Family Health: The Springboard to Success for Children with ASD

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Disclosures

- Dr. Coplan is the author of Making Sense of Autistic Spectrum Disorders: Create the brightest future for your child with the best treatment options (Bantam-Dell, 2010), and receives royalties on its sale

- This presentation may include a discussion of off-label drug use

www.drcoplan.com

Underlying Premise

(“We give our children roots and wings” – Hodding Carter)

Family Health is a key ingredient in outcome for all children, but especially for children with developmental disabilities, who are less able to work around obstacles arising from family dysfunction than children with normal development.

Outline

- Family-Oriented Thinking
  - Family Systems Theory
  - Differentiation (& the baggage we bring to adulthood)
  - Triangles (and other alliances)
  - You, Me, and “US”
  - Family Health & Danger Signs
  - Making Meaning

- Interaction between mental health & family health
  - Child: ASD and Mental Health
  - Parents: “Subclinical” atypicality; non-ASD mental health d/o
  - Know what you don’t know

- Summary & Next Steps
**“The System”**
- School Dist.
- Insurance
- Healthcare
- Legal system

**“The System”**
- Emotional health
- The child
- The parents
- Ability to effect therapies, advocate for child, and assure successful transition to adulthood
- Siblings

**The Unit of Treatment is the Family**

**“House Rules”**
- Both parents must be present for evaluation & counseling
- Exceptions:
  - One parent is:
    - Incarcerated
    - Deceased
    - In the armed forces stationed overseas
    - Unknown (anonymous sperm/egg donor)

**How professionals do unintended harm**

(Parent-Therapist bond replaces marital bond)

**My secret weapon**
PROBE QUESTIONS

- What do you think about X?

- What do you think about what your partner just said?
  - It’s OK to comment on what your partner says, but not on your partner directly (no personal attacks)

- OR (if partner is absent): If your partner were here, what would he/she have to say?

MY AGENDAS

- Both partners need to feel that they have been listened to and given a fair hearing
  - Identify areas of consensus and disagreement
  - The therapy process becomes the template for future partner-partner interactions (Safe; candid but non-blaming)

- “Fixing the problem” is not my goal – at least, not at the beginning

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FAMILY SYSTEMS THEORY

Murray Bowen, 1913-1990

- “A theory of human behavior that views the family as an emotional unit and uses systems thinking to describe the complex interactions in the unit”

http://www.aamft.org

http://www.thebowencenter.org/
Family Systems Theory

- Differentiation of Self
- Triangles
- Nuclear Family Emotional System
  - Family Projection Process
  - Multigenerational Transmission Process
  - Emotional Cutoff
  - Sibling Position
  - Societal Emotional Process

Differentiation of Self

“People with a poorly differentiated ‘self’ depend so heavily on the acceptance and approval of others that either they quickly adjust what they think, say, and do to please others, or they dogmatically proclaim what others should be like and pressure them to conform.”

“In both cases, the underlying objective is conflict avoidance.”

Well Differentiated

Getting to Well-Differentiated

Sense of Self

(Adapted from Erikson)

- Identity
- Self-confidence: Childhood
- Trust: Infancy
  - I cry, and my mother meets my needs
  - The world is a safe place.
  - I can go to people for help when I need it.
Still Face Experiment
(Tronick et al., 1978)

Still Face Experiment

Still Face Experiment

Sense of Self

• Identity
  ➢ Self-confidence: Childhood
    – The sum total of all of one's successes
    – Successful recovery from life's bumps
    – I can do it!
    – (And if I don't quite succeed, it will not kill me!)
• Trust

We Can Do It!

Sense of Self

➢ Identity
  – Adolescence
    • Who am I and where do I fit into the world?
    • I am a person of worth
• Self-confidence
• Trust

“Well when I was sixteen, my father was so ignorant
I could hardly stand to have the old man
around. I was astonished at how much the old
man had learned by the time I turned 21.”

Well-Differentiated Adult

Identity
Self-confidence
Basic Trust
Family Health Honestly Autism Day
4/18/2015

**BAGGAGE**

- Mistrust
- Lack of confidence
- Poor sense of self
- Painful memories

**Family Systems Theory**

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**Triangles**

- A triangle is a three-person relationship system
- A triangle is the smallest stable relationship system
- Triangles can contain much more tension than a dyad [2-person system]... because the tension can shift around three relationships
- Triangles are building blocks of larger emotional systems


**LOAD**

Un-supported span


**Triangles**

- The essential nature of triangles endows them with strength, because it permits avoidance of one-on-one confrontation
- but at the same time, creates a situation with two “insiders” and an “odd man out,” who is trying to become an insider

Example: Mom is angry at teenage child. “Wait till your father gets home and hears about this!”

**Triangles**

- Mom unloads on dad ("You won’t believe what your child did!")
- Some of the anger shifts to dad-child side of triangle
- Mom’s stress is reduced
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http://www.thebowencenter.org/pages/theory.html


Nuclear Family Emotional Systems

- "The basic relationship patterns result in family tensions coming to rest in certain parts of the family"
- "The more anxiety one person or one relationship absorbs, the less other people must absorb. This means that some family members maintain their functioning at the expense of others."
- Triangles can lead to dysfunctional but stable interrelationships that work to the detriment of one or more family members

http://www.thebowencenter.org/pages/theory.html


Triangles

Example: Primary conflict is between parents


OR: By common consent, the parents may both find easier to focus on their child’s failings (real or perceived) than to work on their own issues. The parents remain insiders, and the child is scapegoated as the outsider.


Interlocking Triangles

Parents are in 2 triangles at once. One child has become their preferred child; the other has become their bad child.

Parent #1

Parent #2

Our saintly child

Our troubled child

Signs of Family Mental Health

- Systemic support for differentiation of all members as they are able
- Flexibility
  - Shifting alliances (adults vs. kids, “boys vs. girls,” etc.)
  - Shifting roles (role of “hero” or “in the doghouse”)
  - Shifting solutions (one size does not fit all; “equitable” vs. “equal”)
  - Shifting combinations for activities. All legitimate combinations should come up once in a while.
- Sense of humor / playfulness

Danger Signs

- Inflexibility
  - Fixed roles
  - Fixed solutions
- Hypervigilance
  - Lack of trust in care providers
- Social Isolation
  - “Circle the wagons”
  - “Nobody helps us!”

Where is the problem?

- The person with the identified “problem” may not be the actual source of the difficulty
- The family system itself is often out of balance

You, Me, and US

I + I = WE

You & Me = US
A parent reflects…

“I would compare the experience of having a disabled child to the experience of parenting during the first eight weeks of an infant’s life – intense, exhausting, you are always on duty (vigilant). All other aspects of your life fade into the background…. It’s that intense, and the difference goes on for years”

Marshak, LE and Prezant, FP: 
Married with special needs children 
[A couples’ guide to keeping connected] 
Woodbine House, 2007
Imbalanced Family System

Parent #1 — Parent #2

Older Siblings — Child with DD — Younger Siblings

Dysfunctional (but common) coping responses

- Utilitarian Model
- Enmeshment

Marshak, LE and Prezant, FP:
Married with special needs children
Woodbine House, 2007

“Us” is always at the bottom of the list of things that need to be done.”

Mother of an 8 year old boy with severe ASD, ID, and SIB.
Child is in 40 hr/wk home-based therapy program.
Mom has become certified therapy instructor.

Parent #1

- Relentless self-sacrifice
- Hypervigilance

“Us”

Child

Partners #1 & #2

Mother-Son Enmeshment
(data consistent with maternal mental illness)

Making Meaning (Mister Duckrabbit)

What kind of animal do you see?


Joseph Jastrow, 1999

Making Meaning
(The meaning we read into events drives our actions)

- What is the “meaning” of having a child with a disability?
  - Everything happens for a reason
    - It’s God’s Will
    - Theodicy: “It’s for the good”
    - Everything is a blessing
  - It’s someone’s fault
    - Self-blame
    - Guilt / Shame
  - Punishment
    - Blame others (Dr. / Spouse / ... / Anger
  - Sh*t happens for no reason
  - Life is out of control (pretty scary!!)

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Psychiatric Symptom Impairment in Children with Autism Spectrum Disorders

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD (any type)</td>
<td>83%</td>
</tr>
<tr>
<td>Oppositional defiant disorder</td>
<td>53%</td>
</tr>
<tr>
<td>Conduct disorder</td>
<td>23%</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>70%</td>
</tr>
<tr>
<td>Conduct disorder</td>
<td>23%</td>
</tr>
<tr>
<td>Social phobia</td>
<td>5%</td>
</tr>
<tr>
<td>Major Depressive D/O, Dysthymia</td>
<td>45%</td>
</tr>
<tr>
<td>Manic episode</td>
<td>53%</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>48%</td>
</tr>
<tr>
<td>Any disorder</td>
<td>94%</td>
</tr>
</tbody>
</table>

* Combined Parent & Teacher ratings
** “Impairment” = Symptoms “Often or Very Often”

Cognitive Rigidity
- Difficulty changing mental sets
- Routines
- Transitions
- Repetitious behaviors
- Perfectionism

Anxiety
- GAD
- OCD/TS
- Phobias
- Selective Mutism
- Depression
- Mood
- Substance Abuse
- Reality Testing

Atypicality
- Social:
  - Theory of Mind
  - Language
    - Pragmatic
    - Prosody
  - Cognitive
    - Central Coherence
  - Sensory/Motor:
    - Aversion / Attraction
    - Clumsiness

DD Model Mental Health Model

www.drcoplan.com
Progression of Interventions (DD Model)

Social Skills Groups
Social Stories
DTT
VB
OT
NET, PRT, DIR
SLP
TEACCH

Age

IQ

Atypicality

Coplan, J. Making Sense of Autistic Spectrum Disorders
Random House, 2010

Presentation in Childhood
(Coplan, J., 2010: Making Sense of Autistic Spectrum Disorders, Fig. 3.2)

ASD (Autism, PDD-NOS, AS)
NLD, SPLD

Social Impairment
Communication Impairment
Restricted, repetitive behaviors & interests

Anxiety Disorders
Obsessive-Compulsive Disorder
Depression, Bipolar Disorder
Alcoholism
Schizophrenia

“Broad Autistic Phenotype”

Non-ASD Psych D/O

Extended Family

NLD: Non-Verbal LD, SPLD: Semantic-Pragmatic Lang. Disorder

Adult outcomes for children who “lose the diagnosis”
Coplan, 2010. Making sense of autistic spectrum disorders, Fig. 5.8

ADHD/ADD
Anxiety
Depression
Bipolar D/O

Social Impairment
Communication Impairment
Restricted, repetitive behaviors & interests

Anxiety Disorders
Obsessive-Compulsive Disorder
Depression, Bipolar Disorder
Alcoholism
Schizophrenia

“Broad Autistic Phenotype”

Non-ASD Psych D/O

NLD: Non-Verbal LD, SPLD: Semantic-Pragmatic Lang. Disorder

Parents & Siblings of Children with ASDs:
Issues of Attention and Mood
(self-report survey)

91 adolescents w. ASD (M: 83)

Methods:
- IQ, Adaptive function, neuropsych measures
- “Severe Mood Problems (SMP) Scale”
  - Explosive rage
  - Low mood
  - Depressive thoughts
  - Labile mood
- Maternal self-report (GHQ)
  - maternal mood, anxiety and somatic difficulties
Severe mood problems in adolescents with autism spectrum disorder

Results
• High SMP: 24 (26%)
  – Predictors of High SMP:
    • Emotional & behavioral problems at age 12
    • Autism severity (by parent report)
    • Maternal GHQ: “The current analyses suggest a specific relationship between maternal affective symptoms and SMP in offspring”
  – Not predictors:
    • Full Scale IQ
    • Adaptive function

Bullying Experiences Among Children and Youth with Autism Spectrum Disorders.
Cappadocia, M.C., J.A. Weiss, and D. Pepler, JADD, 2011

Subjects
• 192 children / young adults w. ASD age 5–21
  – HFA (14%)
  – AS (54%)
  – PDD-NOS (13%)
  – Autism (19%)

Results
• Bullied (physical, verbal, social, cyber) within the past month:
  77%
  – 1 time: 11%; 2-3 times: 23%; ≥ 4 times: 43%

Risk factors for being bullied

<table>
<thead>
<tr>
<th>Risk factors for being bullied</th>
<th>p*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child - Gender</td>
<td>NS</td>
</tr>
<tr>
<td>Child - Age (being younger)</td>
<td>&lt; .05</td>
</tr>
<tr>
<td>Child - Social skills deficit</td>
<td>NS</td>
</tr>
<tr>
<td>Child - Communication difficulties</td>
<td>&lt; .05</td>
</tr>
<tr>
<td>Child - Internalizing mental health problems</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Child - Externalizing mental health problems</td>
<td>NS</td>
</tr>
<tr>
<td>Parent - Mental health problems</td>
<td>&lt; .01</td>
</tr>
<tr>
<td>Child - Fewer friends at school</td>
<td>&lt; .05</td>
</tr>
</tbody>
</table>

Cappadocia, M.C., J.A. Weiss, and D. Pepler, Bullying Experiences Among Children and Youth with Autism Spectrum Disorders. JADD, 2011

Vignette #1
• “Obedience is very important to me.”
  – Father of 10 y.o. boy with ASD
    • Untreated anxiety d/o
    • ? Personality D/O
    • ? ASD
    • Unsecured assault weapons in the home
    • Describes son with ASD as “a predator,” because “everything is all about him”

Vignette #2
• “Nobody helps us.”
  – Mother of 14 y.o. boy with ASD
    • Mo.: Untreated Anxiety D/O
    • Family has no social supports
    • Child is on homebound instruction
    • Spends hrs/day playing violent video games
    • Threatens to “kill” the examiner during evaluation when E. interrupts game play
Vignette #3: Know what you don’t know

• Sam: 10 year old boy with disruptive behavior and academic underachievement despite being “bright.” No prior eval or dx.
• My Dx: HFA & Anxiety
• Sam’s father: Software engineer, dept. head, runs things by the book at work and at home (“strict”). “I don’t understand what this is all about. I don’t see the problem. My son just needs to apply himself harder!”

The Boat

Henry goes to a large lake in the summer. Last summer a motorboat sank near his house. The boat had ten men in it. The man who was running the boat brought it very close to the shore when the water was low. The boat hit a big rock under the water. The water came in very fast. All of the men swam to shore.

Q: There’s someone in this story who might get in trouble. Who is it?
Sam: Henry? The ten men?

Sam’s father: I don’t have any idea.
Know what you don’t know

• “I was in High School before I realized that my classmates couldn’t do computer assisted design in their head the way I can. But I was also in High School before I realized that they were capable of passing invisible messages back and forth that I can’t see.” (Paraphrase of Temple Grandin; Thinking In Pictures)

The Art of War
Sun Tsu

Know your enemy and know yourself, and in 100 battles you will never be defeated

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➢ Summary & Next Steps
Summary

Optimal outcome for the child with ASD depends upon addressing family health, including the family system and the parents' mental health issues (if any), as well as the child’s developmental and mental health needs.

Family Health

- Your child with special needs is a member of the family, but should not become the center of the family.
  
  — Ruby Moye Salazar, LCSW, BCD

Family Health

(Preserve yourself, and your “US”)

“One hand for the ship, and one for myself”

Probe Questions

(In ascending order of intimacy)

- Do you and your partner ever go out as a couple? When was the last time?
- Who else do you have as supports?
- What have you told your other children / parents?
- Tell me a little bit about yourself / how you were raised / your own mental health?
- What does it mean to you that your child has a disability?

Making Meaning

- We “make meaning” by superimposing our interpretation on external events.
  
  — Man’s Search for Meaning; Viktor Frankl
- Sometimes, it's not the disability per se, but the meaning we attach to it, that causes problems.

Informing & Educating your child with ASD

- Knowledge is Power
  
  Sir Francis Bacon
- Self-esteem, self-esteem, self-esteem
  
  Jim Coplan
Siblings

“Every child wants not just the love of its parents, but the exclusive love of its parents”

Selma Fraiberg, 1959

Siblings

- Your job is to enable your other children to accept their feelings (whatever they may be) as “OK.”
  - Often, the best thing to say is “I feel that way too sometimes.”
- Trying to talk siblings out of their feelings by reminding them of all the things they can do that their sib with ASD cannot do doesn’t work, and closes of conversation.
- At one time you probably felt that your child’s ASD was your fault, even though you knew that was “crazy.” Your other children may be feeling the same thing.

Parents’ Mental Health as a contributor to family health

- Parents of children with ASD
  - Frequency of neuropsychiatric d/o (esp. anxiety)
  - “Subclinical” issues with Theory of Mind
    - May interfere with parents’ ability to achieve full differentiation
    - May interfere with parents’ ability to respond in a flexible manner to the extraordinary demands of child w. ASD
- Getting help for yourself is the best way to help your child with ASD

Resources

- Married with Special Needs Children; A couples’ guide to keeping connected. Marshak LE and Prezant, FP. Woodbine, 2007
- Voices from the spectrum. Parents, grandparents, siblings, people with autism, and professionals share their wisdom. Ariel, CN and Naseef, R (eds). Jessica Kingsley, 2006
- Man’s search for meaning. Frankl, VE.
- The Bowen Center: http://www.thebowencenter.org/
- The American Association of Marriage and Family Therapy http://www.aamft.org/iMIS15/AAMFT/