

Talking to your Child about His/Her Diagnosis In a Developmentally Appropriate Way

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Goals for this session:

- Discuss ways to share medical information with your child
- Understand children's thinking abilities at different developmental age
- Learn about importance of self-determination
- Discuss developmental conditions that commonly affect children with developmental issues

We all come in as experts



Background

- Our journey as parents to love/accept child relative to hopes/expectations
- Impact of medical/developmental issues on independence, family, work, companionship
- Child factors
 - Developmental level (separate slide)
 - Temperament
 - Showing signs he/she wants more information
- Parent factors
 - Grieving process (denial, anger, bargaining, depression, acceptance)
 - Level of acceptance of child's medical/developmental issues

Thinking/reasoning abilities evolve over time



Sensorimotor

Exploring objects through touch, only think about things in the present

Birth -
Toddler

Preoperational

Think and talk about things beyond immediate experience

Toddler -
7 years old

Concrete operational

Can now reason, but only about concrete, real life situations

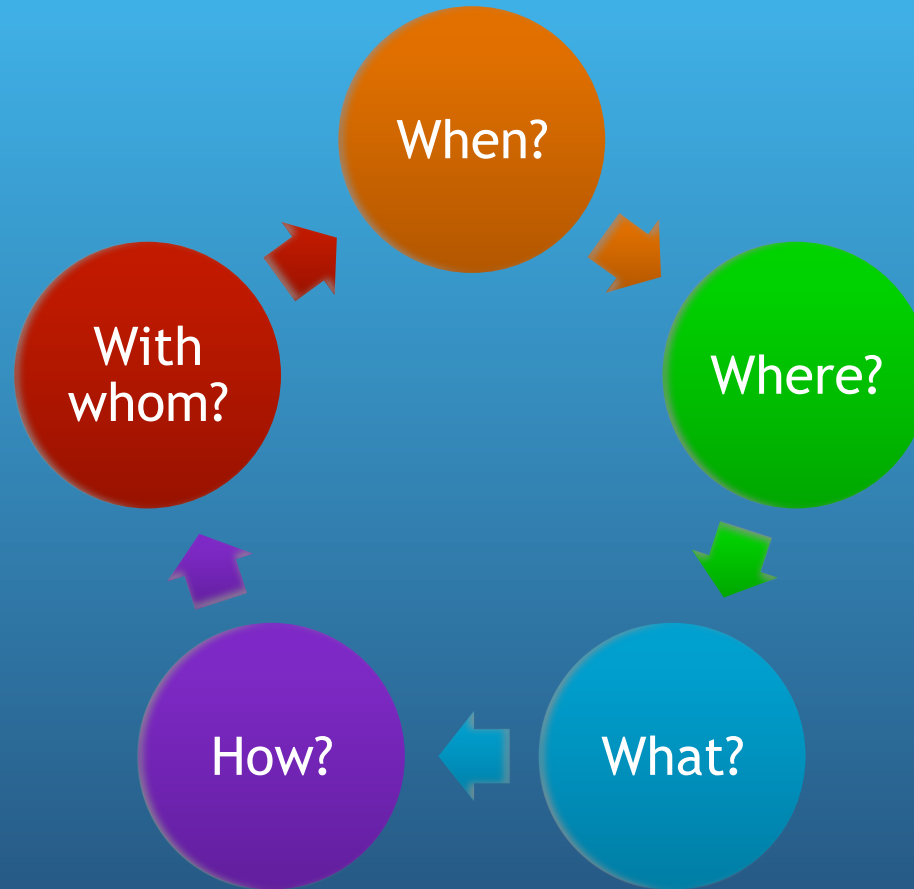
7-12 years
old

Formal operational

Abstract thinking, critical analyses of different points of view

≥12 years
old

Sharing medical information with your child...

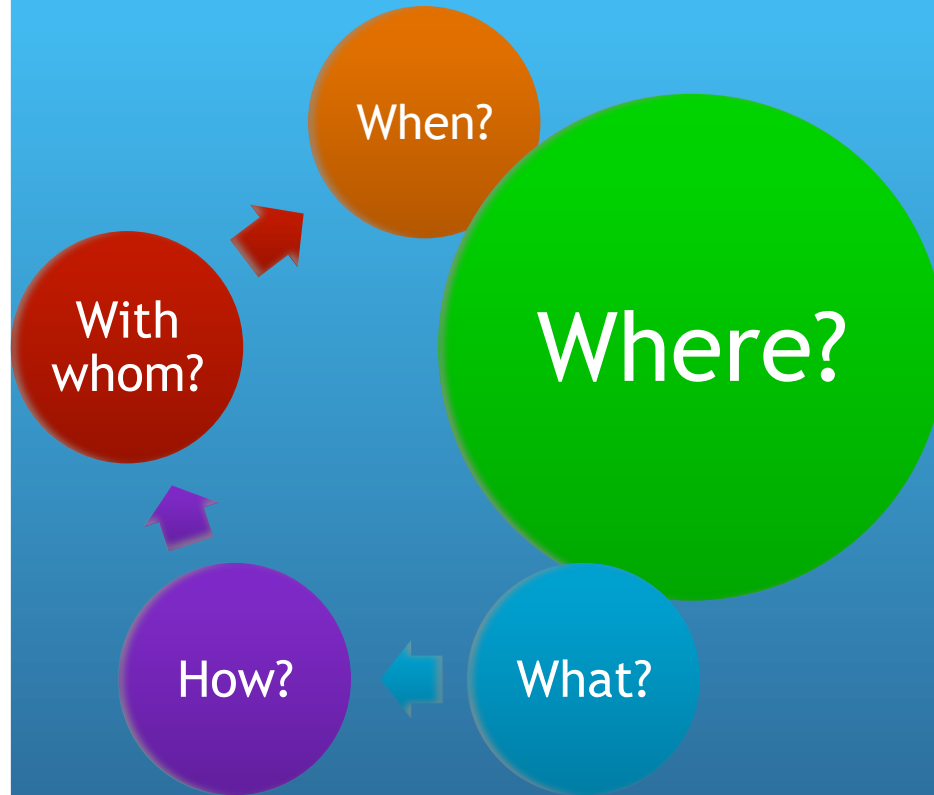


Sharing medical information with your child...



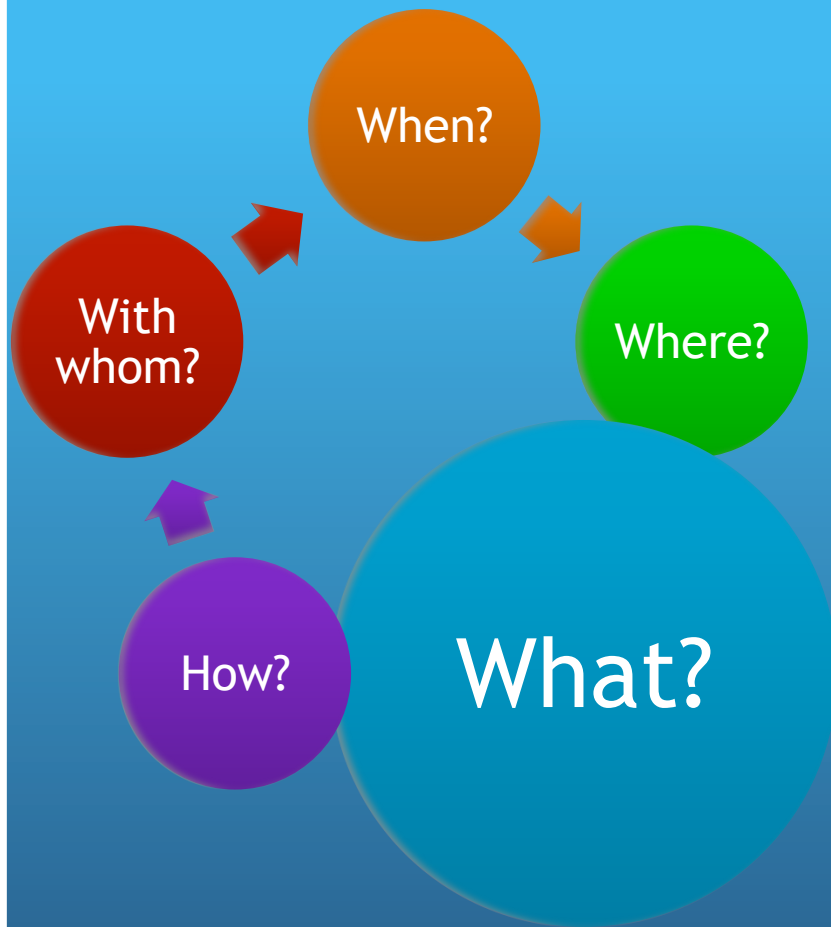
- No exact “right” time
- Gradual unfolding better than one big explanation
- Follow child’s questions
- On the way to appointments - explain why
- Hidden information may be confusing and children may come to their own (often incorrect) conclusions

Sharing medical information with your child...



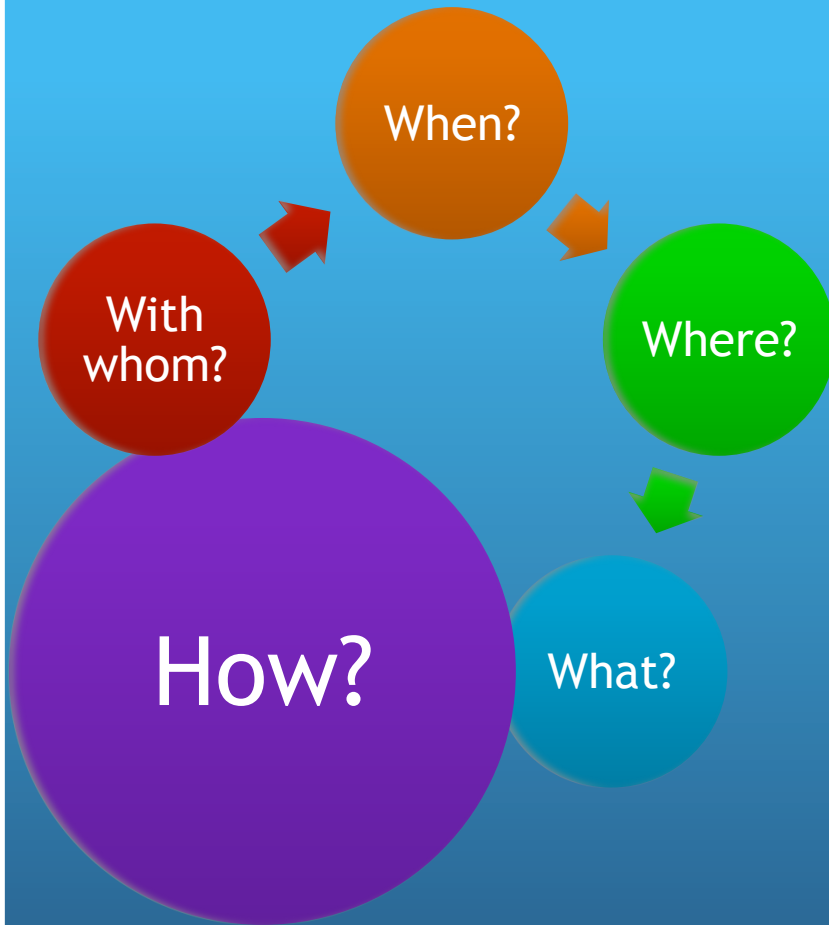
- Anywhere - spontaneous unfolding
- For planned discussions
 - Minimize distractions
 - Comfortable setting
- Avoid delaying while awaiting the “perfect” spot to discuss

Sharing medical information with your child...



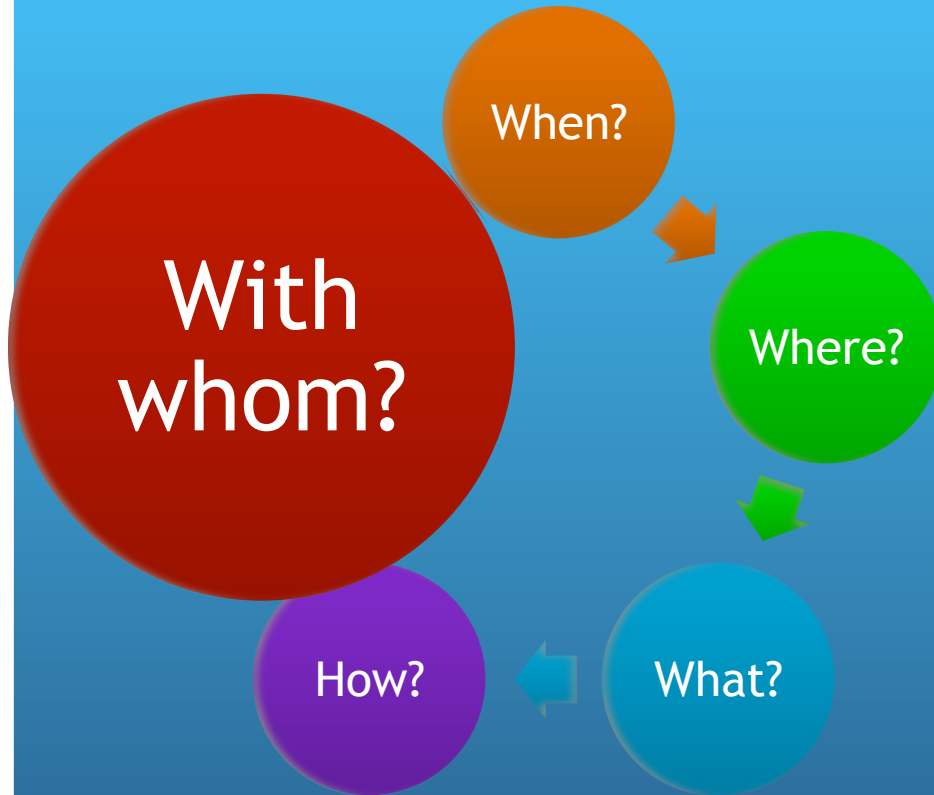
- Identify your child's strengths and areas that are challenging
- Discuss strengths and weaknesses of other family members
- Child's developmental level
- Be sure to answer questions child has asked
- Write down key points ahead of time
- Decide key wording to use
- www.kidshealth.org

Sharing medical information with your child...



- Keep it positive
- Give opportunity for discussion
- Expect follow up questions, keep dialogue open
- Information can be conveyed in ways other than words

Sharing medical information with your child...



- Parents, guardians
- Discuss with siblings separately from first discussion with child
- Consider discussion with therapists, doctors, teachers, babysitters, neighbors, classmates, etc.
- Consider creative ways to communicate with strangers

Using a Strengths Based Approach

- Everyone has strengths and weaknesses
- What are things you are good at? What comes easily?
- What are your challenges or barriers? What is harder for you?
- Use child's words or examples if appropriate

Now, let's put this into action!



Self-Determination

- All individuals have a right to direct their own lives
- Key components:
 - **Autonomy** = Person acts according to his/her own preferences, interests, or abilities
 - **Self-regulated** = Person creates a plan of action and makes changes in this when necessary
 - **Psychologically empowered** = Person speaks up for him or herself
 - **Self-realized** = Person knows what supports are needed for success and knows how to evaluate outcomes

Research on Self-Determination

- Supports the benefits of self-determination
- Wehmeyer and Schwartz (1997)
 - Studied 80 students ages 17-22 years old with cognitive or learning impairments
 - Collected data about student's self-determination prior to high school exit
 - Nearly one year later those with higher self-determination scores were more likely to be employed, earn more, have a checking and savings account, and have a desire to move out of the parents' house

Promoting Self-Determination

- Real-world experience
- Taking risks, making mistakes, and reflecting on those mistakes
- Youths need to know themselves
 - Open and supportive discussion about child's medical/developmental issues
 - Understand how these might affect learning, relationships, employment, and need for supports
- Caregivers must be open to new possibilities and take seriously youths' dreams for the future

Promoting Self-Determination

- Adolescents can prepare for IEP meeting
 - Short list of strengths and what they want to work on
 - Goals for the upcoming year
 - Goals for after school ends
- Specific teaching of self-determination through curriculum
- Hold high expectations and expect some failures as part of the learning process

Common Concurrent Conditions

Increased risk in many developmental disorders, like autism...

- Worldwide population prevalence 1%
- >70% have concurrent conditions
- What you experience regularly may not seem to be a problem

Concurrent Conditions - Autism

- Intellectual disability 45%
- Language disorders (variable definitions)
- ADHD 28-44%
- Tic disorders 14-38% (6.5% Tourette's)
- Motor abnormality 70%
- Epilepsy 8-30%
- Sleep disorders 50-80%
- Anxiety 42-56%
- Depression 12-70%

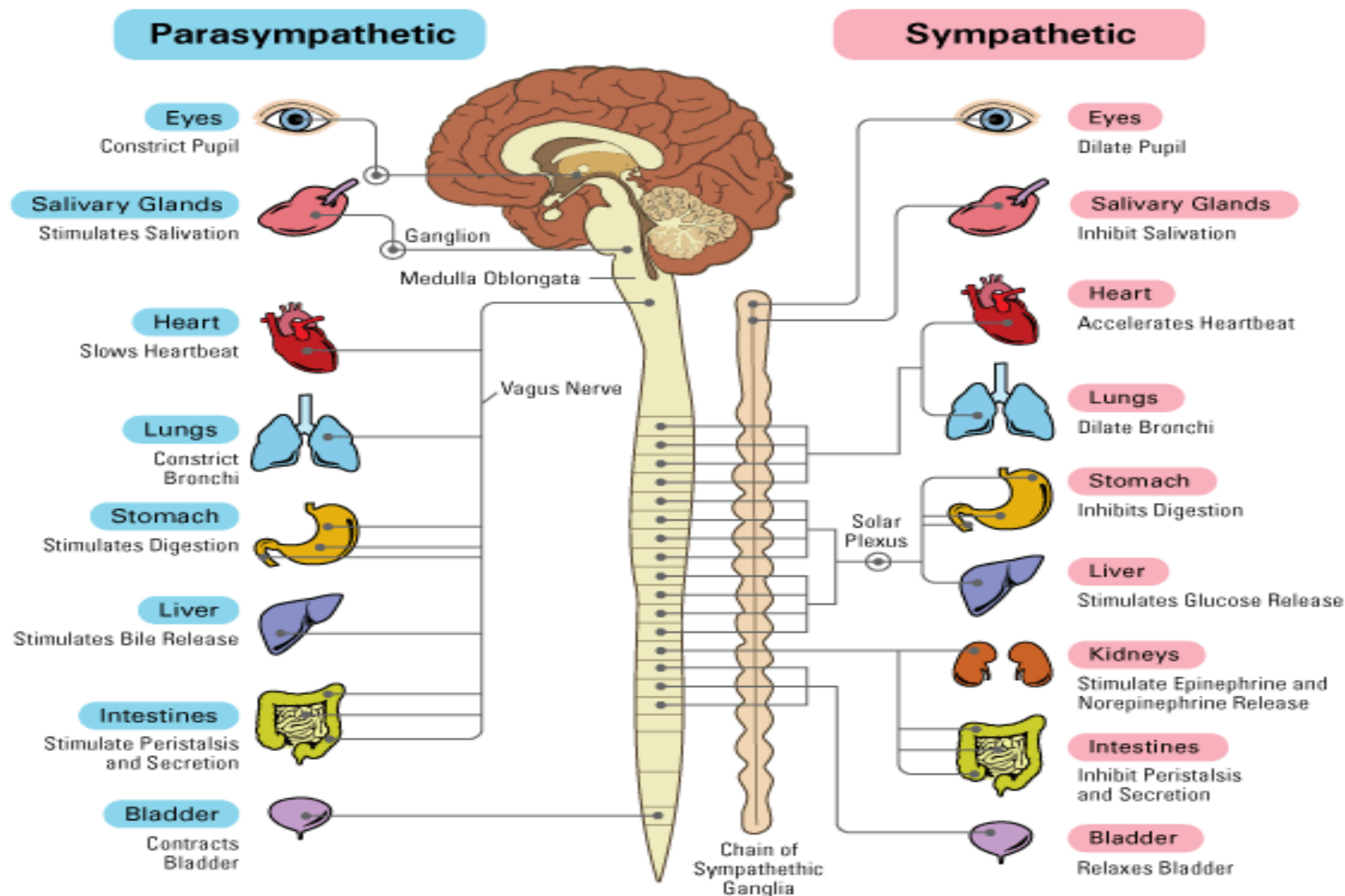
Concurrent Conditions - Autism

- Obsessive-compulsive disorder 7-24%
- Psychotic disorders 12-17%
- Substance abuse 16%
- Oppositional defiant disorder 16-28%
- Eating disorders 4-5%
- Aggression <68%; self injury <50%; pica 36%; suicide ideation/attempt 11-14%

What is Anxiety?

- Anxiety is a sense of uneasiness, worry, fear, or dread about what's about to happen or what might happen
- Natural human reaction that involves mind and body
 - Live preserving at the appropriate level
 - Limiting when excessive
- Fight or flight response (parasympathetic and sympathetic nervous systems)

Schema Explaining How Parasympathetic and Sympathetic Nervous Systems Regulate Functioning Organs



Common Childhood Fears

Age Range	Fear
Infant/Toddler	Loud noises, strangers, dark, large objects, separation
Preschool	Separation, dark, monsters and ghosts, animals, storms
School Age	<i>Bodily injury and death, school performance,</i> natural disasters and storms
Adolescent	<i>Social situations, school performance, health,</i> public speaking

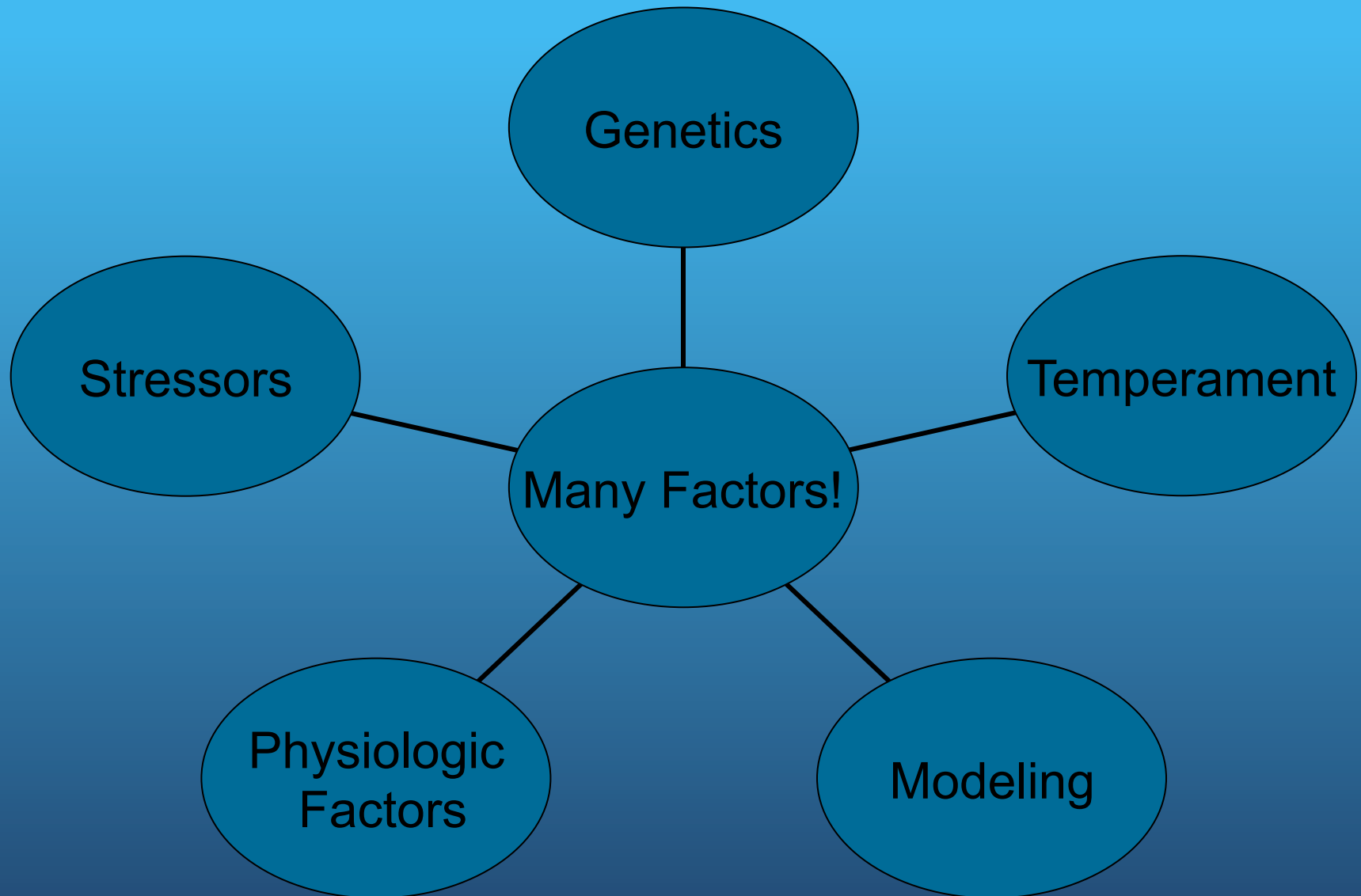
When is Anxiety a Disorder?

- Fears, worries, or anxiety occur outside the range of normal developmental responses
- Responses are extreme
- Cause significant distress or impairment in functioning (school, home, or social settings)
- Fear response is no longer adaptive

How Common are Anxiety Disorders?

- Most common psychiatric disorders in children and adolescents
- 8-10%
- More common in females
- More common in people with medical illnesses, ADHD, learning problems

What Causes Anxiety Disorders?



What do Anxiety Disorders Look Like in Children?

- May occur in specific situations or be generalized
- Stomachaches, nausea, headaches
- Avoidance
- Tantrums, aggression, irritability
- Crying, trembling
- Frequent seeking of reassurance
- Poor concentration, sleep, appetite

Different Types of Anxiety Disorders

- Generalized Anxiety Disorder
- Phobias
- Social Anxiety
- Separation Disorders
- Obsessive Compulsive Disorder
- Panic Attacks
- Posttraumatic Stress Disorder

Treatment

- Therapy/Behavioral Interventions
 - Cognitive-behavioral therapy
 - Accommodations in home and school
- Medications
 - SSRIs
 - Benzodiazepines

Cognitive Behavioral Therapy

- Specific # of treatment sessions with therapist
- Homework often given in between sessions
- Components of therapy:
 - Recognizing mind and body reactions to anxiety
 - Changing thoughts in anxiety producing situations
 - Developing a coping plan
 - Evaluating performance and administering self-reinforcement as appropriate

Accommodations for Anxiety

- Help child recall past instances of anxiety that she has successfully overcome
- Dispel myths about feared situation
- Provide accurate information to remove uncertainty and “unknowns”
- Coach in positive self-talk: “I’ve done it before. I can do it again.”

Accommodations for Anxiety

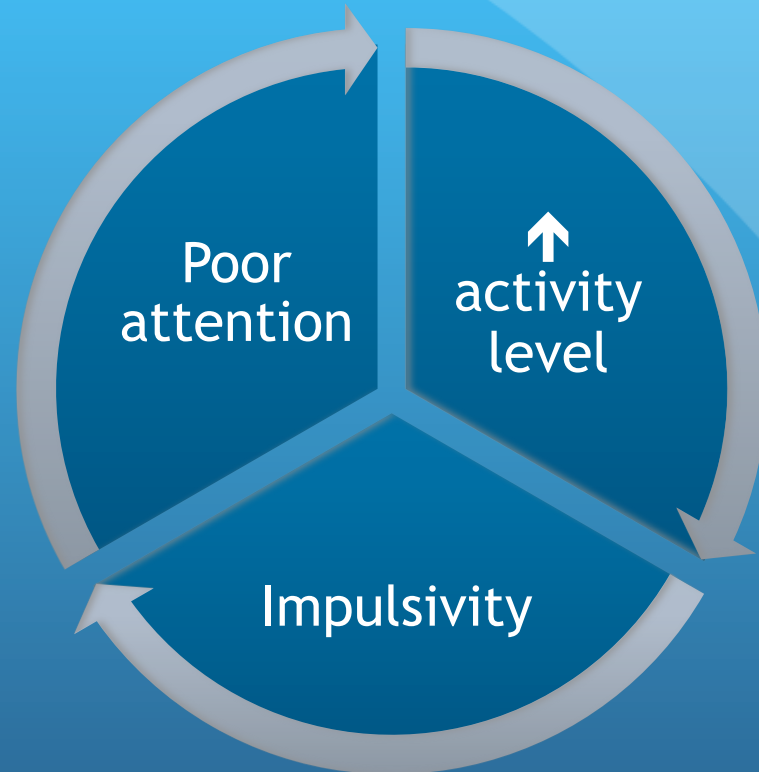
- Have an organized, predictable routine
- Foster tolerance and acceptance
- Normalize and model imperfection
- Teach child to estimate the realistic probabilities of bad outcomes
- Teach to examine worst consequences of making a mistake

Medications for Anxiety

- Selective Serotonin Reuptake Inhibitors (SSRIs)
 - Prozac, Celexa, Zoloft, Luvox, Lexapro, Paxil
 - Take several weeks to work
 - Black box warning for increased suicidal thoughts/activation
 - Can be very effective
- Benzodiazepines
 - Xanax, Klonopin, Ativan
 - Work quickly
 - Used for short term or specific events

Attention Deficit Hyperactivity Disorder (ADHD)

- More difficulty than expected for child's developmental level
- Occurs in multiple settings & causes problems



ADHD = Brain-based disorder



- 8% of school aged kids
- Impacts family life, friendships, learning

Treatment of ADHD

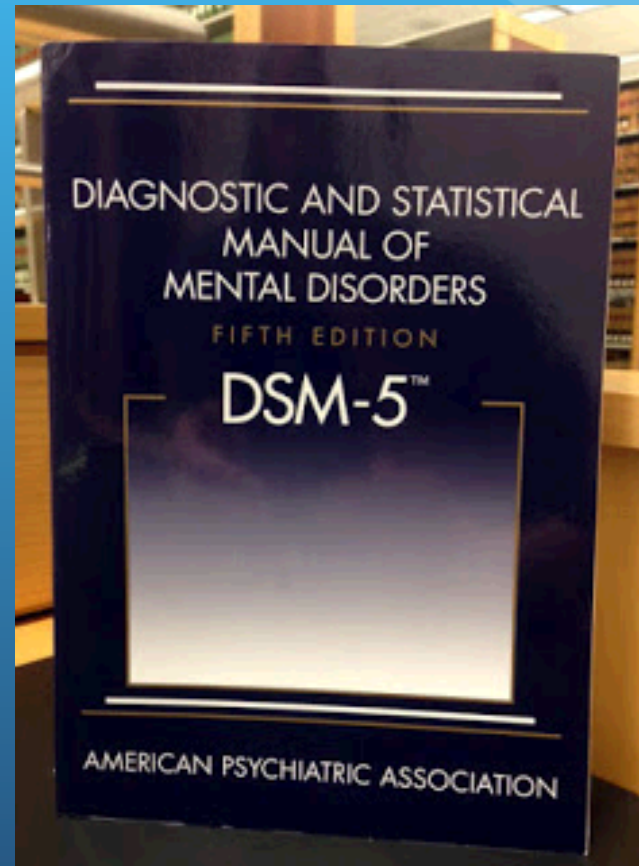
- For school aged children, American Academy of Pediatrics recommends trial of stimulant medication + behavioral therapy
- Goal is to find medication that helps WITHOUT significant side effects
- Behavioral accommodations for home and school

Autism Spectrum Disorders (ASDs)

- Difficulty with social and communication skills with repetitive, restricted behaviors
- ASDs are diagnosed clinically
- Diagnostic and Statistical Manual of Mental Disorders (DSM)

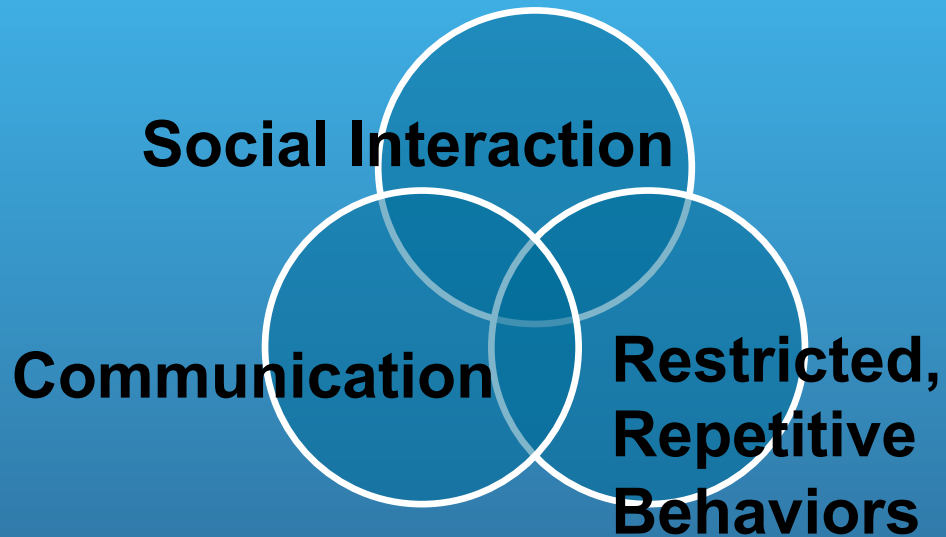
Autism Spectrum Disorders

- Diagnostic criteria changed with release of new DSM-5
- Media coverage
- What do the changes mean?



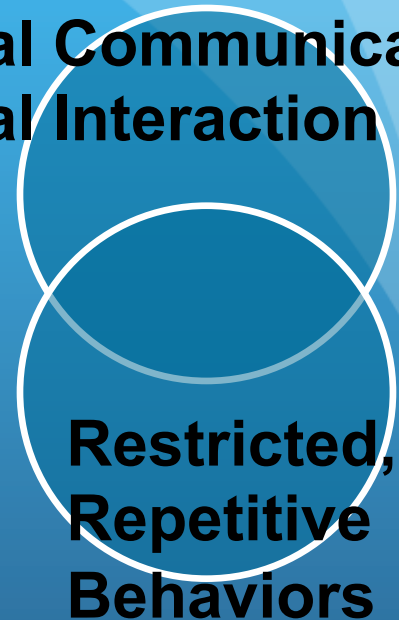
The Changing Criteria

DSM-IV-TR



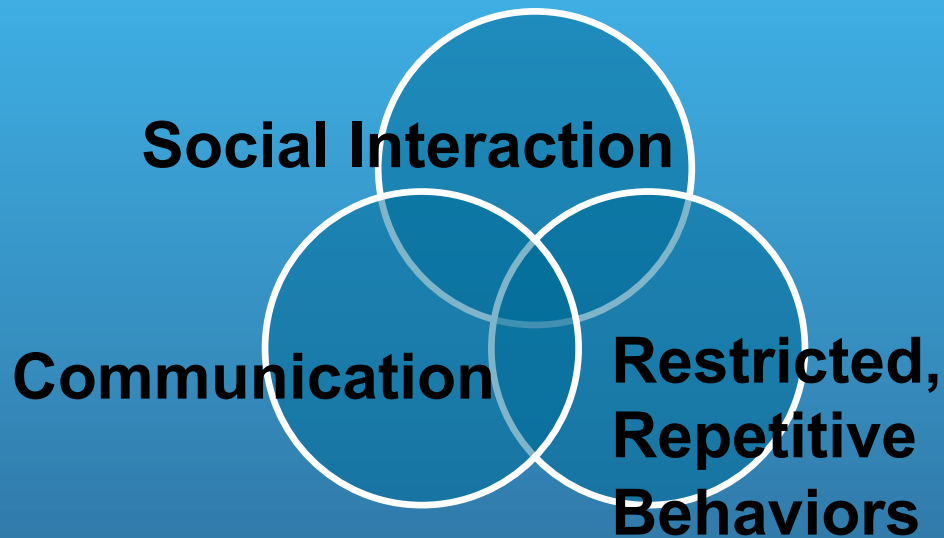
DSM-5

**Social Communication/
Social Interaction**



The Changing Criteria

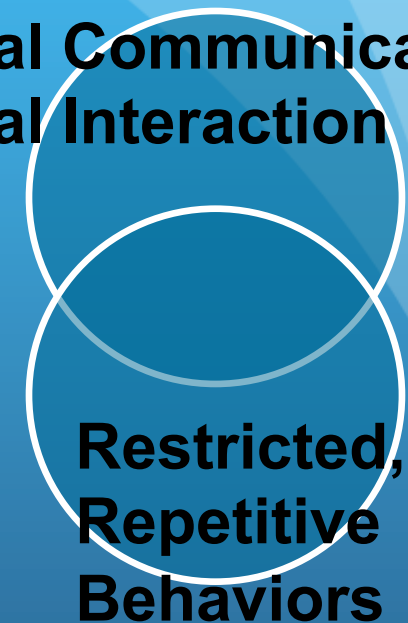
DSM-IV-TR



- ✓ Autistic Disorder
- ✓ Pervasive Developmental Disorder, not otherwise specified (PDD-NOS)
- ✓ Asperger's Disorder
- ✓ Rett Syndrome
- ✓ Childhood Disintegrative Disorder

DSM-5

**Social Communication/
Social Interaction**



- ✓ Autism Spectrum Disorder

Implications of These Changes

- Fewer children may be diagnosed with autism spectrum disorders
- Children who previously would have had PDD-NOS and young children may be less likely to get diagnosis
- More research needed to see how this influences prevalence rates

Thanks for your participation
today!

