DSM -5: Continuing the Conversation

Brian Reichow, University of Conneticut
Laura Carpenter, Medical University of South Carolina
Pauline Filipek, University of Texas
Shannon Haworth, Virginia Commonwealth University

Rethinking Autism Spectrum Disorders: DSM-5

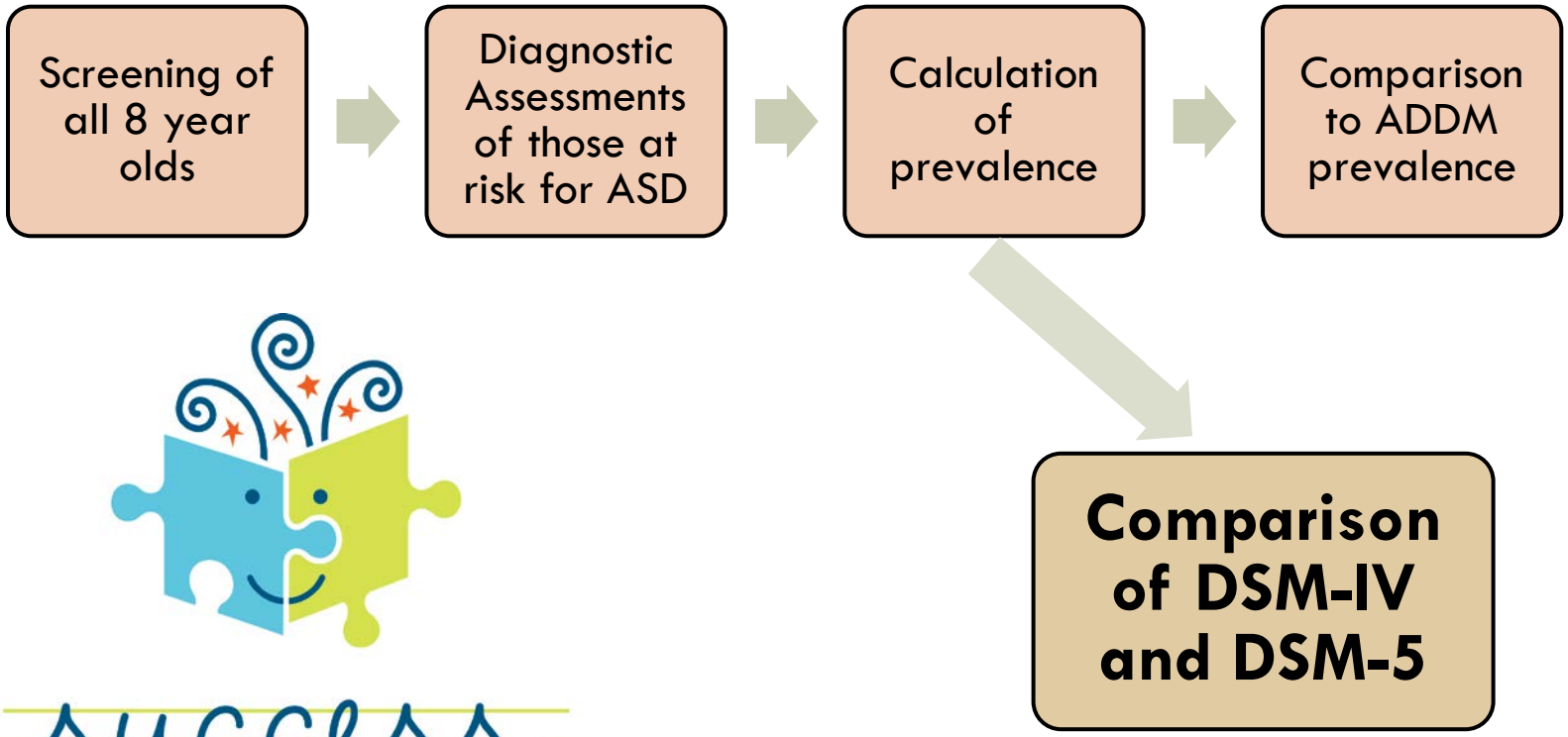
Laura Carpenter, PhD, BCBA

Associate Professor of Pediatrics

Division of Developmental and Behavioral Pediatrics

Medical University of South Carolina (MUSC)

Background: SUCCESS



success

South Carolina Children's Educational Surveillance Study

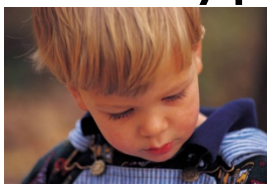
ASD Timeline

- **1943/1944:** Kanner & Asperger
- **1980:** DSM III
  - Infantile Autism
  - Childhood Onset Pervasive Developmental Disorder
- **1981:** Wing's translation of Asperger's Work
- **1987:** DSM III-R
  - Autistic Disorder
  - Pervasive Developmental Disorder Not Otherwise Specified
- **1994:** DSM-IV Pervasive Developmental Disorders
  - Autistic Disorder
  - Rett's Disorder
  - Childhood Disintegrative Disorder
  - Asperger's Disorder
  - Pervasive Developmental Disorder Not Otherwise Specified
- **2013:** DSM-5 Autism Spectrum Disorder

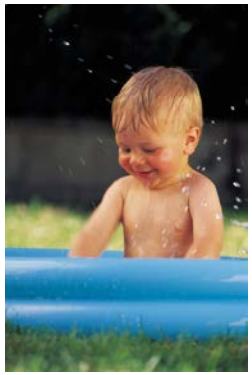
Why change?

Autism is a syndrome

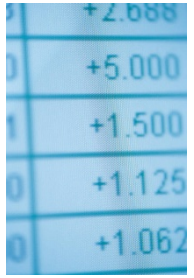
- A collection of symptoms that tend to occur together, typically without known cause



Observations of multiple patients



Statistical analyses of large databases



What do the data tell us?

- Restricted, repetitive behaviors specific to ASD
- Sensory issues specific to ASD
- Communication impairment not specific to ASD
- Problems with subtypes
  - not well distinguished in clinical practice
  - does not predict outcome
  - does not direct treatment

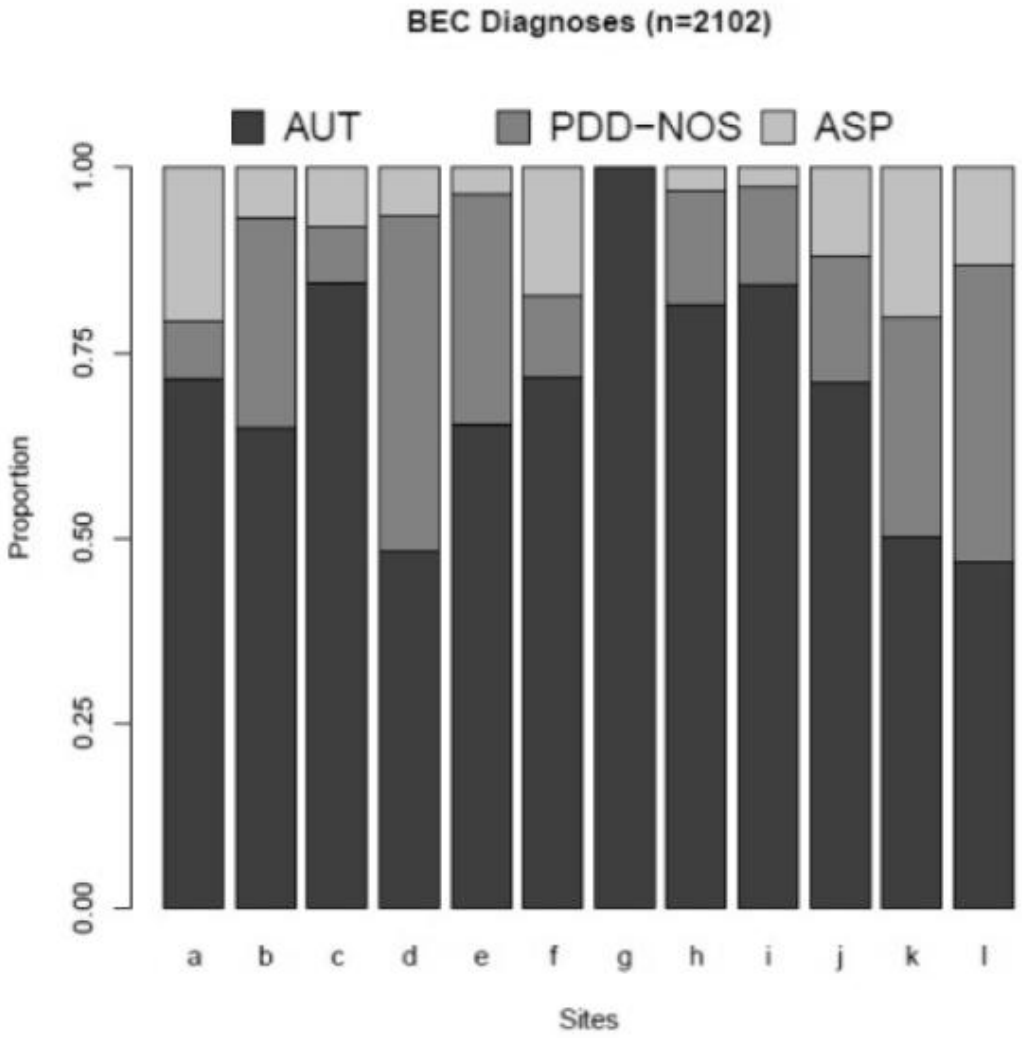
Autism vs. Asperger's vs. PDD-NOS

Lord et al., 2012 (Archives of General Psychiatry)

- Simons Simplex Collection
- 2,102 youth, ages 4-18
- Evaluated at university-based centers
- Completed ADOS, ADI-R, Cognitive, Adaptive
- Diagnosis → Best-Estimate Clinical (BEC) diagnosis according to DSM-IV-TR
  - Autistic Disorder
  - Asperger's Disorder
  - PDD-NOS

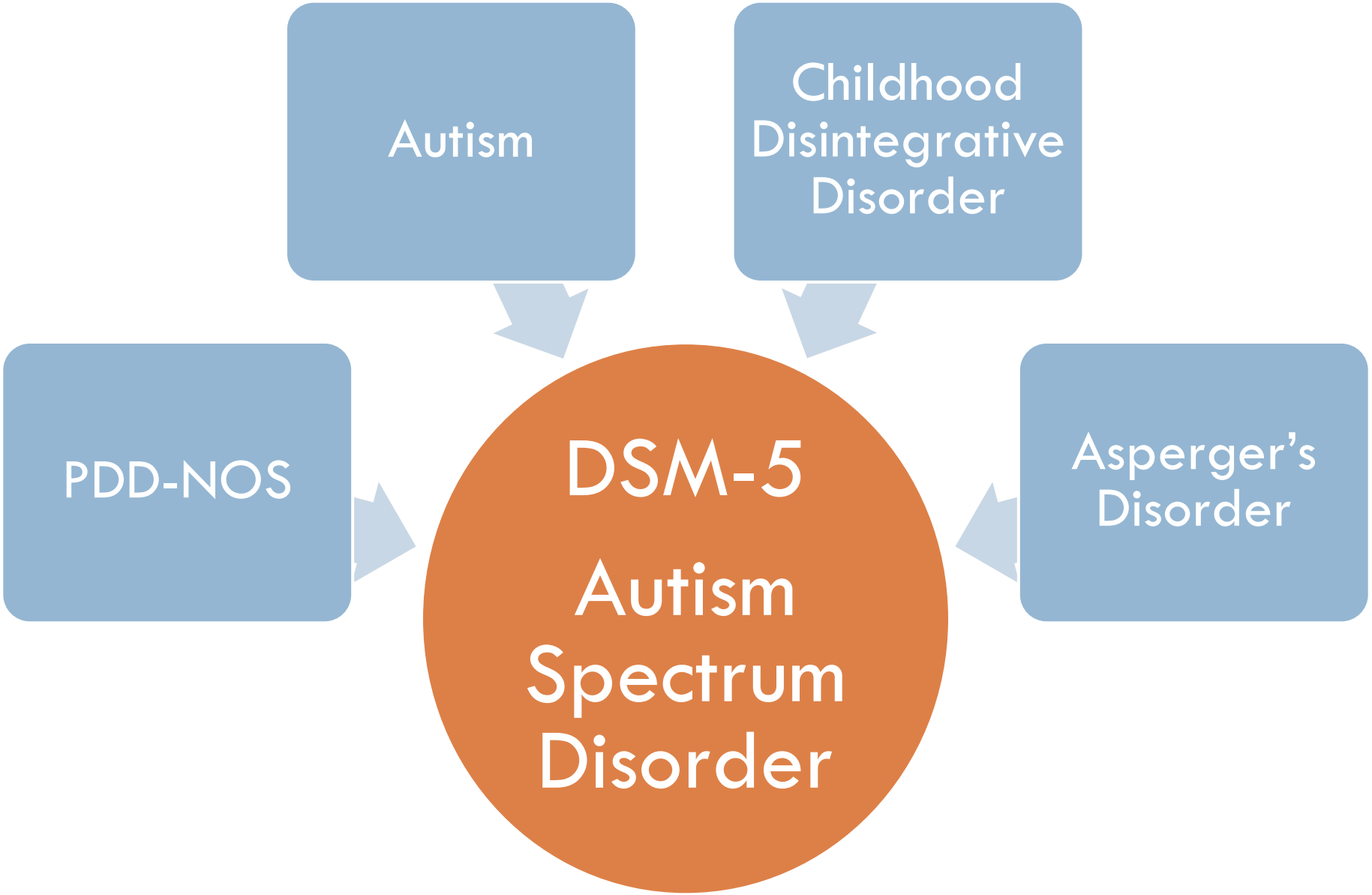
Autism vs. Asperger's vs. PDD-NOS

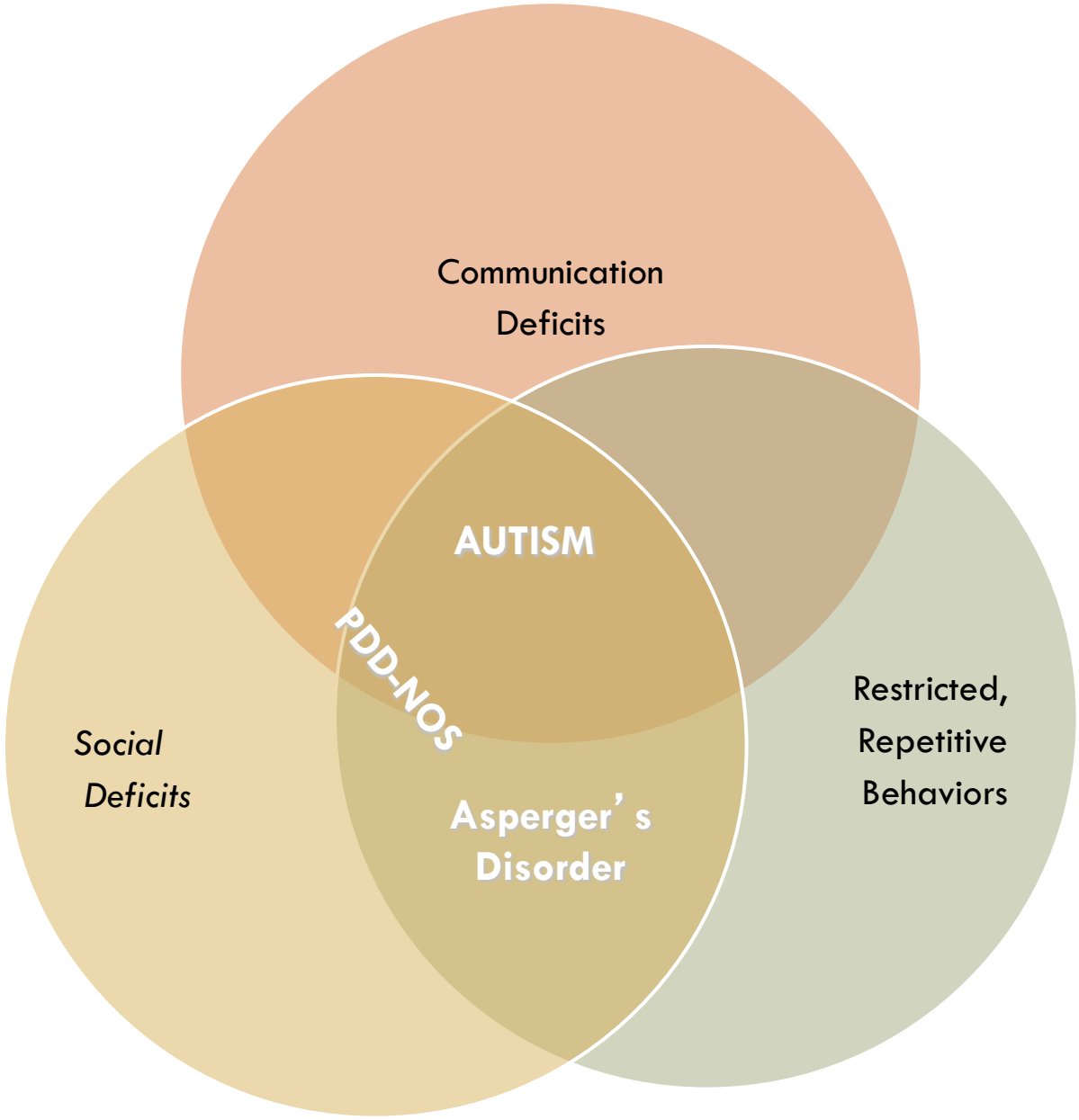
across 12 university-based clinics



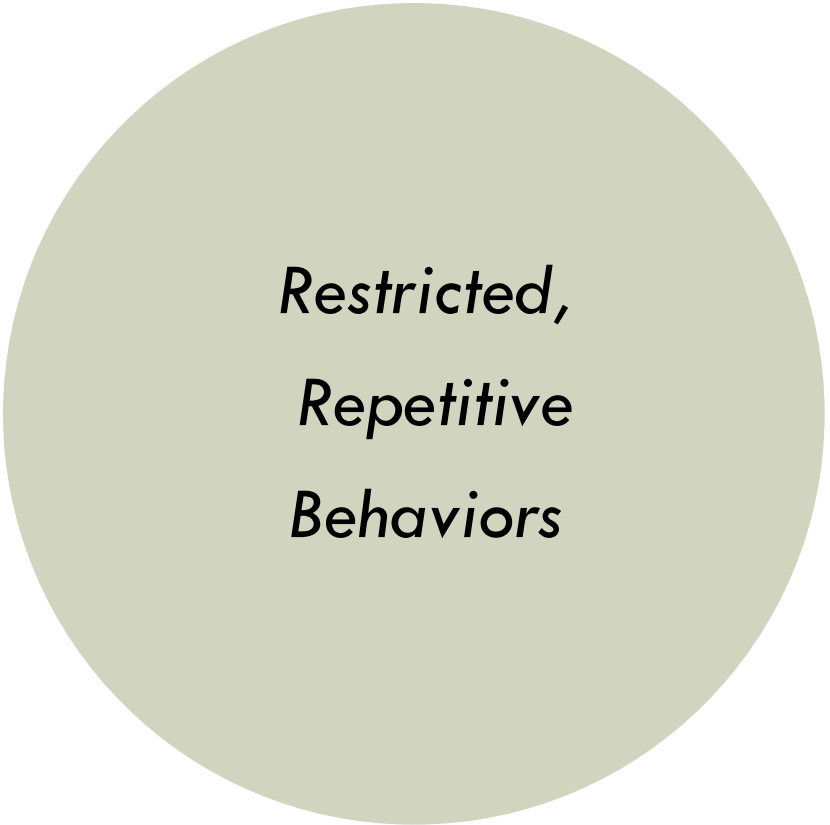
Other problems with the "old" definition

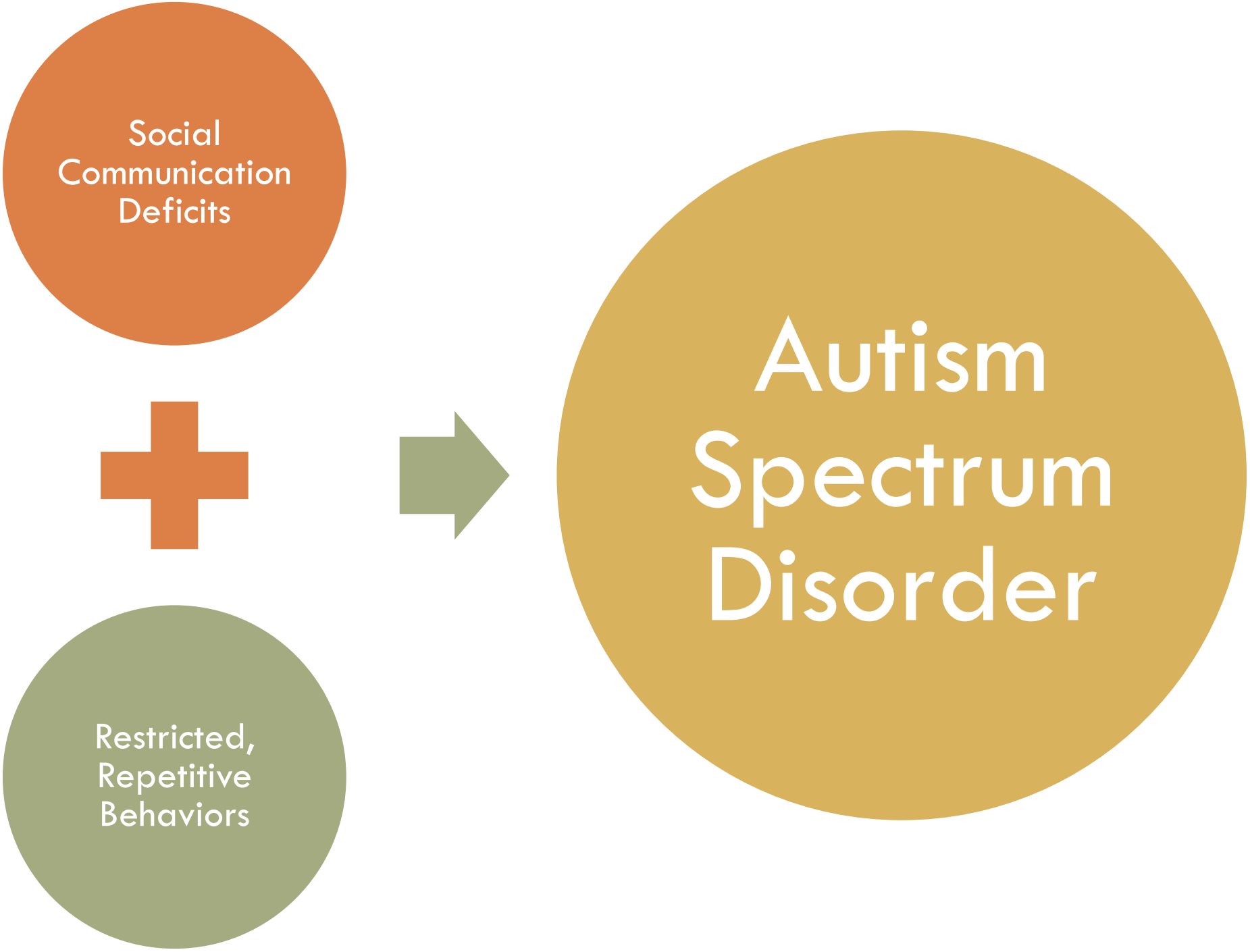
- Age of onset requirements too limiting
  - Older adolescents and adults
  - More mildly affected patients
  - Those adopted or in foster care
- Inconsistencies in definition of Asperger's Disorder made a "real" diagnosis nearly impossible
  - Requirement to rule out autism
  - Requirement of lack of delay in adaptive skills


Autism
Childhood Disintegrative Disorder
PDD-NOS
DSM-5 Autism Spectrum Disorder
Asperger's Disorder


Communication
Deficits
AUTISM
PDD-NOS
Social
Deficits
Asperger's
Disorder
Restricted,
Repetitive
Behaviors


Social
Communication
Deficits


Restricted,
Repetitive
Behaviors


Social Communication Deficits
Restricted, Repetitive Behaviors
Autism Spectrum Disorder

DSM-5: Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by **3 of 3 symptoms**

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by **at least 2 of 4 symptoms**

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning.

Social Communication (3 required)

1. Social-emotional reciprocity

2. Nonverbal communicative behaviors used for social interaction

3. Developing and maintaining relationships

Restricted Repetitive Behavior (2 of 4 required)

1. Repetitive speech, motor movements, or use of objects

3. Restricted interests

2. Routines, rituals, resistance to change

4. Hyper- or hypo-reactivity to sensory input

When is a “quirk” a sign of ASD?

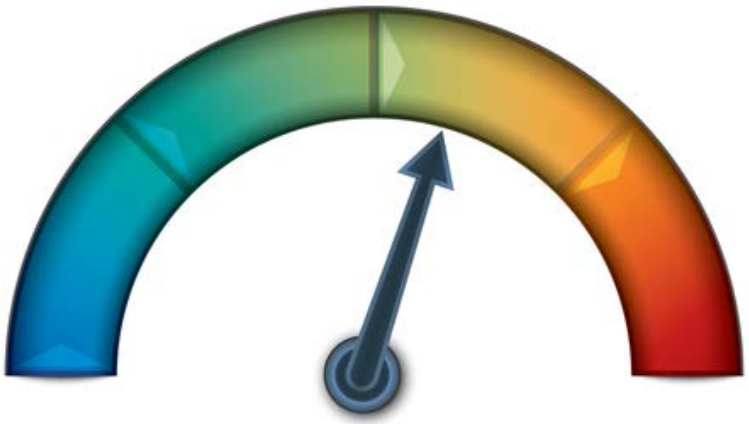
- Look at the full constellation of deficits
- Is the behavior clearly atypical?
- Is the behavior present across multiple contexts?

Severity Specifiers

Severity Level for ASD	Social Communication	Restricted interests & repetitive behaviors
Level 3 'Requiring very substantial support'	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.	Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.
Level 2 'Requiring substantial support'	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest.
Level 1 'Requiring support'	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Rituals and repetitive behaviors (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest.

Questions about severity

- Can it be reliably determined?
- Is it impacted by intellectual disability?
- How can we prevent severity from being used to determine access to services?

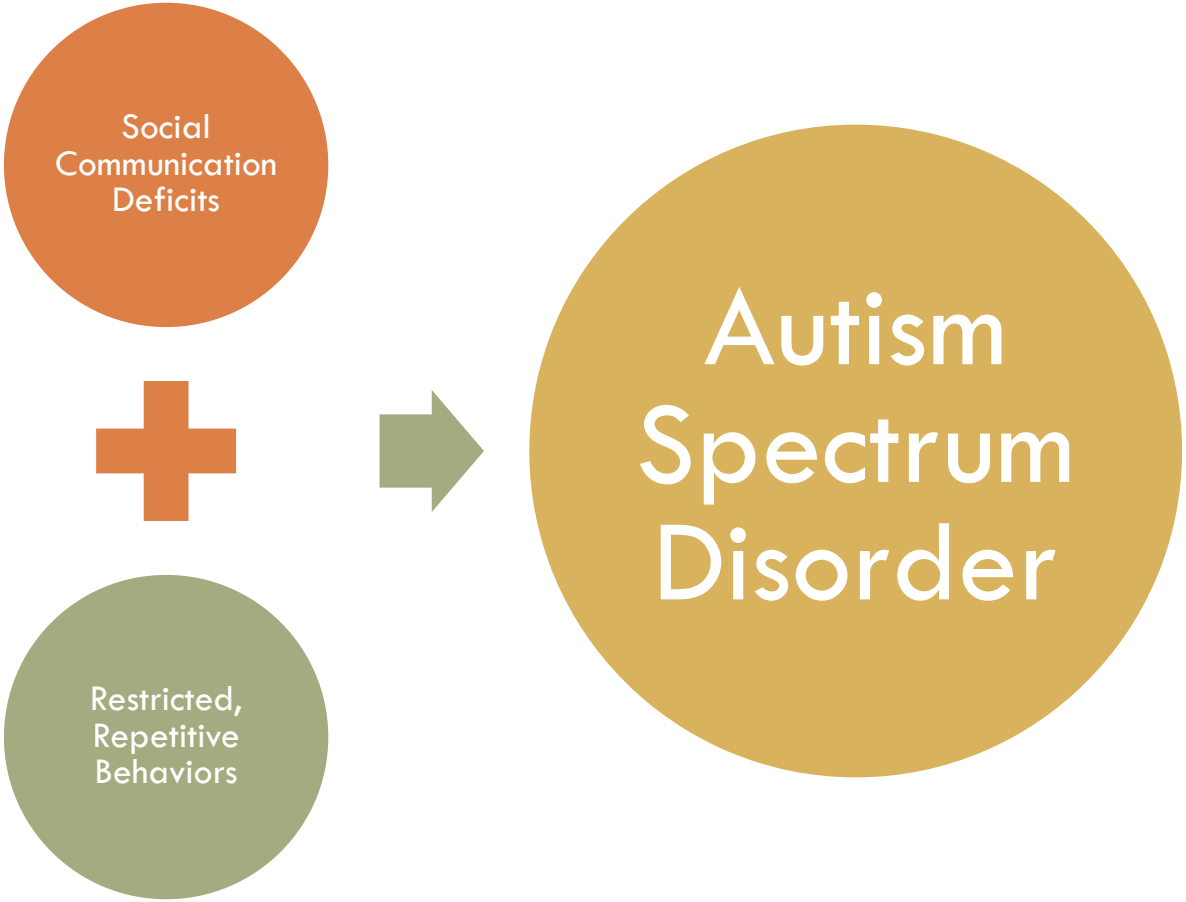


Will anyone "lose" their diagnosis?

Autism?

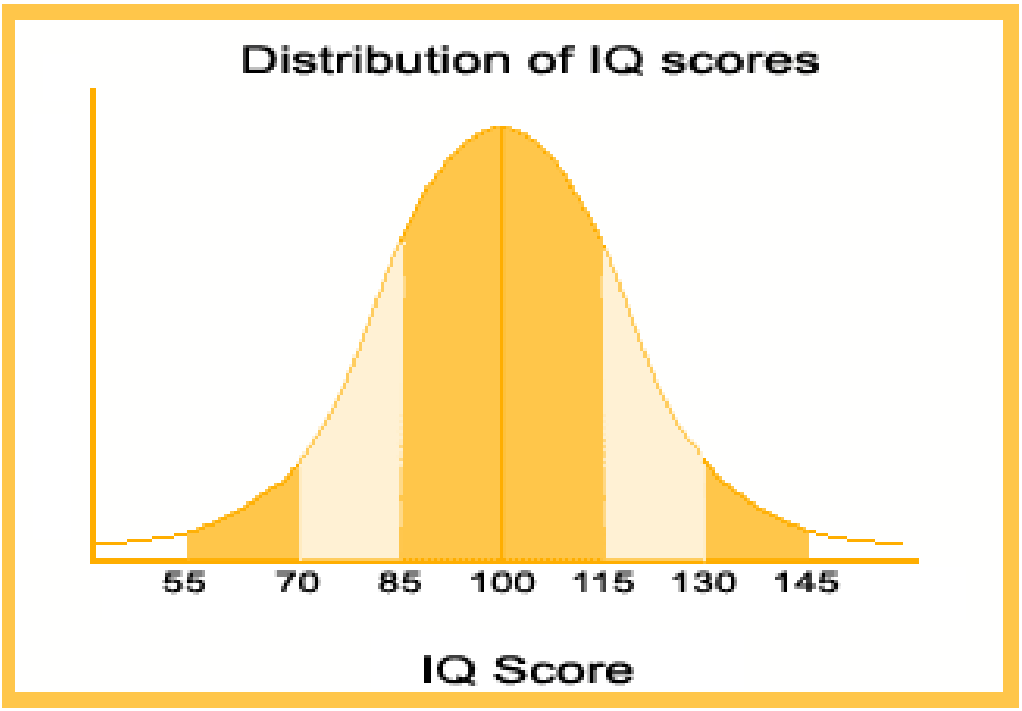
Aspergers?

PDD-NOS?



Aspies: Loss of Identity?

Photo from blog: cutestkidever.org



Changes in Assessment Practice

- Interviews **must** be reorganized to follow DSM-5
  - Sensory issues should be emphasized
  - Play skills may be de-emphasized
  - Language still important to assess (especially social language)
- ADI-R scores clearly based on DSM-IV domains
- ADOS-2: Autism vs autism spectrum
- Social (Pragmatic) Communication Disorder (SCD) is a new differential diagnosis
  - Differs from other differentials (ID, DD, Selective Mutism) in that it requires ASD to be rule out

Challenges

- Criterion a2 excludes kids with great eye contact facial expressions, etc
- Applying criterion a3 to very young children
  - *"Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people"*
- 2 or more RRBs in very young children
- Thorough and accurate assessment of sensory differences
  - Lack of normative information
- New interview tools needed

Social (Pragmatic) Communication Disorder

- Problems with **SOCIAL USE** of verbal and nonverbal communication
  - using communication for social purposes
  - ability to change communication to match context or the needs of the listener
  - following rules for conversation and storytelling
  - understanding what is not explicitly stated

SCD Challenges

- Few assessment tools
- No clear treatment protocol
- No information on prognosis
- Impact of bilingual status??
- Unlikely in kids under 4

How to assess SCD?

- Age 4+?
- Rule out ASD
- Children's Communication Checklist- Second Edition (CCC-2; 4-16)
- Comprehensive Assessment of Spoken Language (CASL; 3-21)
- Social Language Development Test (6-11; 12-17)
- Language sample (need to develop norms)

Diagnostic Dilemmas: DSM-IV *versus* DSM-5 in Toddlers

Pauline A. Filipek MD
Professor of Pediatrics
Children's Learning Institute
&
Division of Child and Adolescent Neurology
UT Health Science Center at Houston

LoneStar LEND
Leadership Education in Neurodevelopmental & Related Disabilities

ACT EARLY TEXAS!

CHILDREN'S LEARNING INSTITUTE
Learning from science.

UTHealth | Medical School
The University of Texas Health Science Center at Houston

Comparisons of DSM-IV *versus* DSM-5

Citation	N/ Mean Age	N / DSM-IV-TR*	N / DSM-5
Mattila ML, Kielinen M, Linna SL, et al. Autism spectrum disorders according to DSM-IV-TR and comparison with DSM-5 draft criteria: an epidemiological study. JAACAP 2011;50:583-92 e11.	5,484 8yo	FSIQ > 50 → 26 PDD	12/26 ASD (46%)
Frazier TW, Youngstrom EA, Speer L, et al. Validation of proposed DSM-5 criteria for autism spectrum disorder. JAACAP 2012;51:28-40.	8,911 2-18yo in IAN	8,911 PDD Sensitivity= 0.95 Specificity= 0.86	Se= 0.81 / Sp= 0.97
McPartland JC, Reichow B, Volkmar FR. Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder. JAACAP 2012;51:368-83.	657 Mean 9.2yo	657 PDD	398/657 ASD (60.6%) IQ > 70 = 50% Asperger/ PDD-NOS = 25% Se= 0.61 / Sp= 0.95
Matson JL, Kozlowski AM, Hattier MA, Horovitz M, Sipes M. DSM-IV vs DSM-5 diagnostic criteria for toddlers with autism. Developmental Neurorehabilitation 2012;15:185-90.	**2,721 Mean 26mo (17-36mo)**	**795 PDD/ 1,926 Non-PDD**	**415/795 ASD (52%) 75% AD 11% PDD-NOS**
Gibbs V, Aldridge F, Chandler F, Witzlsperger E, Smith K. Brief report: an exploratory study comparing diagnostic outcomes for autism spectrum disorders under DSM-IV-TR with the proposed DSM-5 revision. JADD 2012;42:1750-6.	132 Mean 6yo (2-16yo)	111 PDD / 21 Non-PDD 59 AD 18 Asperger 34 PDD-NOS	84/111 ASD (64.4%) 53/59 AD (89.8%) 15/18 Asperger (83.4%) 17/34 PDD-NOS (50%)
Taheri A, Perry A. Exploring the proposed DSM-5 criteria in a clinical sample. JADD 2012;42:1810-7.	131 Mean 6.4yo (2.10-12.7yo) Mean FSIQ= 46.3 (8-111)	131 PDD 93 AD / 36 PDD-NOS	82/131 ASD (63%) 75 AD (81%) 6 PDD-NOS (17%)
Huerta M, Bishop SL, Duncan A, Hus V, Lord C. Application of DSM-5 criteria for autism spectrum disorder to three samples of children with DSM-IV diagnoses of pervasive developmental disorders. AJP 012;169: 1056-64.	5,143 CPEA Mean 6.4yo UMich Mean 6.6yo Simons Mean 9.4yo	4,453 PDD / 690 Non-PDD	4,052 ASD **(91%) using ADOS Threshold of 1**
Wilson CE, Gillan N, Spain D, et al. Comparison of ICD-10R, DSM-IV-TR and DSM-5 in an Adult Autism Spectrum Disorder Diagnostic Clinic. JADD 2013;43:2515-25.	150 Mean 31yo (18-65yo)	150 PDD	117/150 ASD (78%)
Jashar D, Brennan L, Robins D, Barton M, Fein D. DSM-5 Criteria Applied to Toddlers Diagnosed with ASD by DSM-IV-TR. Presented at IMFAR 2013.	**332 Mean age 26.0mo (16-39mo)**	**234 PDD / 98 Non-PDD**	**166 / 234 ASD (71%) 68% not meeting DSM-5 were PDD-NOS**
Barton ML, Robins DL, Jashar D, Brennan L, Fein D. Sensitivity and Specificity of Proposed DSM-5 Criteria for Autism Spectrum Disorder in Toddlers. JADD 2013; 43(5):1184-95.	**844 Mean 25.8mo (16.8-39.4)**	**568 PDD 276 Non-PDD**	**219/284 ASD (77%)**

* DSM-IV-TR PDD = Combined AD, Asperger and PDD-NOS

DSM-IV *versus* DSM-5 in Toddlers

Matson JL, Kozlowski AM, Hattier MA, Horovitz M, Sipes M. DSM-IV *vs* DSM-5 diagnostic criteria for toddlers with autism. *Developmental Neurorehabilitation* 2012;15:185-90.

- N= 2,721
  - Mean 26mo (range 17-36mo)
  - 795 DSM-IV PDD/ 1,926 no PDD
- Used BISCUIT- Part 1, BDI-2 and M-CHAT
- 415 / 795 met DSM-5 ASD criteria (52%)
  - 75% DSM-IV AD met DSM-5 ASD
  - only 11% DSM-IV PDD-NOS met DSM-5 ASD

DSM-IV *versus* DSM-5 in Toddlers

Barton ML, Robins DL, Jashar D, Brennan L, Fein D. Sensitivity and Specificity of Proposed DSM-5 Criteria for Autism Spectrum Disorder in Toddlers. *JADD* 2013; 43:1184-95.

- N=422, cohorts in Georgia and Connecticut
  - Mean age 26mo (range 16.8-39.4mo)
  - 284 DSM-IV PDD / 138 Non-PDD
- Used ADOS threshold of 2 (not 1 per *Huerta et al.)* to map to DSM-5
- 219 / 284 met DSM-5 ASD criteria (77%)

DSM-IV *versus* DSM-5 in Toddlers

Jashar D, Brennan L, Robins D, Barton M, Fein D. DSM-5 Criteria Applied to Toddlers Diagnosed with ASD by DSM-IV-TR. Presented at IMFAR 2013.

- N= 332 from larger cohort
  - Mean age 25.95mo (range 16-39mo)
  - 234 DSM-IV PDD / 98 Non-PDD

- 166 / 234 met DSM-5 ASD criteria (71%)
  - 46 / 68 (68%) not meeting DSM-5 criteria had DSM-IV diagnosis of PDD-NOS
    - 15% of DSM-IV Autistic Disorder
    - 51% of DSM-IV PDD-NOS

DSM-IV *versus* DSM-5 in Toddlers

Jashar D, Brennan L, Robins D, Barton M, Fein D. DSM-5 Criteria Applied to Toddlers Diagnosed with ASD by DSM-IV-TR. Presented at IMFAR 2013 (continued).

HOWEVER,

- 17 / 98 (17%) from DSM-IV Non-PDD group met DSM-5 ASD criteria;
  - 13/17 (76%) had [Global] Developmental Delay
  - 4/17 (24%) had DLD/SLI

Case 1 – 26 months

26mo female

- Covered eyes at social encounters much of the time
- Did give eye contact / smiles some of the time
- Long delay before asking for help
- Responds to her name only if mother calls
- Only a few words, without babbling or gibberish
- Very little communicative intent
- No pointing or other gestures
- Unable to follow gaze and follows a point rarely
- Preferred cause-and-effect toys
- Played in isolation unless she needed help
- Did not often respond to verbal requests
- Does not engage in pretend play
    - Uninterested in pretend birthday party- Repetitively dropped plates onto the table and threw doll on the floor instead of “putting it to sleep”

Case 1 – 26 months

26mo female

- Did imitate some but not flexibly with a variety of objects
- Inconsistent use of eye contact and nonverbal behaviors for communication
- Did gaze shift several times if a desired object was out of reach
- Gave a cookie container to her mother without any eye contact or communication to request
- When she did not get what she wanted (*e.g.,* cookie) she simply “moved on”
- Did not show anything “to share” although she did give “to fix”
- Preoccupied with a knob on the wall and repeatedly went back to it during the evaluation, exploring it visually and tactilely
- Showed unusual interest in chair buttons and bumps in rug
- Did a lot of aimless wandering around the room
- Hit herself in the head when she became frustrated

Case 1 – 26 months

Vineland SS / AE	Communication	70	1-1
	Daily Living Skills	76	1-5
	Socialization	81	1-3
	Motor Skills	87	1-8
	Adaptive Behavior Composite	72	
MSEL T-Scores / AE	Visual Reception	33	1-7
	Fine Motor	39	1-10
	Receptive Language	20	0-11
	Expressive Language	28	1-3
	Early Learning Composite		SS 63
ADI-R Totals	Reciprocal Social Interaction	13	
	Communication-Nonverbal	10	
	Repetitive Behaviors	0	
ADOS Module 1 Totals	Communication	3	
	Reciprocal Social Interactions	5	
	Communication + Social Interactions	8	
CARS	Total Score	28.5	
DIAGNOSIS:	PDD-NOS		

Case 1: DSM-5 Criteria for ASD

A		**Persistent deficits in social communication and social interaction across contexts, currently or by history:**
✓	A1	Deficits in social-emotional reciprocity;
✓	A2	Deficits in nonverbal communicative behaviors used for social interaction;
✓	A3	Deficits in developing, maintaining and understanding relationships.
B		**Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following, currently or by history:**
	B1	Stereotyped or repetitive motor movements, use of objects or speech;
	B2	Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior;
	B3	Highly restricted, fixated interests that are abnormal in intensity or focus;
✓	B4	Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment.

Case 2 – 27 months

27mo Male

- Vocalizations consisted of babbling
- ~8 words noted during the evaluation, plus counting 1-4, labeling shapes
- Did combine “bye” with waving
- Pointed only to close objects but never to share, without coordination of eye gaze or vocalization
- Some vocalizations were directed at others but only to obtain help, never to share or direct attention
- Vocalizations had peculiar intonation
- Some echolalia
- Some shared enjoyment
- Very active and difficult to engage – fleeting attention
- Made eye contact but not to communicate needs and interests
- Did not show “to share” – only gave “to fix”
- Did not include anyone in his activities

Case 2 – 27 months

27mo Male

- Used “hand-over-hand” to get his needs met
- Spun most toys, as well as repetitively pushing buttons
- Did not understand most of what was asked of him
- When given a choice for a snack, he simply reached for what he wanted without eye contact or other communicative intent
- Favored toyed included Poppin’ Pals and Jack-in-the-box, which he spun briefly
- Gave mother some blocks, smiled at her, then grabbed her hands to make them spin without eye contact
- Had no interest in toy miniatures but did prompted ball play
- Liked to climb onto furniture, get himself into small spaces, bang his head on a couch

Case 2 – 27 months

Vineland SS / AE	Communication	71	1-3
	Daily Living Skills	70	1-4
	Socialization	72	1-1
	Motor Skills	75	1-6
	Adaptive Behavior Composite	66	
MSEL T-Scores / AE	Visual Reception	20	1-5
	Fine Motor	20	1-8
	Receptive Language	20	0-11
	Expressive Language	32	1-6
ADI-R Totals	Reciprocal Social Interaction	12	
	Communication-Nonverbal	7	
	Repetitive Behaviors	1	
ADOS Totals	Communication	6	
	Reciprocal Social Interaction	9	
	Play	5	
	Stereotyped Behaviors/ Restricted Interests	2	
CARS	Total Score	27.5	
DIAGNOSIS:	Autistic Disorder		

Case 2 – DSM-5 Criteria for ASD

	A	**Persistent deficits in social communication and social interaction across contexts, currently or by history:**
✓	A1	Deficits in social-emotional reciprocity;
✓	A2	Deficits in nonverbal communicative behaviors used for social interaction;
✓	A3	Deficits in developing, maintaining and understanding relationships.
	B	**Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following, currently or by history:**
✓	B1	Stereotyped or repetitive motor movements, use of objects or speech;
	B2	Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior;
	B3	Highly restricted, fixated interests that are abnormal in intensity or focus;
	B4	Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment.

Case 3 – 25 months

And because there is an apparent clinical misconception that toddlers not qualifying for DSM-5 ASD miss criteria only in *B: Restricted, Repetitive Patterns of Behavior, Interests, or Activities*

and never in *A: Persistent Deficits in Social Communication and Social Interaction Across Contexts…*

Case 3 – 25 months

25mo Male

- Became distressed when adult tried to engage him
- Mostly babbled, with some single words
- Directed vocalizations mostly to just to get help with a few occasions of expressing interest in the activity
- Limited use of gestures- did clap and once pointed to an object but without eye contact towards an adult "to share"
- Made spontaneous eye contact sometimes, although mostly failed to make eye contact when adults tried to engage him
- Sustained eye contact only when highly motivated (*e.g.*, bubbles)
- Looked to mother several times to "check in"
- Spent most of the evaluation following his own interests
- Did not respond to his name or to smiles of others
- Directed facial expressions only when upset or did not want to continue an activity

Case 3 – 25 months

25mo Male

- Particular interest in spinning of wheels on cars
- Difficult to redirect his attention from the cars
- Particularly liked to hold linear objects, like pretzels or a fork, on a vertical plane while spinning around in a circle
- Did not seek any input or respond to adults' statements or gestures when not in a highly motivating activity
- Did not show "to share"
- Did not initiate or respond to joint attention prompt
- Played appropriately with some cause-and-effect toys
- Played more repetitively with cars, spinning the wheels but not pushing them along
- No make believe play

Case 3 – 25 months

Vineland SS / AE	Communication	77	1-4
	Daily Living Skills	83	1-7
	Socialization	77	1-2
	Motor Skills	75	1-4
	Adaptive Behavior Composite	72	
MSEL T-Scores / AE	Visual Reception	20	1-2
	Fine Motor	20	1-2
	Receptive Language	20	0-10
	Expressive Language	28	1-3
	Early Learning Composite		
ADI-R Totals	Reciprocal Social Interaction	10	
	Communication-Nonverbal	7	
	Repetitive Behaviors	3	
ADOS Totals	Communication	3	
	Reciprocal Social Interactions	10	
	Play	4	
	Stereotyped Behaviors/ Restricted Interests	4	
CARS	Total Score	31	
DSM-IV DIAGNOSIS:	Autistic Disorder		

Case 3 - DSM-5 Criteria for ASD

	A	**Persistent deficits in social communication and social interaction across contexts, currently or by history:**
✓	A1	Deficits in social-emotional reciprocity;
✓	A2	Deficits in nonverbal communicative behaviors used for social interaction;
	A3	Deficits in developing, maintaining and understanding relationships.
	B	**Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following, currently or by history:**
✓	B1	Stereotyped or repetitive motor movements, use of objects or speech;
	B2	Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior;
	B3	Highly restricted, fixated interests that are abnormal in intensity or focus;
✓	B4	Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment.

So – What's a Diagnostician To Do?

- As an "alternative" diagnosis, Social Communication Disorder cannot be diagnosed until age 4 years or older
- Social Communication Disorder probably will not be eligible to receive any benefits through the schools or insurance in many states (including mine)

So what happens to these toddlers in particular, who will be unable to obtain services without an appropriate diagnosis ???

- Remember: Barton *et al* determined its DSM-IV/DSM-5 accordance rates by mapping ADOS items onto DSM-5 and by only using ADOS items with a score = 2 (and not 1)

- May be more foreboding for research studies than for clinical diagnosis (although the jury is still very far out on this concept)
  - An experienced clinician who clearly recognizes a clinical diagnosis of ASD should theoretically should be able to make a clinical diagnosis
  - Less experienced clinicians, well…..

- ICD-11 will go into effect in 2014-5, reportedly maps better onto DSM-IV than onto DSM-5 for autism

- With the recent focus on identifying the earliest signs and symptoms of ASD is even the very youngest infants…
- With the recent empiric documentation that the earliest initiation of intensive intervention produces definite benefits…
- We must continue to advocate for our patients to insure that they receive the best possible services…

DSM-5
Family Perspectives

Shannon M. Haworth, MA, QMHP

Background

- Mother of a child with an Autism Spectrum Disorder (high functioning).
- Former Va-LEND Trainee, in the Family Discipline.
- Worked with families and treated children across the Autism spectrum, as a behavior analyst.
- Project manager for the ASD Early STEP project, for the Partnership for People with Disabilities (VCU), & Va-LEND Clinic Coordinator.
- Very hard to get a diagnosis for my child.
- Finally at 4 – diagnosed with PDD-NOS (not Asperger's - speech delay) by a developmental pediatrician.
- At 6 it changed to Autistic Disorder (ADOS testing).


Logan
'12

Background

- He is very high functioning, at 7, Psychiatrist changed his label to mild-moderate Autism. She did this to line up with the DSM-5.
- I was told by professionals that as my son gets older functions as a child with Asperger's. This has now become the case.
- He has specifically benefitted from insurance sanctioned therapies, school services, and accommodations.
- He is on grade level (2nd grade), ahead in math, science and technology.
- Behaviors that kept him in a more restrictive environment have been significantly reduced (near zero levels).
- He is in general education almost all day with a 1:1 aide, and in the Autism Classroom 45 minutes per day , or when he gets overwhelmed and needs a break.
- What if he did not have all these supports due to a change in his diagnosis?

Change of Diagnosis?

- Now that the Autism is classified differently, families like mine wonder how services for their children with HFA/Asperger's will be affected.
- It has been a struggle to receive a diagnosis and services for my child.
- School services and accommodations have been a constant battle. He tests very well, so some of his services have already been reduced (speech, OT).
- Fought to keep him in LRE, with an aide.
- Had a lawyer from the VOPA because his rights were being trampled on.
- He does not fit into many peoples idea of Autism, which makes things harder.
- We don't qualify for Medicaid/SSI, but we did qualified for a waiver for my child (EDCD), on the wait list for the DD waiver.
- **The concern is this:** Will families who have children with High functioning Autism or Asperger's be denied services because of the new classifications?

Highlights of Changes from DSM-IV-TR to DSM-5:

:

"**Autism spectrum disorder** is a new DSM-5 name that reflects a scientific consensus **that four previously separate disorders are actually a single condition with different levels of symptom severity in two core domains.**

ASD now encompasses the previous DSM-IV autistic disorder (autism), Asperger's disorder,

childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified.

ASD is characterized by 1) deficits in social communication and social interaction and 2) restricted repetitive behaviors, interests, and activities (RRBs)."

http://www.dsm5.org/

PANIC!

Questions I heard the most from families:

•Will my child with high functioning autism or Asperger's lose there diagnosis (label)?

•Will my change receive a different diagnosis?

•Will my child's eligibility for services and supports change at school because of the changes?

•Will my child still qualify for an IEP?

•Will my child lose their Medicaid Waiver because of a label change?

•Will it be harder to justify services for my child with insurance companies if he is no longer on the spectrum? Will I have to pay for therapies?

Parents who already had to fight for services for their children were in **a panic** when the changes took place.

What May Happen

- How the DSM-5 classifies autism may affect some families.
- Children like mine who are high functioning, or previously diagnosed with Asperger's may no longer be classified as having Autism.
- They may have a different diagnosis instead of none at all.
- In addition to speaking with families, I also researched the topic, and spoke with schools and Providers (Psychologists, Psychiatrists, Pediatricians, etc.) for more information.

School Systems

I cannot say this applies to all school but for **Virginia**, the VDOE provided a document to explain how the changes will/or should affect children diagnosed with Autism.

VDOE Response to DSM-5

•**Question:** Will the changes in the DSM-5 affect my child's special education and related services?

•**Answer:** **No. While autism spectrum disorders (ASD) and related disorders have changed from the DSM-IV diagnostic criteria to the DSM-5 diagnostic criteria, it is Virginia's special education regulations and laws that regulate the delivery of special education and related services in the commonwealth.** Virginia's regulations and laws have not changed; therefore, there should be no changes to your child's Individualized Education Program (IEP) supports and services as a result of the changes in the DSM.

•May be similar for other school districts.

School Systems

VDOE Response to DSM-5

- **Question:** Will changes in the DSM-5 effect evaluation and eligibility decision making processes in the area of ASD in schools?
- **Answer:** **No. There should be no changes in evaluation and eligibility decision making as a result of changes in the DSM-5.** *The Virginia Regulations Governing Special Education Programs for Children with Disabilities* **contain specific eligibility criteria for each disability category and are not impacted by the release of the DSM-5.** Schools should continue to follow the Virginia regulations and laws, rather than the DSM.

School Systems

VDOE Response to DSM-5

• **Question:** If my doctor notifies me of changes, how will this impact my child's education?

•**Answer:** While the changes in the DSM-5 may result in changes to clinical or medical practice in Virginia, educational identification practices have not changed. **Medical diagnosis or DSM criteria is not required by state regulation as part of an eligibility determination as a student with autism.** Virginia provides specific eligibility criteria that local school divisions may follow. VDOE Guidance on Evaluation and Eligibility for the Special Education Process (2009) highlights the distinction between educational identification and medical diagnosis.

http://www.doe.virginia.gov/

Providers View

I asked professionals who diagnose developmental disabilities in children if the DSM-5 definition of Autism will negatively impact families and children like mine.

Responses:

•Short answer is "no" (at least theoretically).

•The DSM-5 definition of ASD includes the statement:

"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 autism spectrum disorder."

•Unusual " include that statement in a diagnostic manual," but helpful from an " advocacy perspective"

• Some systems " through ignorance or perversity," may try to exclude some children because of the revised definition.

The Reality

- **The DSM-5 definition of ASD includes the statement:**

"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 autism spectrum disorder." - Children previously diagnosed with Asperger's or HFA should continue to have a diagnosis of Autism Spectrum Disorder (mild-moderate-severe).

- I have not specifically been told by families that their child's eligibility for services in school has been affected, or that they have lost a Medicaid waiver, or it has been harder to qualify for one.
- School systems, and providers state that these changes will not affect most children who already receive services.
- As for insurance companies, I can only hope they don't deny more claims for treatments.
- **In reality no one knows at this time how the changes will affect families in the long run**.
- Parents need to continue to be advocates for their children.
- The specific "label" does not matter, as long as they receive adequate services for their children, because research shows that with the correct supports, children with ASD can be successful, and improve.

Contact Information

Shannon M. Haworth, MA, QMHP
Partnership for People with Disabilities
Virginia Commonwealth University

haworths@vcu.edu
804-827-8770

Thank you

Questions?

Discussion

Thank You!