

Families of Children with Autism:

Taking Care of Everyone's Needs



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Dimensions of the Spectrum

- Childbirth: A parent is born
- Understanding the diagnosis and treatment
- The parental relationship: Male and Female
- What about the siblings?
- What happens in adolescence and adulthood
- Some thoughts on acceptance

Diversity is the New Normal



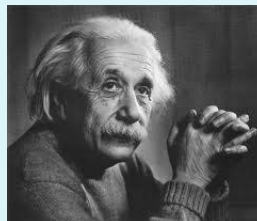
- Single Mothers
- Single Fathers
- Blended Families
- Same-Sex Parents
- Step-Parents
- Grandparents
- Adoptive Parents
- Foster Parents
- Nuclear Families

The simplest things can be the most profound

- "Educate each child according to his ways."
-Proverbs 22:6
- "Start where the child is and make contact."
-Bertram Ruttenberg, MD
- Start where each family member is and learn together how to cope and grow from there.



What is Evidence?



"Not everything that can be counted counts, and not everything that counts can be counted."

- Albert Einstein

Deepening Autism Awareness: Our Human Challenge

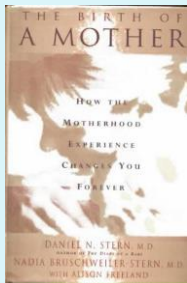


Autism Awareness 2017

CDC: 1 in 68 children diagnosed with ASD
1 in 42 boys; 1 in 189 girls
All of whom are part of the human family



1. Becoming and Being a Parent from *The Birth of the Mother*



- As the infant emerges, there are two other births: the woman becomes a mother and the man becomes a father. The family is born. The experience of parenthood changes us forever.
- Drs. Daniel Stern & Nadia Bruschweiler-Stern

Making eye contact at 1 day old!



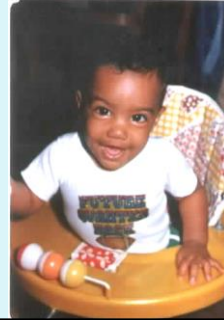
My Story: Meeting Milestones



My Story: Everyday Joy



Imagining the Future



A Big Milestone



Second summer: **No longer playing normally**
What was it like for you?



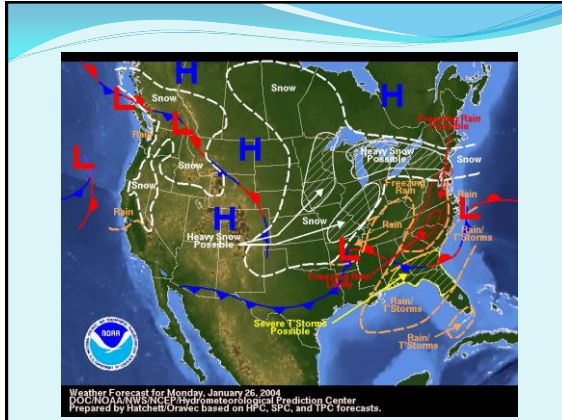
2. Understanding the Diagnosis: Social-Communication Red Flags

- No big smiles or other warm, joyful expressions by 6 months or thereafter
- No back-and-forth sharing of sounds, smiles, or other facial expressions by 9 months or thereafter
- No babbling by 12 months
- No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
- No words by 16 months
- No two-word meaningful phrases (without imitating or repeating) by 24 months
- Any loss of speech or babbling or social skills at any age
- from www.firstsigns.org


Families are thrown into emotional turmoil

- Fear
- Guilt
- Depression
- Anxiety
- Grief
- *Loneliness*

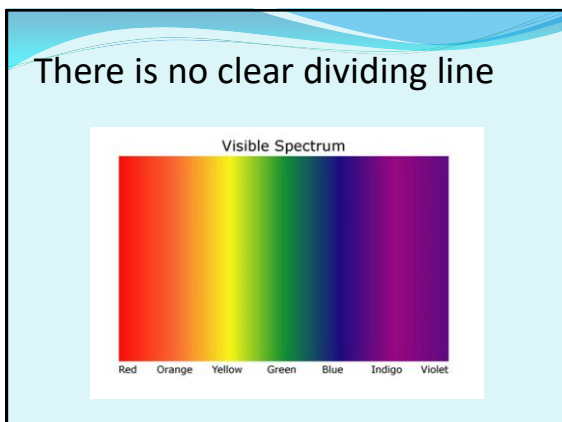
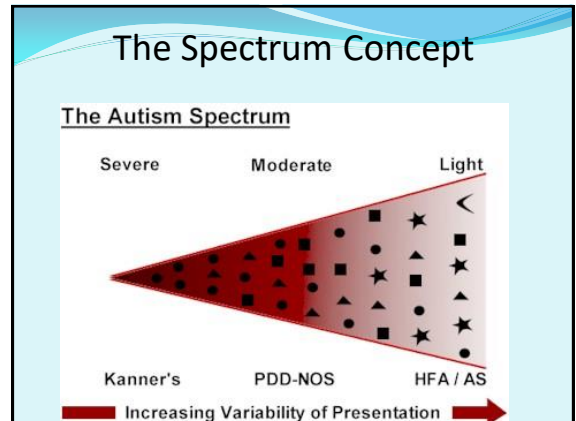




"Groundhog Day"



- Stuck and re-living the same day for who knows how long?
- If he does nothing different events repeat. If he changes his behavior, people respond differently and then possibilities open up.
- What we can do is to relate to our lives differently accepting that change is inevitable and believing it's possible.
- Even the most challenging situation is always unfolding and shifting.



The Natural History of Autism Spectrum Disorders

- Kanner was the first observer of the phenomenon that some children with ASD show remarkable improvement during the middle childhood years.
- The best known predictors of functional outcome are cognitive ability, language development, and age at diagnosis. Changes in screening and diagnosis plus the availability of early intervention show promise in altering the course or development of autism.
- Wherever a child begins on the spectrum, chances are good that the child will become less impaired over time.

Wide Variability and Uniqueness

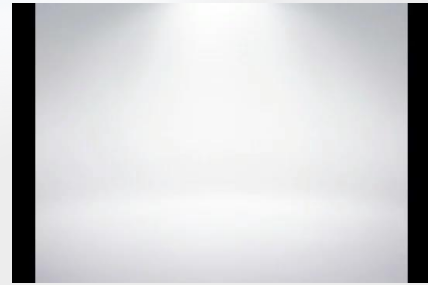


"LOW FUNCTIONING
means our abilities are not
acknowledged.

HIGH FUNCTIONING
means our challenges are
not addressed."

~Laura Tisoncik

A Humanistic Perspective on Autism



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Words of Wisdom

"I think mothers are helped by being able to voice their agonies at the time they are experiencing them. Bottled up resentment spoils the loving which is at the back of it all."

-D.W. Winnicott

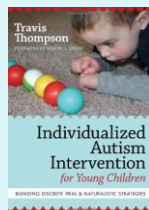
Most mothers are passionate and obsessed with the challenge



According to Winnicott "Primary maternal preoccupation is a consuming attachment to one's baby, a normal sickness from which most mothers recover." He was talking about the mothers of typical children—who presumably have a little less to be preoccupied with on the average.

Contemporary Models

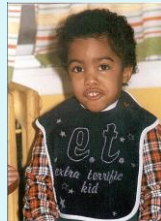
- Prizant: "ABA is not the only way." (2010)
- Thompson (2011): Autism has become a battlefield among psychology's warring factions much to the detriment of children, their families, and therapists. Treatment which is often complicated can be planned with a blend of approaches in a logical child-centered way.



- Positive Behavior Support, Denver Model, DIR, STAR, etc. all incorporate blended approaches.



Is autism a puzzle to be solved or a child to be embraced and loved as she is?



This dichotomy is unavoidable. It often obsesses the family. The answer is that it is both– and that the balance is found through struggle and reflection.

3. Autism Challenges the Relationship



“There is a strain on any marriage whenever a baby is sick. And we always have a sick baby”

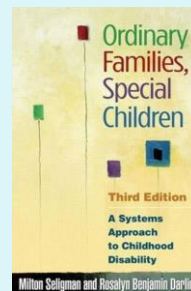
Josh Greenfeld in *A Child Called Noah* (1970).

80% Divorce Rate Myth: Impact on Families

- Greater distress
- Hopelessness
- Self-fulfilling prophecy

A diagnosis of autism is not a prognosis of divorce

Prior to 2010: No Evidence for ASD and Divorce



- Research is sparse and contradictory.
- Marital conflict occurs during adjustment.
- Some marriages improve.
- Greater stress for single parents.
- Disability as a red herring that distracts from fundamental issues.
- Poverty, racism, and mental illness make it harder to cope.
- “Straw that broke camel’s back.”

Most Recent Evidence

- No evidence of an association between a child having an ASD diagnosis and that child living in a family with both biological or adoptive parents versus other family types
- The high percentage of children with an ASD living with married biological or adoptive parents (64%) is far different than the 80% divorce rate often reported by the media.
- None of the models resulted in factors suggesting a lower incidence of intact families for families of children with ASD
- Freedman, et al. 2011

From “Friends” Male-Female Differences



You're Not the Only One

- 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.

-from www.gottman.com

Taking care of yourself is vital



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.

4. Our Family Images : A Cozy Set



"My Brother...Ahhhhhhh!" by Zoë Naseef



- "My brother always hogs my dad... Whenever we go canoeing: Dad hogger. When we go hiking: dad hogger. Every time he is around and I try to go near my dad: dad hogger."

Birth Order Can Be Reversed



- The younger child may surpass the older developmentally and therefore the older child may always be the baby of the family. The sibling then loses a role model as well as a "normal" playmate.

What siblings want and need

- Parents to notice their accomplishments
- A fair amount of attention
- Time alone with parents
- Time alone with friends
- Freedom to complain
- A family life as “normal” as possible
- Information about their brother’s or sister’s condition

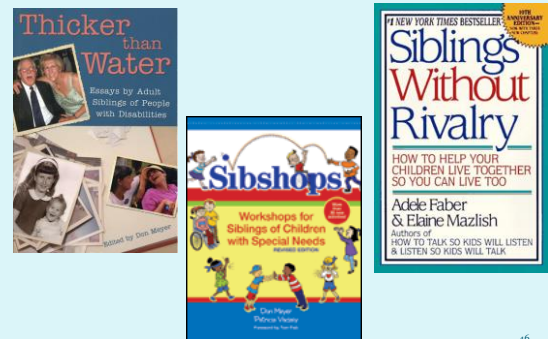
Parent Strategies: Information

- Listen actively to your children
- Serve as a model
- Be open and honest about your own thoughts and feelings
- Provide answers at your child’s level
- Notice the nonverbal cues
- Facilitate questions
- Follow up previous conversations

Strategies: Encourage Interactions

- Look for things everyone enjoys
- Have realistic expectations based upon developmental levels
- Select activities and toys that facilitate interactions
- Teach interaction and give positive feedback
- Limit care-giving responsibilities
- Recognize each child’s accomplishments

Resources for More Information



4. Transitioning: Adolescence

- Worries about bullying, sexuality, independence cannot be deferred.
- Teens with ASD are more vulnerable.
- Less adequate services and role models.
- Mood swings and rebellion are normal but exacerbated.
- Many teens worry that they might be homosexual. May be harder to resolve because of the tendency of the mind to get stuck on the possibility.



- Parents: “I can’t even die.”
- Steinberg (2011): parents’ emotions in response to teenagers may be exacerbated by their own struggle with middle age.

What About When They Grow Up?

- Seltzer (2010): 240 young adults over a ten-year period. Overall improvement in autism symptoms and internalized behaviors. Rates of improvement slowed after leaving school **especially those who did not have an ID as well as those with lower SES.**
- 18% without ID employed or getting services compared to 86% with ID.
- Increased stress for families especially mothers.



- “Development delayed, is not development denied.” -Don White
- This is an ethical/moral imperative for society and our profession.

Racism and Poverty: Impact on Age at Diagnosis

- Mandell, et al. (2009) report racial/ethnic disparities—African American children Dxed on average 2 years later than European Americans.
- Reasons: inadequate screening, slow response to parent concerns, or misdiagnosis as behavioral disorder.
- More educated parents may be more aware of the symptoms of ASD.



- Despite ability to diagnose autism in very young children, the parent-professional interaction lies at the heart of these disparities.

Do Children Recover from Autism?

- Small % of children with autism does move off the spectrum
- communicate and socialize much like their typically developing peers
- Still mildly affected by anxiety, depression, impulsivity, etc. which slightly affected their social functioning.
- These individuals had milder symptoms, learned to process faces through intensive intervention, and had fewer self-stimulatory or repetitive behaviors.
- Fein, et al. (2013) Optimal outcome in individuals with a history of autism. Journal of Child Psychology and Psychiatry

5. Reflections on Acceptance



"The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart".
-Helen Keller



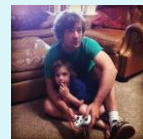
Learning to be with him



- When you love someone you love to be with him or her...
- Children with autism are often hard to be with...
- Finding joy in the relationship is where we do have some control

Start where your child is

- This father would rather have a catch with a football but his son may be more interested in computer games or legos.
- Start where your child is. Watch, wait, observe. Often finding out something that you can build on.



Acceptance does not mean giving up

- It does not mean wanting or liking autism.
- It does not mean changing your opinion.
- It does not mean resignation.
- It does not mean giving up on life or possibilities.

Acceptance is about opening up

- To the sad and the sweet in life.
- To the possibilities and the alternatives.
- To the lessons that come with really hard experiences.
- What are some of your lessons?

Life: A Balancing Act



Serenity Prayer

Give us grace

To accept with serenity the things that cannot be changed,

Courage to change the things that should be changed,

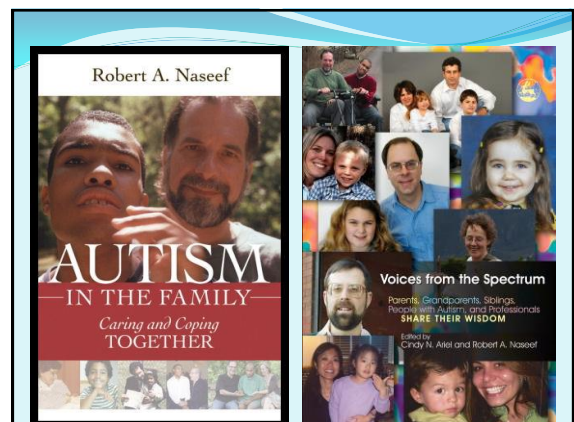
And the wisdom to discern the one from the other.

-Reinhold Niebuhr

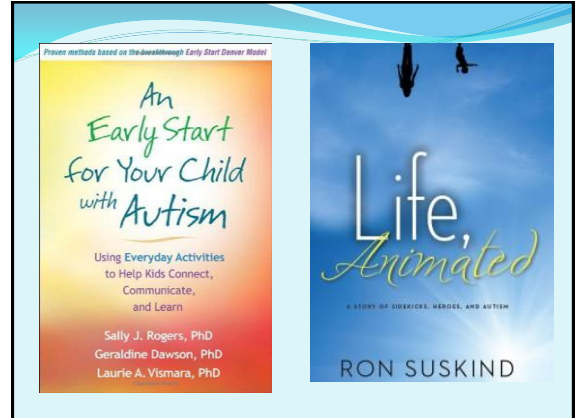
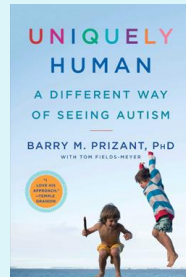
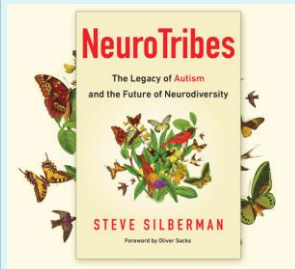
"You don't have to be normal to be happy."



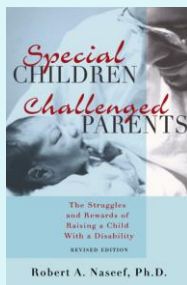
- Nor do you have to make your child or any other autistic person normal to be happy.
- But this is not an easy journey.



Highly Recommended Reading



The simplest lesson



As I wrote to Tariq,
"I have tried so
hard to change
you, and in the
end it was you who
changed me.
Instead of
becoming the son I
wanted you to be
you made me
become the man I
needed to be."

Take what helps you, and leave the rest...



- I invite you to visit:
www.alternativechoices.com
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