2013 BCBA Conference

Arizona Association for Behavior Analysis

Arizona Autism Coalition

November 9, 2013

Disability Empowerment Center

5025 E. Washington Street

Phoenix, AZ 852034

southwest human development

Everything you wanted to ask a Developmental Pediatrician (almost)

Daniel B. Kessler, MD, FAAP

Medical Director, Children's Developmental Center

Easter Seals Southwest Human Development

Daniel B. Kessler MD and Associates

Developmental and Behavioral Pediatrics

Clinical Professor of Pediatrics

University of Arizona College of Medicine

Phoenix, AZ

Easter Seals DISABILITY SERVICES

southwest human development

Everything you wanted to ask…? almost

- What is a Developmental and Behavioral Pediatrician?
- How is that different from a child psychiatrist or child psychologist?
- What kinds of kids or situations would a DBP evaluate?
  - What ages?
  - In what kinds of settings?
- How do I evaluate kids?

Easter Seals DISABILITY SERVICES

southwest human development

What is a Developmental Pediatrician?

- Developmental Pediatrics?
  - Developmental and Behavioral Pediatrics
    - Specialty "sub-board" under the American Board of Pediatrics
      - Developmental-behavioral pediatricians are Medical Doctors (MDs or DOs)
      - 4 years of medical school
      - 3 years of residency training in pediatrics
      - Board Certification in Pediatrics
      - Additional subspecialty training in developmental-behavioral pediatrics
    - A pediatric "specialist" like a pediatric cardiologist or pediatric dermatologist
    - Board Certified—must sit for and pass a subspecialty examination
      - Must meet other specified requirements (maintenance of certification)
      - In 2002 the American Board of Pediatrics began certifying DBPs via a comprehensive examination
  - "A pediatrician who specializes in developmental and behavioral pediatrics possesses skills, training and experience to foster understanding and promotion of optimal development of children and families through research, education, clinical care and advocacy efforts. The physician assists in the prevention, diagnosis and management of developmental difficulties and problematic behaviors in children and in the family dysfunctions that compromise children's development."

Easter Seals DISABILITY SERVICES

southwest human development

What is a Developmental Pediatrician?

- Developmental Pediatrics?
  - Neurodevelopmental Pediatrics
    - Specialty "sub-board" under the American Board of Neurology and Psychiatry
    - A specialist in pediatric neurology and developmental disabilities
    - Board Certified—must sit for and pass a subspecialty examination
      - Must meet other specified requirements (maintenance of certification)
    - A Pediatrician or Neurologist who focuses on the evaluation and treatment of chronic conditions that affect the developing and mature nervous system such as cerebral palsy, mental retardation and chronic behavioral syndromes and neurologic conditions
    - In practice and in training the two specialties do overlap somewhat
    - Many academic medical centers and training programs have programs in both areas of specialization
    - Providers tend to practice in the areas in which they trained, but not always

What is a Child Psychologist?

- A psychologist is an expert in the study of human behavior. A child psychologist specializes in understanding thought processes and actions of children and interpreting them to guide appropriate mental health treatment. A child psychologist needs a master's degree or doctoral degree with emphasis and additional training in children's mental health. State licensing is also required.
- Routine duties include assessment and treatment recommendations for children and teens. The process typically involves a number of mental health tests as well as interviews with the child, and parents. The psychologist must figure out whether the child has mental health problems significant enough to fit the criteria for diagnosis. Depression, anxiety, and ADHD are some of the common disorders child psychologists encounter (among others).
- A child psychologist cannot prescribe medications in this State

Easter Seals DISABILITY SERVICES

southwest human development

What is a Child and Adolescent Psychiatrist?

- The child and adolescent psychiatrist is a physician who specializes in the diagnosis and treatment of disorders of thinking, feeling and/or behavior affecting children, adolescents, and their families.
- Child and adolescent psychiatric training requires four years of medical school, a least three years of approved residency training in medicine, neurology, and general psychiatry with adults and two years of additional specialized training in psychiatric work with children, adolescents and their families in an accredited residency in child and adolescent psychiatry.
- Initially a comprehensive diagnostic examination is performed to evaluate the current problem with attention to its physical, genetic, developmental, emotional, cognitive, educational, family, peer, and social components. The child and adolescent psychiatrist arrives at a diagnosis and diagnostic formulation, shares it with the child and family then designs a treatment plan.

http://www.aacap.org

Easter Seals DISABILITY SERVICES

southwest human development

What is a Developmental Pediatrician?

- What kinds of kids or situations would a DBP evaluate?
  - It depends on their training and experience as well as where and how they are practicing (hospital based team, clinic, private practice, etc) but in general a DBP will see kids birth to 21 years with :
    - Learning disorders including dyslexia, writing difficulties, math disorders, and other school related learning problems
    - Attention and behavioral disorders including ADHD and associated conditions including oppositional-defiant behavior, conduct problems, depression and anxiety disorders
    - ***Autism and autistic spectrum disorders***
    - Tics, Tourette's Syndrome and other habit disorders
    - Regulatory disorders including sleep disorders, feeding problems, discipline difficulties, complicated toilet training issues, enuresis (bedwetting) and encopresis (soiling)
    - Delayed development in speech, language, motor skills , and thinking ability
    - Developmental and behavioral problems complicating the full range of pediatric chronic illnesses and disabling conditions
    - Developmental disabilities

Easter Seals DISABILITY SERVICES

southwest human development

What about Autism?

May 2002

May 2006

Easter Seals DISABILITY SERVICES

southwest human development

Autism: The Good The Bad and The Ugly

- **The Good**
  - We've come a long way baby!
    - More interest, more money, more research
    - The hope for better insurance coverage for what works
- **The Bad**
  - We aren't there yet
  - We still don't really know what autism is
    - The autistic spectrum vs the "autisms"
  - We don't know what causes autism(s)
- **The Ugly**
  - DSM-5?

Easter Seals DISABILITY SERVICES

southwest human development

The History of Autism

Expansion and Contraction?

- 1943
  - Leo Kanner publishes a description of 11 children who shared high intelligence, a profound preference for being alone and an "obsessive insistence on the preservation of sameness."
- 1950's -60's
  - Autism was thought to be a form of childhood schizophrenia
  - Psychoanalysts linked autism to emotionally distant mothering (the "refrigerator mother")
- 1970's
  - Autism understood as a brain based/biological disorder of development
- 1980
  - DSM-III distinguishes autism from childhood schizophrenia
  - Individuals had to meet all listed diagnostic criteria

www.autismspeaks.org/science/science-news/autism-70--kanner-dsm-5

The History of Autism

- 1987
  - DSM-III-R introduces a checklist of criteria for autism; a subset could be applied for diagnosis
- 1994-2000
  - DSM-IV and DSM-IV-TR further expand the definition of autism with Asperger Syndrome added in 1994
    - Minimum of 6 behavioral criteria; two from social impairment, one from communication and one from RRBs
    - Onset prior to three years
- 2013
  - DSM-5 folds all autism sub-categories into one spectrum diagnosis—the autism spectrum disorder
    - Does not require a delay in communication skills but adds sensory challenges
    - Onset in childhood (~ 8 years)
    - Goes from requiring 6 of 12 behaviors to requiring 5 of 7 behaviors
    - Identifies a new disorder called Social (Pragmatic) Communication Disorder

www.autismspeaks.org/science/science-news/autism-70--kanner-dsm-5

DSM-IV and DSM-IV-TR: Why not?

- Expanding definition provided greater access to services but made it difficult to determine the kinds of therapies (and how much) were needed
  - "If you meet one child with autism you have met one child with autism"
    - Estimated number of symptom combinations in the DSM-IV: 2,077
- Experts differed on how they interpreted DSM-IV criteria
  - Though standardized assessments provided reliable data
  - Patterns of diagnosis were identifiable according to regional sites, with factors such as verbal IQ and language level influencing the process of diagnostic "labeling"
  - Asperger's Disorder is hard to distinguish from HFA because accurately measuring language delays retrospectively is a challenge
    - Language delay may have little role in adult outcomes
- DSM-IV criteria were faulted with how well they diagnose autism in children less than 5 years, adolescents, females and ethnic minority groups

Easter Seals DISABILITY SERVICES

southwest human development

DSM-5: Why?

- While DSM-5 will not directly solve this problem the new criteria are felt to represent a move toward a more rigorous definition of autism.
- The American Psychiatric Association's stated goals for the changes in diagnostic criteria are
  - "to accurately and completely identify" individuals with autism by production of reliable and valid diagnostic criteria
  - in order to offer a clearer, simpler, more reliable diagnostic scheme and recognize "the essential shared features of the autism spectrum"
    - The changes were meant to increase specificity and reduce false positive cases

DSM-5: Why?

- The goal was to streamline the diagnosis, create a more homogenous diagnostic group to aid in future research along genetic and biological pathways
- The concern on the part of parents and providers is whether or not the new diagnostic category will lead to a loss of services and fewer children being eligible
  - Studies indicate that individuals diagnosed with Asperger Syndrome or PDD-NOS, those with higher IQ, and females with the disorder may be at the most risk of under diagnosis under DSM-5
  - Will individuals with an established DSM-IV diagnosis require re-evaluation per the DSM-5 criteria?
  - Will insurance companies and educational systems continue to accept DSM-IV criteria for coverage?
  - What about Arizona? DDD?

DSM-5: Why?

- *"Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autistic spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder."*

DSM-5: American Psychiatric Association; 2013

Easter Seals DISABILITY SERVICES

southwest human development

Autistic spectrum disorder (299.00)

- What does the DSM-5 do to autism?
  - Changes the criteria for an autism diagnosis
    - This year's revision represents one of the most contentious because 'it reflects one of the central themes in the history of autism: a debate over where to set its boundaries.'
  - ***Autism at 70 — Redrawing the Boundaries***
    - Jeffrey P. Baker, M.D., Ph.D.
    - N Engl J Med 2013; 369:1089-1091September 19, 2013
      - DOI: 10.1056/NEJMp1306380

The NEW ENGLAND JOURNAL of MEDICINE

Easter Seals DISABILITY SERVICES

southwest human development

What does the DSM-5 do?

- Autism, Asperger's disorder and PDD-NOS will be combined into a single category—autistic spectrum disorder (299.00)
- Number of "domains" goes from 3 to 2
  - Combines domains for social and communication problems into one set of deficits that is labeled social communication and interactive problems
  - The domain of restricted, repetitive interests remains in DSM-5 but unusual sensory behaviors have been added
  - Characteristics can be present currently or by history

DSM-5: American Psychiatric Association; 2013

Easter Seals Disability Services

southwest human development

What does the DSM-V do?

- Social and communication deficits (all): Criterion A
  - Problems reciprocating social or emotional interaction
  - Non-verbal communication problems
  - Severe problems maintaining relationships
- Repetitive and Restrictive Behaviors (two of the following): Criterion B
  - Repetitive movements, use of objects or speech
  - Extreme adherence to routines and patterns and resistance to change in routines
  - Intense and restricted interests
  - Hyper- or hyporeactivity to sensory information or strong seeking or avoiding of sensory input

DSM-5: American Psychiatric Association; 2013

Easter Seals Disability Services

southwest human development

What does the DSM-V do?

- Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies later in life). (Criterion C)
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning (Criterion D)
- These disturbances are not better explained by intellectual disability or global developmental delay (Criterion E)
  - The two conditions often occur together
  - To consider the two co-morbid social communication should be below that expected for general developmental level

DSM-5: American Psychiatric Association; 2013

Easter Seals DISABILITY SERVICES

southwest human development

What does the DSM-V do?

- Recording Procedures: Specify if
  - With or without accompanying intellectual impairment
  - With or without accompanying language impairment
  - Associated with known medical or genetic condition or environmental factor
  - Associated with another neurodevelopmental, mental or behavioral disorder
  - With catatonia

DSM-5: American Psychiatric Association; 2013

Easter Seals Disability Services

southwest human development

What does the DSM-V do?

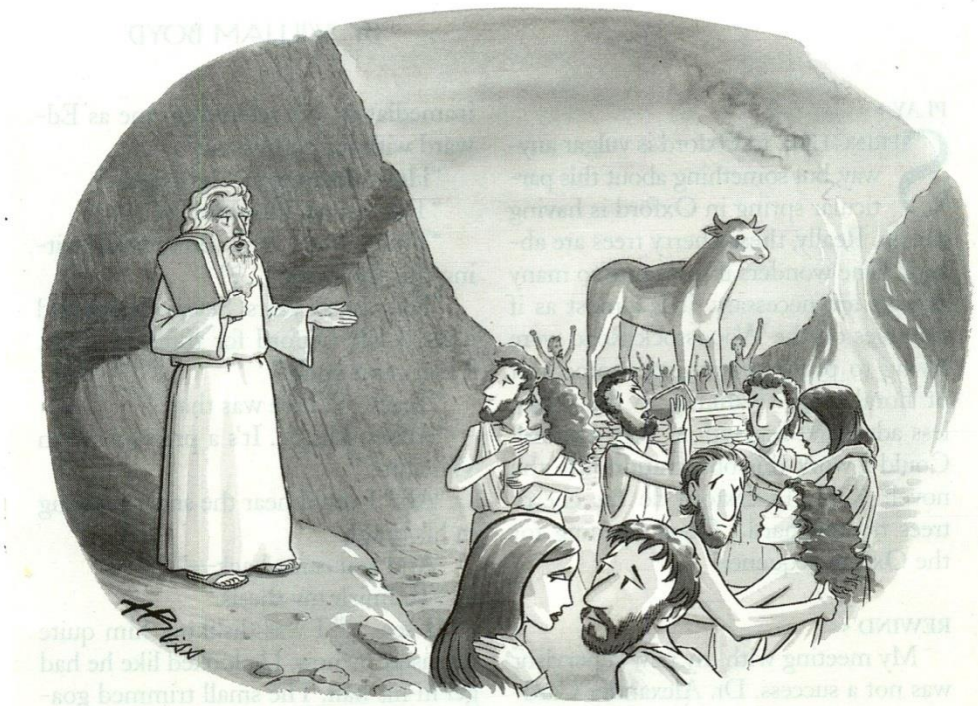
- Severity levels: for each domain (social communication and interaction and restricted repetitive behaviors) the clinician is asked to specify current severity
- Three levels are specified
  - Requiring very substantial support (Level 3)
  - Requiring substantial support (Level 2)
  - Requiring support (Level 1)
- Examples are provided for both SC and RRB
- "severity may vary by context and fluctuate over time."
- *"The descriptive severity categories should not be used to determine eligibility for and provision of services; these can only be developed at an individual level and through discussion of personal priorities and targets"*

DSM-5: American Psychiatric Association; 2013

Easter Seals DISABILITY SERVICES

southwest human development

DSM-5: What now?



"Well, actually, they are written in stone."

Easter Seals DISABILITY SERVICES

southwest human development

DSM-5: What now?

- Embrace the DSM-5; Then Transform It
  - Herb Pardes MD on AutismSpeaks.org
    - Wednesday May 22, 2013
      - Psychiatrist; Executive Vice Chairman Board of New York Presbyterian Hospital; Director NIMH; President American Psychiatric Association; Dean Columbia University College of Physicians and Surgeons; Member of the Board Autism Speaks
  - The DSM-5 still describes the limits of our knowledge
    - At present we can describe these conditions only by their symptoms and still struggling to understand their causes
  - Individuals with the same diagnosis may have differences in both symptoms and their underlying brain circuitry
  - While clusters of behaviors may be helpful for diagnosis we must focus our research efforts on the genetics and the other biological factors that cause brain disorders such as autism

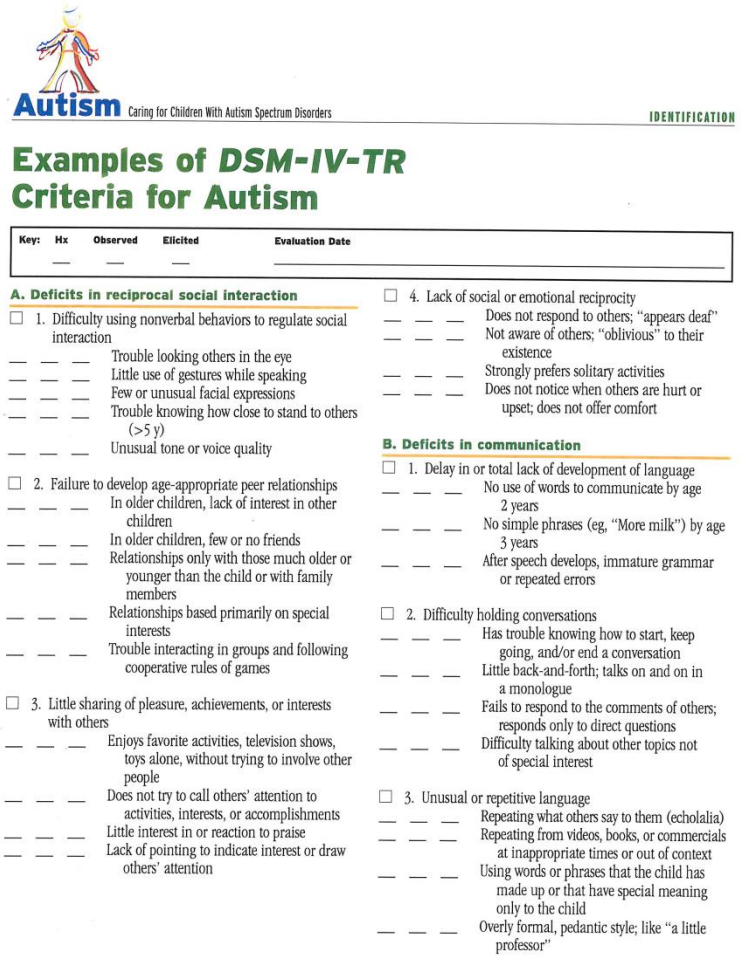
DSM-5: What now?

- Embrace the DSM-5; Then Transform It
- Question?
  - Are the criteria sensitive enough?
    - Will they pick up everyone with ASD?
  - Will clinicians be able to apply the new criteria better than the old?
    - The Devil is in the details…
      - Examples of characteristic behaviors are suggested in the criteria themselves (as a range) and additional descriptors are in the text
        - *"examples are illustrative, not exhaustive: see text."*
      - Will clinicians learn to identify them?
        - Not every child with autism doesn't have good eye contact

Easter Seals DISABILITY SERVICES

southwest human development

Behavioral Exemplars for DSM-IV



Autism Caring for Children With Autism Spectrum Disorders

IDENTIFICATION

Examples of *DSM-IV-TR* Criteria for Autism

Key:	Hx	Observed	Elicited	Evaluation Date
	—	—	—	

A. Deficits in reciprocal social interaction

☐ 1. Difficulty using nonverbal behaviors to regulate social interaction

— — — Trouble looking others in the eye
— — — Little use of gestures while speaking
— — — Few or unusual facial expressions
— — — Trouble knowing how close to stand to others (>5 y)
— — — Unusual tone or voice quality

☐ 2. Failure to develop age-appropriate peer relationships

— — — In older children, lack of interest in other children
— — — In older children, few or no friends
— — — Relationships only with those much older or younger than the child or with family members
— — — Relationships based primarily on special interests
— — — Trouble interacting in groups and following cooperative rules of games

☐ 3. Little sharing of pleasure, achievements, or interests with others

— — — Enjoys favorite activities, television shows, toys alone, without trying to involve other people
— — — Does not try to call others' attention to activities, interests, or accomplishments
— — — Little interest in or reaction to praise
— — — Lack of pointing to indicate interest or draw others' attention

☐ 4. Lack of social or emotional reciprocity

— — — Does not respond to others; "appears deaf"
— — — Not aware of others; "oblivious" to their existence
— — — Strongly prefers solitary activities
— — — Does not notice when others are hurt or upset; does not offer comfort

B. Deficits in communication

☐ 1. Delay in or total lack of development of language

— — — No use of words to communicate by age 2 years
— — — No simple phrases (eg, "More milk") by age 3 years
— — — After speech develops, immature grammar or repeated errors

☐ 2. Difficulty holding conversations

— — — Has trouble knowing how to start, keep going, and/or end a conversation
— — — Little back-and-forth; talks on and on in a monologue
— — — Fails to respond to the comments of others; responds only to direct questions
— — — Difficulty talking about other topics not of special interest

☐ 3. Unusual or repetitive language

— — — Repeating what others say to them (echolalia)
— — — Repeating from videos, books, or commercials at inappropriate times or out of context
— — — Using words or phrases that the child has made up or that have special meaning only to the child
— — — Overly formal, pedantic style; like "a little professor"

From: AAP. AUTISM: Caring for Children with Autism Spectrum Disorders; A Resource Toolkit for Clinicians, 2000

Easter Seals Disability Services

southwest human development

DSM-5: What now?

- Behavioral Exemplars
  - Criterion A1: Deficits in social emotional reciprocity, *ranging, for example from* abnormal social approach and failure of normal back-and-forth conversation; *to* reduced sharing of interests, emotions, or affect; *to* failure to initiate or respond to social interactions.
    - *From the text: Deficits in social-emotional reciprocity (i.e., the ability to engage with others and share thoughts and feelings) are clearly evident in young children with the disorder, who may show little or no initiation of social interaction and no sharing of emotions, along with reduced or absent initiation of others' behavior. What language exists is often one-sided, lacking in social reciprocity, and used to request or label rather than to comment, share feelings or converse. In adults…*

DSM-5: What now?

- Suggested Behavioral Exemplars: A1
  - Abnormal social approach
    - *Unusual social initiations (e.g., intrusive touching; licking of others)*
    - *Use of others as tools*
  - Failure of normal back and forth conversation
    - *Poor pragmatic/social use of language (e.g., does not clarify if not understood; does not provide background information)*
    - *Failure to respond when name called or when spoken directly to*
    - *Does not initiate conversation*
    - *One-sided conversations/monologues/tangential speech*
  - Reduced sharing of interests
    - *Doesn't share*
    - *Lack of showing, bringing, or pointing out objects of interest to others*
    - *Impairments in joint attention (initiating and responding)*

Laura Carpenter, PhD; February 2013; DSM-5 Autism Spectrum Disorder. Guidelines and Criteria Exemplars; assistance from Catherine Rice PhD and CDC Autism and Developmental Disorders Monitoring Project

Easter Seals DISABILITY SERVICES

southwest human development

DSM-V: What now?

- Suggested Behavioral Exemplars
  - Reduced sharing of emotions/affect
    - *Lack of responsive social smile (focus here is on the response to another person's smile)*
    - *Failure to share enjoyment, excitement, or achievement with others*
    - *Failure to respond to praise*
    - *Does not show pleasure in social interactions*
    - *Failure to offer comfort to others*
    - *Indifference/aversion to physical contact and affection*
  - Lack of initiation of social interaction
    - *Only initiates to get help; limited social interactions*
  - Poor social imitation
    - *Failure to engage in simple social games*

Laura Carpenter, PhD; February 2013; DSM-5 Autism Spectrum Disorder. Guidelines and Criteria Exemplars; assistance from Catherine Rice PhD and CDC Autism and Developmental Disorders Monitoring Project

Easter Seals DISABILITY SERVICES

southwest human development

DSM-V: What now?

- Suggested Guidelines for the DSM-V
  - One example of a specific criterion may not be sufficient to assign the criterion as being present
    - Is the example behavior clearly atypical?
    - Is the example behavior present across multiple contexts?
    - Distinguish between behaviors that are clearly atypical and present across multiple contexts and those that are on the borderline of being atypical or rarely occur/occur in only one context
  - Avoid using the exact same behavioral exemplar to satisfy two criteria
    - Repetitively putting hands over ears may satisfy the criteria for repetitive motor movement (B1) or it may represent an adverse reaction to sound (B4); it is up to the clinician to decide where the behavior is best represented

Laura Carpenter, PhD; February 2013; DSM-5 Autism Spectrum Disorder. Guidelines and Criteria Exemplars; assistance from Catherine Rice PhD and CDC Autism and Developmental Disorders Monitoring Project

What about Arizona?

- DES/DDD Update; June 2013
  - ***New Definitions for Autism are Coming***
    - **by Dr. Robert Klaehn**
    - After many years of work, the new descriptions for all mental health conditions are being released in May. Called "DSM-V," the 5th version of the "Diagnostic and Statistical Manual," includes new descriptions of autism…The old definitions in the "DSM-IV" split Autism Spectrum Disorders into several conditions such as Autism; Asperger's Disorder; and Pervasive Developmental Disorder, Not Otherwise Specified ("PDD-NOS"). ***Only Autism was covered by the Division. With DSM-V, all the old definitions go away. There will be only one diagnosis; Autism Spectrum Disorder (ASD) which will be covered by the Division. It is important to note that there must be serious problems with a child's ability to function in daily life plus a diagnosis of Autism Spectrum Disorder to be eligible for DDD services.***

Functional Impairment

- State Definitions: DES/DDD Policy and Procedure Manual
  - Chapter 500—Eligibility
    - 502.5.6 Substantial Functional Limitations: In addition to a diagnosis of cognitive disability, cerebral palsy, epilepsy, or autism before the age of 18, documentation must be available to verify substantial functional limitations, attributable to one of the diagnoses noted above, in at least three (3) of the major life activities defined below:
      a. Self Care

      A functional impairment regarding self care may apply when a person requires significant assistance in performing eating, hygiene, grooming or health care skills or when the time required for a person to perform these skills is so extraordinary as to impair the ability to retain employment or to conduct other activities of daily living.

      b. Receptive and Expressive Language
      c. Learning
      d. Mobility
      e. Self-Direction

Easter Seals Disability Services
southwest human development

Any Questions?