forgive yourself.”

- The Autism Dad?



- The Autism Dad



- **The Autism Dad**
- In the final Lord of the Rings film, Aragorn proposes a noble mission that is almost certainly doomed to failure. Gimley, the dwarf, responds, "Certainty of death, small chance of success...what are we waiting for?"



Top 10 ways to stay married (with Autism in the family)

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- Common enemy
- Bathroom reading material

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#2 – Take Action

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- Understand from the get go that you will be facing a multitude of small battles and you will certainly win (at least) some of the time
- Fake it till you make it. *There is a principle in therapy that it is sometimes useful to start with a behavior change, and then an emotional change will follow. This means that you may not have your heart in changing, but if you accept this concept intellectually, your own attitude may change when you start seeing results.**
- Two year plan. Commit for two years. Then reevaluate.

Top 10 ways to stay married (with Autism in the family)
#3 – Realistic Hope

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- Vroom's Expectancy Theory – Motivation requires an expectation of a favorable outcome
- Cannot win fight = withdrawal (my biggest mistake)

Top 10 ways to stay married (with Autism in the family)
#4 – Involvement

- **Do what you know (make lemonade)**
- Software
- Music
- Extreme sports

Top 10 ways to stay married (with Autism in the family)
#5 - Balance

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–Of course, but HOW?

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- Make time for yourselves as a couple.
–Of course, but HOW?
- There is no short cut to recovery by denying your needs – the martyr doesn't finish first

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#6 - Sex**

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- Ladies – sex is security AND intimacy to a man (as well as stress relief for both partners)
 - Don't stop having sex with your husband
 - Jump his bones occasionally

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 - Don't stop having sex with your husband
 - Jump his bones occasionally
- Gentlemen – don't forget to romance your lady (there is a lot on her mind and it may take a moment for her to shift gears)
 - The Romance Novel Principle
 - Don't try to get to second base when she is organizing the supplements

**Top 10 ways to stay married (with Autism in the family)
#7 – Let Go Of Your Ego**

- **No ego parenting**
- Give your wife credit for the phrase
- It's not about you, it's about your kid
- Guilt, blame, withdrawal – all useless (see next slide)
- You have to do SOMETHING to help your child
- "I didn't sign up for this"

**Top 10 ways to stay married (with Autism in the family)
#8 – Guilt**

- Serenity Prayer: "God, grant me the serenity to accept the things I cannot change, Courage to change the things I can and the Wisdom to know the difference."
- *It is essential not to confuse mourning with self-pity. The issue with self-pity is the amount of time spent with these feelings.**
- *Guilt, self blame, and other problems related to adjusting emotionally to a child's disorder may cause an unhealthy devotion to the child's needs.**
- *Don't assume your partner is consumed voluntarily – he or she may simply need more help!**
- Silence. *Being The Other One* by Kate Strohm. Mom wants to talk – Dad needs to process.

**Top 10 ways to stay married (with Autism in the family)
#9 – Denial – part 1**

- **Denial** is a defense mechanism postulated by Sigmund Freud, in which a person is faced with a fact that is too uncomfortable to accept and rejects it instead, insisting that it is not true despite what may be overwhelming evidence.
- The subject may use:
- **simple denial** - deny the reality of the unpleasant fact altogether
 - **minimisation** - admit the fact but deny its seriousness

**Top 10 ways to stay married (with Autism in the family)
#9 – Denial – part 2**

- Dad denial – "There's nothing wrong with my son" – "It's not autism." – "It's not as bad as you make it out to be." – "You are making too big of a deal out of this."
- Mom denial – "I'll have him recovered by Kindergarten" – "Once Johnny is recovered we can get back to normal." – "I only have this small window of time, so everything else has to wait." – "I don't care if we take out a second mortgage, it has to be done now."
- Both types of denial neglect other members of the family
 - Dad denial neglects child's and mom's needs
 - Mom denial neglects all but child's needs (including mom)
- COMMUNICATION

**Top 10 ways to stay married (with Autism in the family)
#10**

**• Heal your child –
heal yourself**

On the web

- TACA Dads Yahoo group
- <http://health.groups.yahoo.com/group/TACADads>
- TACA USA – Yahoo Group
- <http://health.groups.yahoo.com/group/taca-usa/>

Ian John wrote this as a single parent to a special needs child:

- Your child being born with special needs has nothing to do with your manhood. Leave the macho stuff behind.
- Do not put distance between yourself, what happened, and your family.
- Go through the grieving, deal with your emotions, learn from them.
- Men stay and find solutions, boys make excuses and forsake their commitments.
- Your focus should not be on what has happened to you, but on what has happened to your child.
- The fact that your child is born with special needs is not going to change: you have to change!
- Your spouse/partner needs your support on this one.
- Your child needs a father, so "step up to the plate."
- Ask for help, it's a strength to do so. Join a support group, find another man who has a child with special needs because you need to learn about your child's disability and your new world.
- You are now an exceptional father entering a higher level of manhood: take good care of yourself.

Brilliant Summation

Place holder for Brilliant Summation

(I got nothing)

Summary

- The job of parenting is to prepare your child to be an independent adult (autism or not)
- No Ego Parenting
- Team work (communication)
- Get real (expectations)
- Involvement, involvement, involvement (direct or indirect – all good)
- Celebrate small victories
- Dads – your wives want you to listen to them, but not necessarily to solve their problems
- TACA Yahoo groups or other support systems
- Heal your child – Heal yourself