

The Impact of Autism on the Family:

Challenges and Strategies for Successful Coping

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Why focus on families?

- If you focus on children with ASD, don't families improve?
- Families have a hard time focusing on themselves
- At the end of the day, it's all about family

What will we discuss today

- Impact of ASD on:
 - Mothers and fathers
 - Couplehood
 - Siblings
- Strategies for working with family members

Historical Context

- Refrigerator Mother Theory
 - 1940's-1960's
- Leo Kanner
 - Comments related to parent characteristics: lack of warmth and willingness to play
 - Broader Autism Phenotype?
- Bruno Bettelheim
 - Leading analyst who popularized and perpetuated theory
- Reports that the theory continues to be used in Europe, South Korea

Impact of Historical Context

- Inappropriate and incorrect blaming of parents
- Feelings of guilt
- Defensiveness and lack of trust
- Potential overcompensation for feelings of guilt, resulting in overwhelming stress

...all of this while parenting a child with autism!

Impact of Autism on the Family: Core Deficits & Assoc Symptoms

- Communication
 - Unable to understand your child's needs
- Social Interaction
 - Difficult for your child to make friends
 - Difficult to develop relationship with siblings
- Behavioral
 - Restricts family activities

Parenting a child with ASD

- High stress
- More mental health problems and less marital satisfaction
- Contribution of child's environment in contributing to stress:
 - Begins with ID of symptoms
 - Continues with fight for school services
 - Perpetuated by challenges in developing relationships
 - Additional issues once child reaches adulthood

Unique challenges of ASD

- Symptoms aren't always easy to identify
- Peaks and valleys of knowledge and skills
- Confusing when academically a child does well but socially they struggle
- Much of what individuals with ASD struggle with is inherent to us
- Lack of difference in physical appearance can create more challenges
- Difficulty in generalizing and need to practice learned skills

Additional unique challenges

- Behavior challenges: difficult to predict
- Regression – roller coaster ride continues
- Aspergers and HFA
 - Academically may be doing well (at least early on) – impact school support eligibility
 - Social and adaptive functioning deficits are difficult for others to understand
 - Targets for teasing/bullying

Impact on Individual and Family

- Behavior Challenges + Stigmatization = Increased isolation
- Less connection to community
 - Including vital resources (e.g., religious groups)
- Increased vigilance = less time for self and couple

Mothers

- High levels of stress
- Depression and other mental health issues
- Balance the role of mother/therapist/case manager
- Implications for spending significant time with the child

Fathers

- High levels of stress
 - Differences across research
- Don't have same level of risk for mental health problems
- Presence of "Broader Autism Phenotype"
- Impact if more often away from the child
- Challenge of financial pressure (both moms and dads)
- Challenge in multiple roles

Couples

- Marital satisfaction is lower
- Not enough time for each other
- Differing styles create more challenges
- Differences in time and knowledge can create challenges
- But parents are more resilient than you'd expect!

Family Resilience

- "Families of children with autism display factors of resilience – reporting having become stronger as a result of disability in the family." Bayat, M., (2007)

"Experts" say the divorce rate is 80%

- Oprah
- Dr. Phil
- Jenny McCarthy
- Speakers at conferences who presumably should know better.

• ***There is no source for these claims.***

80% Divorce Rate: Fact or Myth?



"How high is the divorce rate among parents of children with autism?"

- There is no published empirical evidence that is a source for the commonly quoted 80% divorce rate.
- Marriages are certainly distressed and often feel extremely fragile. This is confirmed by countless studies.
- Couples also report great love and coming closer as a result of autism in the family.

80% Divorce Rate Myth: Impact on Families?

- Greater distress
- Hopelessness
- Self-fulfilling prophecy

A diagnosis of autism is not a prognosis of divorce

Divorce Research

- Low divorce rates have been described for ASD families – primarily in qualitative studies
- Divorce rate of parents of children with ASD: **23.5%** (Hartley et al., 2010)
 - Between 8 and 30 years old, increased risk for divorce as compared to parents of typically-developing children.
 - Sample of children with ASD only represented two states
 - Need to control for variables that have been previously implicated in impacting divorce among all families (SES; Parent health status)

Divorce Research

Freedman et al (2012):

- Little difference between families of children with ASD (64%) and children without ASD (65.2%)
- **No evidence** of an association between a child having an ASD diagnosis and not living in a family with both biological or adoptive parents
- Symptom severity does not seem to play a role in predicting family structure
 - Consistent with literature

Theories of Impact on Families

- Experiencing a continuous traumatic event
- Fantasy of father-son relationship
- Broader phenotype in parents
 - Difficulty with coping
 - Less inclined to seek out social support

Thoughts/Comments

Phases of the child and family

- Many describe parenting a child with ASD as an experience that involves re-experiencing of a traumatic event
- Each phase of the child's life represents new opportunities and challenges for the child and family
- How a family gets through each phase:
 - Depends less on actual skill gain
 - More so on the family's outlook
 - Overall well-being of members of the family
 - Connection to resources and the community

Infancy/Toddlerhood

- First signs and diagnosis
 - Getting someone to pay attention
 - Finding someone who can assess
- How moms and dads may see their child differently
- Intensive early intervention: importance of both getting involved and striking a balance

Infancy/Toddlerhood

- Stressors (Davis & Carter, 2008):
 - Parent-child relationship and social skill deficits (moms and dads)
 - Self-regulation; ie eating, sleeping, emotions (moms)
 - Behavior challenges (dads)
 - Less stressful: IQ and verbal skills
- Coping (Dabrowska & Pisula, 2010):
 - Emotion-focused coping & Avoidance coping
→ greater stress

School-age

- Greater expectations of assumed social understanding
- The dreaded IEP meetings
- Finding the right inclusion plan
- Behavior challenges become more intense
- Less cute = greater stigmatization
- Loss of fantasy continues to play out
- Greater risk for divorce? (Hartley et al, 2010)

Adolescence & Young Adulthood

- Physical and mental health challenges increase
- Decisions, decisions, decisions:
 - diploma vs. certificate track
 - Next steps: employment; postsecondary education; day programs
 - Living situation
- End of entitlement programs requires a shift in thinking, approach
- Role of the parent as decision-maker changes

Adolescence & Young Adulthood

- Relationship between mother-child becomes more strained (Taylor & Seltzer, 2010)
 - More prevalent for individuals without ID
- Renewed sense of loss
- Attribution of challenges shifts to the individual

BREAK!

Intervention with Families

- Strategies for helping families to decrease stress
- Direct intervention with families
- Changes to clinical approach
- Incorporation into child's treatment

Helping parents to feed themselves

- Balance of being a therapist and a parent
- Giving themselves proverbial stickers
- Find some alone time
- Keep track of personal goals
- Will be uncomfortable at first

Ways to Reduce Stress

- Seeking out support from others
 - Family, friends
 - Support Groups: ASA, Autism Institute
 - Bailey et al., 1999
- Participate in your child's services
 - Estrada & Pinsof, 1995; Harris et al., 1988; Dunn et al., 2001
- Take advantage of respite care services
 - Factor et al., 1990

Coping: Circle of Influence



Support from Extended Family and Friends

- Not always easy
- Use another family member as your "spokesperson"
- Let me them know:
 - What is helpful
 - How they can support you
- Provide them with a specific role

Using your Support System

- Families who understand autism
 - Support groups
- Getting involved in activities/fundraisers
- Having a support group that are separate from the "autism world."
- Have them help you to take a break!

Golden Nuggets

- Focusing on your child's achievements
- Write them down
 - On a weekly/monthly basis
 - During periods of change/transition for your child and your family
- Using a different measuring stick
- Recognize that they are working hard
- Allow yourself to be proud

Recognizing Strengths

- In your child
 - What do you like about your child?
 - What activities do you enjoy about your child?
- In your family
 - What do we do well as a family?
 - When are we at our best?

The Power of Positive Thinking

- Not just a cliché
- Research supports the importance of finding a frame for seeing something in a positive light

Challenges and Weighing “Now” vs. “Later” Stressors

- Allowing others to care for your child when they won't do things in the same way you'd like them to be done
- Pulling back after your child was completely dependent for so long
- Teaching your child age-appropriate behaviors (e.g., adolescence)

Taking advantage of resources

- Communication with the school
- Involvement in your child's therapy
- Support Groups
- Parent trainings and seminars

Understanding each other's needs and experiences

- Acknowledge that life has veered sharply from what you expected
- Try not to blame each other
- Teach them to be kind to themselves

Why is it harder to be a mom?

What do mothers say that they want?

- To be appreciated
- 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

Why is it harder to be a dad?

What do fathers say that they want?

- To understand they are trying to help, and that we will 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

Help parents spend alone time together

- Research finds satisfied couples describe their spouses as best friends.
- Best friends enjoy activities together.
- Who would marry someone who wasn't fun?
- You can start with sharing a cup of coffee or tea...

Tips for Couples

For men:

- Learn to listen without trying to fix.
- Tell her what she is doing well.
- **Do something** to give her a break.
- Find romance in everyday life.

For women:

- Tell him to just listen—that's all you need.
- Tell him what he is doing well.
- Tell him what he **can** do for you.
- Find romance in everyday life. ... and offer a little more sex

Make Your Own Action Plan

- Be honest with yourself!
- Appreciate your partner!
- Catch him or her being right!
- Find the things you can enjoy doing with each other now!
- Find time to take a breath for yourself...

Supporting during diagnostic process

- Rigorous, tiring process for all
- Be mindful of amount of recommendations and levels of understanding
- Offer opportunity for lengthy discussion as a component of services
 - Either at initial or follow-up
- Offer support for families on informing child of diagnosis

Tips for Working with Families of Young Adults

- Reflect empathy, not judgment
- Recognize and articulate the parent's value
- Offer specific strategies on how they can support the achievement of greater independence.
- Offer to support them developing their communication system
- Help parents reflect on advances their child has made in order to help them reframe

Marriage and Family Resources

- The Gottman Institute: www.gottman.com
- National Center for Health Statistics: www.cdc.gov/nchs/fastats/marriage.htm
- National Fathers Network: www.fathersnetwork.org
- The Beach Center on Families and Disabilities www.beachcenter.org
- Interactive Autism Network (IAN): www.iancommunity.org
- 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.
- Naseef, R. (Fall 2012). *Special Children, Challenged Parents: Raising a Child with Autism While Taking Care of Everyone's Needs*, Second Revised Edition.
- 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.

Specific resources for the transition process and parental support:

- A Guide for Transition to Adulthood from Organization for Autism Research
<http://www.researchautism.org/resources/reading/documents/TransitionGuide.pdf>
- Transition Tool Kit from Autism Speaks
<http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit>
- The Parent's Guide to College for Students on the Autism Spectrum by Jane Therfield Brown et al.

Thank you!

Questions? Comments? Tomatoes?

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