

Disclosures

 Dr. Coplan is 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.

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Session Description

 Children with ASD place unique demands on parents. Furthermore, due to the genetic nature of ASD, parents of children on the autism spectrum are often coping with cognitive or mental health issues of their own. School psychologists have a unique opportunity to engage parents, assess family function, and facilitate intervention when needed

Learning Objectives

Attendees will be able to:

- List the mental health conditions commonly encountered in parents of children with autism spectrum disorder, and the impact of these conditions on child functioning
- 2. Define the concept of "Family Health," and will list the signs of family health and the warning signs of family dysfunction
- 3. Describe family-centered techniques they can use in their own work, as well as resources to whom they can refer families for additional services when indicated

Outline

- How is ASD different from all other disabilities?
- Family Centered Intervention
- Resources & Summary

Outline

- How is ASD different from all other disabilities?
 - Complexity
 - Natural History
 - Genetics
- Family-centered intervention
- Resources & Summary

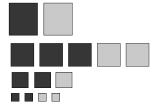
Key Features of ASD

- Impaired Social Reciprocity
 - – Y Eye Contact, Theory of Mind (ability to infer inner cognitive & emotional state of others, take multiple points of view, read social cues)
- Impaired Language & Speech
- Pragmatics (social language)
 - Echolalia
 - ▼ Topic Maintenance (talks "at" not "with" others)
 - . Difficulty with higher-order language (Humor, Sarcasm)
 - Prosody (Tone, pitch: sing-song, stilted, robotic)
- Repetitive Behaviors / Insistence on sameness
 - Cognitive Rigidity
- Stereotypies (Flapping, spinning, etc.)
- Abnormal Sensory Processing
 - Heightened or blunted responses to sensory stimuli

Cognitive Rigidity (Difficulty shifting mental sets)

Task:

1. Group by size, then by color



Cognitive Rigidity (Difficulty shifting mental sets)

Task:

2. Now group by color, then by size!

?

Cognitive Rigidity (Difficulty shifting mental sets)

Task:

2. Now group by color, then by size!

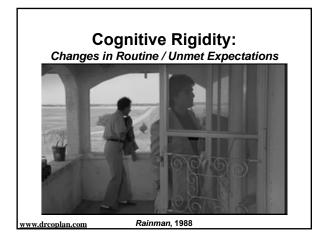


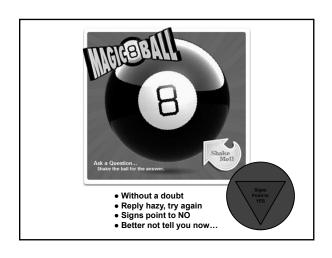
Cognitive Rigidity → Anxiety → Disruptive Behavior

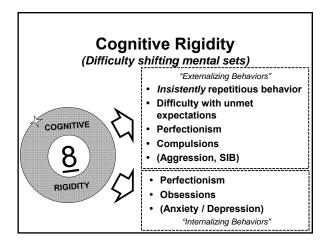
"Our son experiences extreme anxiety when what he anticipates isn't what happens...When we know a change is coming we can prepare him, but those we can't anticipate are still very upsetting for him...The switch flips in his mind, and it's out of his control."

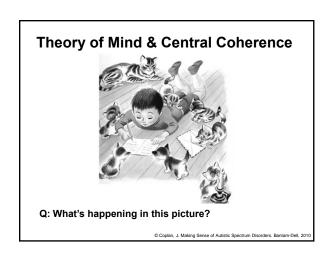
6 y.o. boy with ASD, anxiety, and normal nonverbal IQ

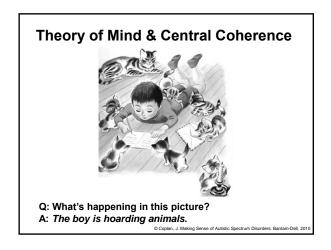
MRN 12-0782

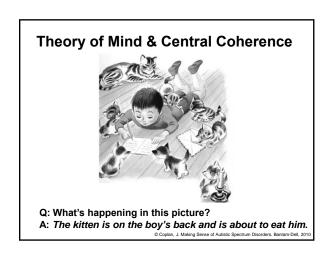












MUFF

(1st Grade reading level)

Muff is a little yellow kitten. She drinks milk. She sleeps on a chair. She does not like to get wet.

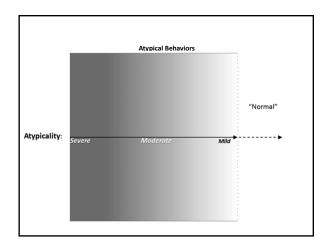
Q: How would Muff feel, if you gave her a bath?

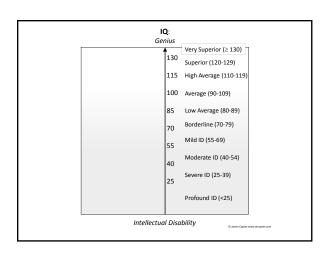
A: I don't know. We haven't read that part of the story yet.*

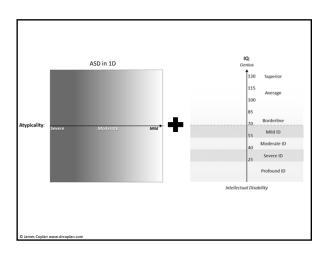
A: I don't know. We haven't read that 'part of the story yet."

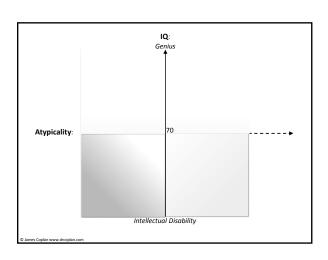
*6 ½ y.o. boy with ASD and superior IQ www.drcoplan.com MRN 01-0938 Natural History: "The temporal course a disease from onset to resolution"

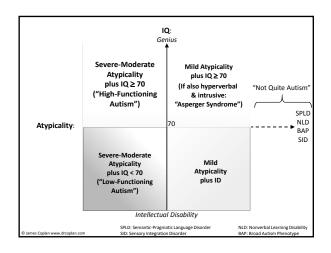
ASD is not a "disease," but it has a *Natural History*

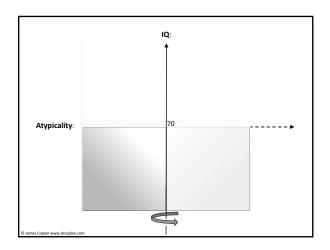


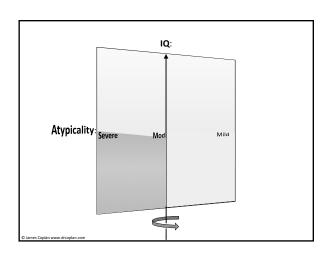


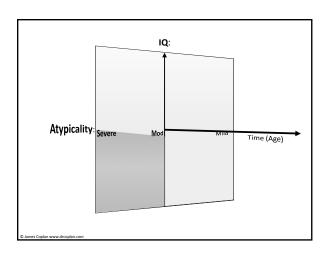


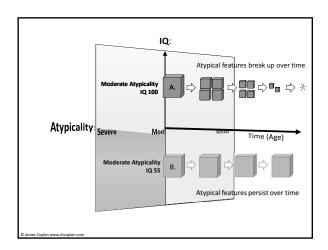










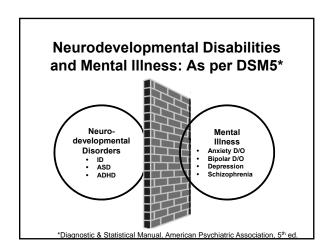


The Boat (3rd Grade reading level) Henry goes to a large lake in the summer. Last summer a motorboat sank near his house. The boat had ten men in it. The man who was running the boat brought it very close to the shore when the water was low. The boat hit a big rock under the water. The water came in very fast. All of the men swam to shore. Q: There's someone in this story who might get in trouble. Who is it? A (Patient: 12 year old boy with ASD): Henry? The ten men? A (Patient's father; Master's Degree): I have no idea.

The Myth of "Co-Morbidity"

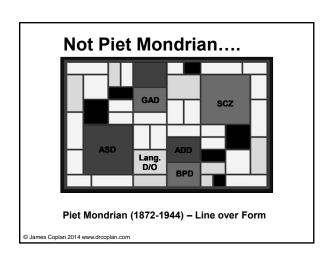


"A, B, C.... etc. are completely separate entities, that just happen to co-exist."

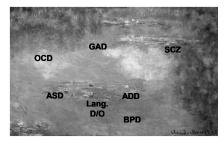


Reality

- Not "co-morbidity," but
 - -Continuum, and
 - -Metamorphisis



...but Claude Monet



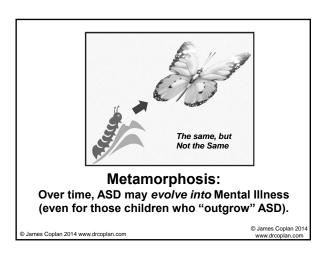
Claude Monet (1840-1926) - Water Lilies

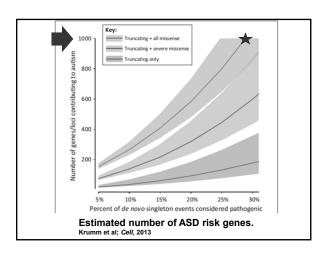
Psychiatric Symptom Impairment in Children with Autism Spectrum Disorders

Kaat, A.J., et al. Journal of Abnormal Child Psychology, 2013

Disorder	Prevalence (%)*	
District	Impairment**	DSM-IV criteria
ADHD (any type)	83%	82%
Oppositional defiant disorder	53%	34%
Conduct disorder	23%	9%
Anxiety disorders	70%	47%
 Generalized anxiety disorder 	• 48%	• 32%
Social phobia	• 51%	• 23%
Major Depressive D/O, Dysthymia	45%	19%
Manic episode	53%	18%
Schizophrenia	48%	10%
Any disorder	94%	84%

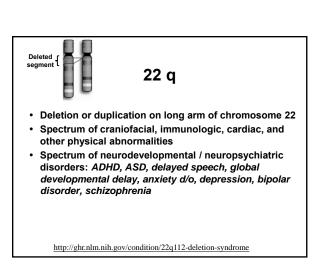
- Combined Parent & Teacher ratings
 "Impairment" = Symptoms "Often or Very Often"

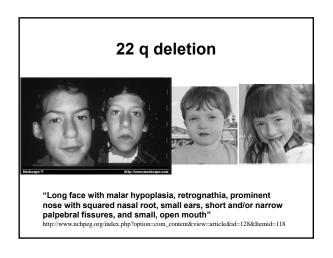


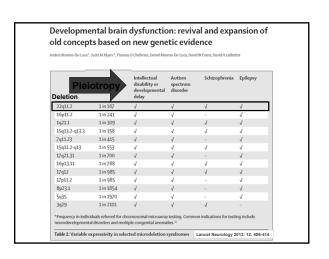


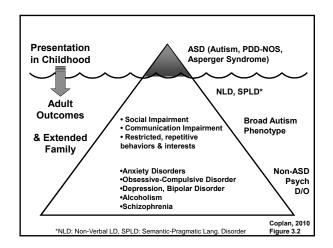
"Pleiotropy"

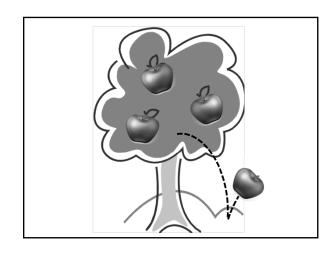
 Same underlying genetic lesion, but different neurodevelopmental outcomes

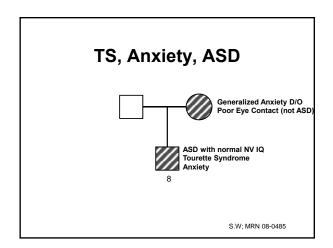


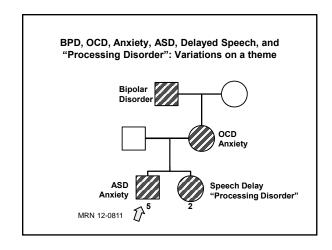


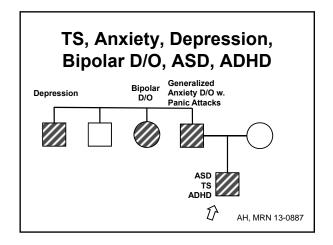










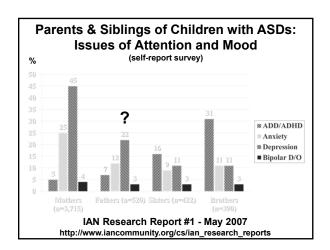


Severe mood problems in adolescents with autism spectrum disorder Simonoff, E., et al., Journal of Child Psychology and Psychiatry, 2012. 53(11): p. 1157-1166 • 91 adolescents w. ASD (M: 83) • Methods: - IQ, Adaptive function, neuropsych measures - "Severe Mood Problems (SMP) Scale" • Explosive rage • 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

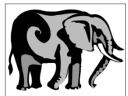
- 192 children / young adults w. ASD age 5-21
 - HFA (14%)
 - AS (54%)
 - PDD-NOS (13%)
 - Autism (19%)

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

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

	Risk factors for being bullied	р*
	Child - Gender	NS
	Child - Age (being younger)	< .05
	Child - Social skills deficit	NS
	Child - Communication difficulties	< .05
	Child - Internalizing mental health problems	< .001
	Child - Externalizing mental health problems	NS
	Parent - Mental health problems	< .01
<i>'</i>	Child - Fewer friends at school	< .05
	*NS = Not statistically significant. Smaller p = less likely to occur	r by chance.

The Elephant in the Room



Child w. ASD + Parent with untreated MH D/O



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Outline

- How is ASD different from all other disabilities?
- > Family Centered Intervention
- Resources & Summary

The Unit of Treatment is the Family



"House Rules"

- Both parents must be present for evaluation & counseling
- Exceptions: If one parent is:
 - Uninvolved (termination of parental rights)
 - Unknown (anonymous sperm/egg donor)
 - Incarcerated
 - In the armed forces stationed overseas
 - Deceased

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Typical excuses

- My spouse is too busy
- My spouse refuses to come
- "We already agree on everything"
- We are separated / divorced and we don't get along

How professionals do unintended harm (Parent-Therapist bond replaces marital bond) Partner #1 Therapist Child

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 about X?

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 or family interview 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



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.thebowencenter.org/

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Family Systems Theory

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

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

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Differentiation of Self Well Differentiated Poorly Differentiated

Differentiation of Self

"A person with a well-differentiated 'self' recognizes his realistic dependence on others, but he can stay calm and clear-headed enough in the face of conflict, criticism, and rejection to distinguish thinking rooted in a careful assessment of the facts from thinking clouded by emotionality."

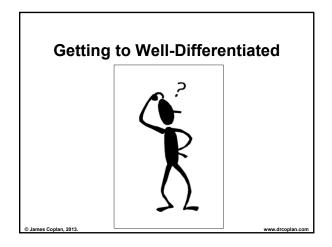
http://www.thebowencenter.org/pages/theory.html

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 to eliminate difference of opinion (jc)

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

ww.drcoplar



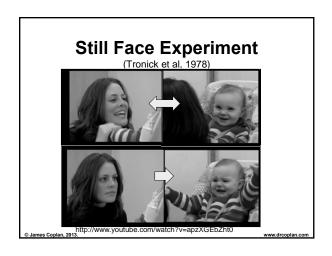
Sense of Self

(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.

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Sense of Self

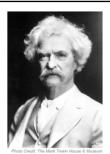
- Identity
- > Self-confidence: Childhood
 - The sum total of all of one's successes +
 - Successful recovery from life's bumps
 - I can do it!
- (And if I don't quite succeed, it will not kill me!)
- Trust



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



"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."

Family Systems Theory

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

Triangles

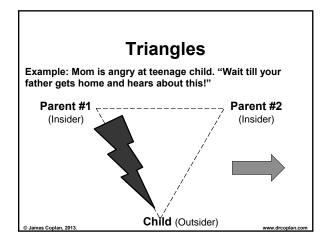
- A triangle is a three-person relationship system
- A triangle is the smallest stable relationship system
- Triangles can contain much more tension than a dyad [2-person system]... because the tension can shift around three relationships
- Triangles are building blocks of larger emotional systems

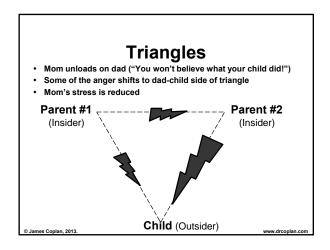
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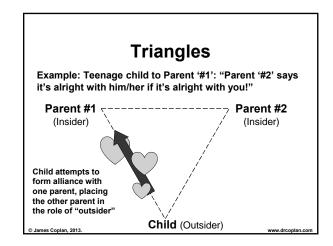
Triangles

- 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

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







Family Systems Theory

- > Differentiation of Self
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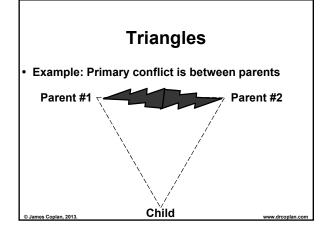
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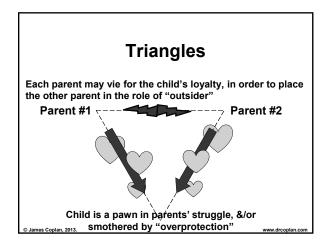
es Coplan, 2013. www.thebowencemer.org/pages/theory.html

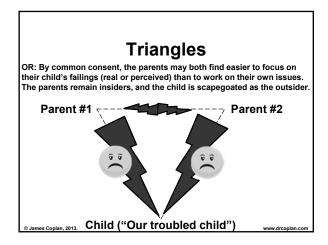
Nuclear Family Emotional Systems

- "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







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



Signs of Family Health

- · Systemic support for differentiation
 - Parents encourage children's development
- 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

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Danger Signs

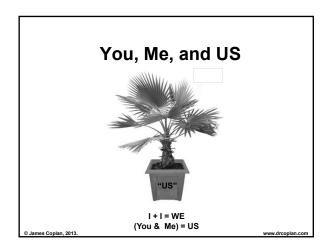
- Inflexibility
 - Fixed roles
 - Fixed solutions
- Hypervigilance
 - Lack of trust in care providers
- Social Isolation
 - "Circle the wagons"
 - "Nobody helps us!"

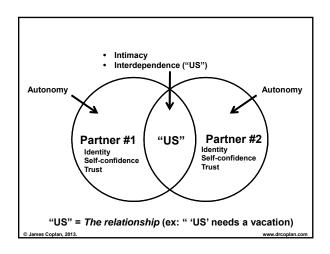
Vignette #1

- "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





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

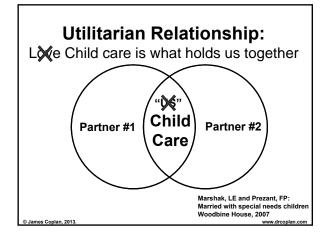
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Dysfunctional (but common) coping responses

- Utilitarian Model
- Enmeshment

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

Coplan, 2013. www.drcopla



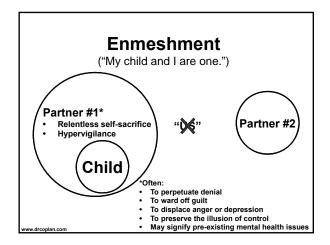
Utilitarian Relationship

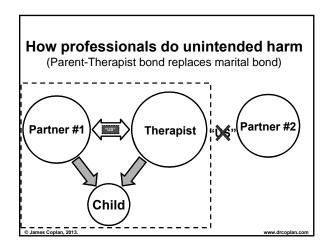
(Child care is what holds us together)

" '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.

DC. MRN 13-0837





Probe Questions

- · Who do you have as supports?
- What have you told your other children / parents / the affected child?
- Do you and your partner ever go out as a couple? When was the last time?
- 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 ASD? What are your immediate & long-term concerns / hopes?

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The Perfect Storm



SHOOTING AT SANDY HOOK ELEMENTARY SCHOOL

- Parents divorced
- Adam Lanza: ASD?, Anxiety/Depression?; Severe weight loss
 Nancy Lanza (Mother): Falsified her own medical history ("MS")
- Enmeshed mother-son relationship: Adam in "parentified" role
- Extreme social isolation; removed from school by mother

http://www.ct.gov/oca/lib/oca/sandyhook11212014.pdf

Outline

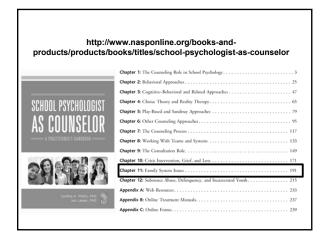
- How is ASD different from all other disabilities?
- Family Centered Intervention
- ➤ Resources & Summary



https://www.acf.hhs.gov/sites/defa ult/files/cb/family_assessment.pdf

COMPREHENSIVE FAMILY ASSESSMENT GUIDELINES

for
CHILD WELFARE



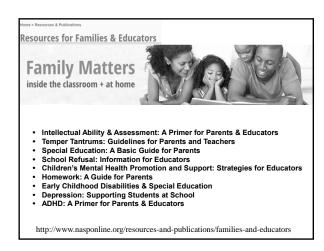
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http://www.nasponline.org/publications/periodicals/spr/volume-16/volume-16-issue-4/resolving-school-problems-with-structural-family-therapy

Resolving School Problems With Structural Family Therapy

Cindy I. Carison
pp. 457-468 Mini-Series on Family Systems Assessment and Intervention

Download





- "School refusal is often the result of separation anxiety, social anxiety, or performance anxiety (e.g., about speaking in front of others), or anxiety related to test-taking, athletic competition, or academic difficulties...
- "Anxiety, depression, and physical complaints are frequently associated with school refusal..



School Refusal: Information for Educators

 "Students with separation anxiety, which is most common in younger children*, become preoccupied with thoughts of harm befalling a loved one and are overly dependent on parents and other caregivers. They may cry, kick, or run away to avoid coming to school." **

Should say:

* "First becomes evident," not "most common."

** "To avoid leaving home," not "to avoid coming to school." For example, the child may refuse birthday parties, slumber parties, etc., for fear of being away from parents / home. Pediatric analog of agoraphobia?



School Refusal: Information for Educators

 Social/performance anxiety. Students with social/performance anxiety worry about what others think, are concerned about how they will be judged, and fear humiliation. They may have intense anticipatory anxiety about giving speeches, taking tests, or participating in sports.

- Generalized anxiety disorder. Students with generalized anxiety disorder (GAD) have excessive anxiety and worry about any number of situations and events. Their worry and anxiety is over and above what the situation calls for
- Other anxiety disorders, such as obsessive-compulsive disorder (OCD), posttraumatic stress disorder (PTSD), panic attacks, and agoraphobia, can be associated with school refusal.
- → Most children w. ASD also meet criteria for Anxiety D/O



School Refusal: Information for Educators

"When teachers or parents suspect that a student is refusing to go to school due to emotional reasons, they should take immediate action. A team approach to assessment and early intervention that involves family, educators, and community providers increases the probability of a successful solution. The team can include the teacher, principal, school counselor, school psychologist, school social worker, school nurse, and community members working with the child (therapist or physician), as well as the student's parents...



School Refusal: Information for Educators

"Teams need to consider whether there is a parent-related reason for the student not coming to school, as in the case of abuse or school withdrawal. Some parents are dealing with their own mental health problems; in these situations, treatment needs to start with the parent.* School staff assessing the reasons for a student's absences often find that refusal to attend school is the result of a complex combination of factors."

- Anxiety and Depression are strongly genetic; thus, the child with Anxiety D/O is quite likely to have a parent w. anxiety/depression
- If parental anxiety is unacknowledged or unaddressed, the anxious parent may actively feed the child's anxiety, and/or seek homebound instruction by the time of middle school or HS.



School Refusal: Information for Educators

"Medication may be used in combination with cognitive-behavioral therapy for a student who has a psychiatric disorder such as severe anxiety or depression. School personnel should refer the parents to mental health providers outside the school when the problem is severe and/or the student needs more help than can be provided by school staff."

- What is the school's role in ascertaining whether the parent is getting MH treatment (for self or child)?
- When does failure of a parent to seek MH services (for self or child) constitute reportable suspicion of medical neglect?

Additional Resources

- Coplan, J. Making Sense of Autistic Spectrum Disorders. Random House, 2010.
- 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
- The Bowen Center: http://www.thebowencenter.org/
- The American Association of Marriage and Family Therapy http://www.aamft.org/iMIS15/AAMFT/
- Google search "Family Therapy Training"

Points to Ponder

 Every child with ASD has a 50% chance of having at least one parent with significant cognitive or mental health issues

Points to Ponder

 Given the prevalence of parental MH issues, and the risk of educationally significant family dysfunction, a strong case can be made for routine, proactive, mental health screening of all children with ASD and their parents / nuclear family

Goals & Hurdles

- Limited Resources
- Limited Training
- Limited institutional support
- · "Role identity"
 - Everyone wants Family Health to be someone else's problem
 - Stigma of Mental Illness
 - Privacy concerns

Goals & Hurdles

 "If it's not causing academic failure or disruptive behavior, there is no educationally relevant problem, so it's not our business."

IDEA, Section 614(d)(2)(B)

http://idea.ed.gov/explore/view/p/,root,statute,I,B,614,d

- (B) Consideration of special factors.--The IEP Team shall--
- (i) in the case of a child whose behavior impedes the child's learning or that of others, consider the use of positive behavioral interventions and supports, and other strategies, to address that behavior.



This site was created to provide a "one-stop shop" for resources related to IDEA and its implementing regulations...

- Comment: A few commenters recommended that Sec. 300.324(a)(2)(i) refer specifically to children with internalizing and externalizing behaviors.
- Discussion: We do not believe it is necessary to make the recommended change because Sec. 300.324(a)(2)(i) is written broadly enough to include children with internalizing and externalizing behaviors.
- · Changes: None.

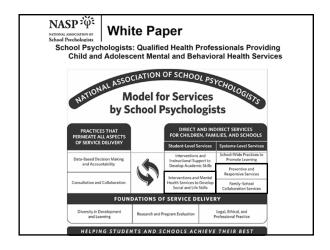
http://idea.ed.gov/explore/view/p/,root,regs,preamble2,prepart2,D,2766

Behavior

IDEA

- As a practical matter, however:
 - "Behavior" is tacitly interpreted by many school districts to mean externalizing behavior
 - "Impedes Learning" is equated with academic failure
 - "Assessment" rarely addresses internalizing behavior / mental health

Locking the barn door after the horse has run off Unaddressed Internalizing Externalizing





Behavior

School Psychologists: Qualified Health Professionals Providing Child and Adolescent Mental and Behavioral Health Services

- According to the Affordable Care Act, school psychologists who are credentialed at the licensed or certified level are considered mental health service professionals.
- Despite statutory recognition of school psychologists as MH professionals, some state Medicaid plans and other relevant programs do not recognize school psychologists as qualified MH professionals. This situation prevents some children and youth from being able to access high quality school MH services.
- When considering the best way to address the mental and behavioral needs of students, school policy makers should consider the extent to which they can utilize (and seek funding support for) the services of school psychologists currently employed by school districts, while also incorporating the contributions that can be made by community-based providers.

